Health and Human Rights Journal

JUNE 2020, VOLUME 22, NUMBER 1

SPECIAL SECTION

Mental Health and Human Rights

GUEST EDITORS
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Publisher
FXB Center for Health and Human Rights, Harvard University
Dornsife School of Public Health, Drexel University

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Health and Human Rights Journal (online) ISSN 2150–4113

MASTHEAD

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EDITORIAL

Reimagining the Mental Health Paradigm for Our Collective Well-Being

AUDREY CHAPMAN, CARMEL WILLIAMS, JULIE HANNAH, AND DAINIUS PŪRAS

When we planned the special section of this issue and distributed our call for papers, we wanted to present a collection that would reflect our view that not only is there is no health without mental health, but there is no mental health without human rights. We were hopeful that papers from around the world would illustrate human rights-based approaches to easing mental distress, critique the status quo in how we understand and respond to mental health, and illuminate the scale of suffering that arises from our unequal, racist, discriminatory, and violent world. The issue was timed to coincide with guest editor Dainius Pūras's completion of his second and final term as United Nations (UN) Special Rapporteur on the right to health. Mental health has been a special focus of his mandate, resulting in several reports on the subject, and he also contributed to the two UN resolutions affirming mental health as a human right.[1] In his most recent report to the UN General Assembly and in his final report to the Human Rights Council, Pūras examines the social determinants of mental health and calls for discussions and actions that are "rights-based, holistic and rooted in the lived experience of those left furthest behind by harmful sociopolitical systems, institutions and practices."[2] Of great relevance now to our post-pandemic world, he stresses that these discussions are needed at global, regional, and national levels to better understand the collective failures of the status quo in mental health systems.

Indeed, one of the critically important lessons the world has learned in 2020 is how important global conversations, social justice activism, and community cooperation are. COVID-19 has cruelly demonstrated our interconnectedness, our shared humanity, and our shared suffering. It has equally illuminated the injustice of our economic and political systems and the cruelty of the inequality and systemic discrimination they have produced. The UN and many others are also acknowledging the long-lasting impact that the pandemic will have on our mental well-being.[3]

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Competing interests: None declared.

So the timeliness of this special section could not be more appropriate. We urgently need these conversations to address the inter-relatedness of human rights and to consider the real causes of mental distress. The pandemic sadly provides ample evidence of human rights failings that lead to unequal and unfair health outcomes. Discrimination, disempowerment, and social exclusion are producing excessive COVID-19 death rates in racial and ethnic minority populations across the world; the same patterns will be seen in the mental distress caused by the pandemic. Likewise, it is essential to develop an evidence base of the disastrous harms created by COVID-19 public health policies—political choices that have caused unimaginable suffering among society's most marginal, including (but not limited to) the elderly, those who are homeless, people detained in prisons, and people living in psychiatric facilities and institutions and care homes. Technical solutions being proposed to these structural problems and policy harms—such as vaccines, telemedicine, and apps for well-being—are woefully inadequate.

Right now, there is both an urgency and an opportunity to change the way mental health services are framed, governed, and delivered, worldwide. We anticipate that the papers in this issue will be useful for policy makers and health and social workers who want to embed human rights and adopt right to health approaches to the changes that must take place in mental health. One of the aims of this special section is to identify alternative mental health approaches to the reductionist biomedical paradigm that has contributed to the exclusion, neglect, coercion, and abuse of people with intellectual, cognitive, and psychosocial disabilities, and those who deviate from prevailing cultural, social, and political norms. In our call for papers, we wrote that the status quo, preoccupied with excessive biomedical interventions, including psychotropic medications and non-consensual measures, is no longer defensible.

The pandemic presents not just the opportunity but the necessity of providing a different form of care and support for the millions of people who are now suffering its consequences. Given the anticipated need for mental health support, there is no possible way that dominant models can cope with, let alone address, the demand. The pandemic is providing a profound illustration of interconnected determinants of mental health: the impact of loss of freedoms, for example, on people having to stay at home when that home may be violent; the impact of loss of employment on people who are already poor, living on minimum wages without health insurance and perhaps in crowded homes; the impact of risk exposure to COVID-19 on health workers and other "essential workers" who are from minority groups and suffer discrimination in the workplace and are given no option but to work; the loss of access to nutrition for the school children whose most nutritious meal was provided by their school.

A rights-based approach to mitigating the mental health consequences of a global health and economic crisis responds to the ways these hardships intersect, ensuring that people who lose their income and others in financially precarious positions are protected by government support packages, that people do not lose their homes, and that all social rights are protected. These and similar measures are often effective at protecting mental health, and especially in today's COVID-19 environment.

Civil society, particularly movements led by users and former users of mental health services and organizations of persons with disabilities, have brought attention to the failures of traditional mental health services to meet their needs and secure their rights. They have challenged the drivers of human rights violations, developed alternative treatment approaches, and recrafted a new narrative for mental health. This has resulted in a paradigm shift, including an evolving human rights framework in mental health. The adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 laid the foundation for that paradigm shift, with the aim of leaving behind the legacy of human rights violations in mental health services.

The right to the highest attainable standard of health has much to contribute to advancing this shift and provides a framework for the full realization of the right of everyone to mental health. But progress has been slow. Effective, acceptable, and scalable treatment alternatives remain on the periphery of health care systems, deinstitutionalization has stalled, and the insufficient mental health investment continues to be focused predominantly on a biomedical model, despite increasing global recognition that mental health is a human development imperative.

We hope that readers find this collection of papers useful. It demonstrates the role of human rights as envisaged by people using mental health services, by people providing services, and by a broad movement seeking to shift the entire paradigm of mental health away from focusing on biology and brains to focusing on relationships and other social determinants of health. Mental health services cannot be transformed and cannot satisfy the need for them without directing attention and funding toward the structural causes of poor mental health and distress. Rights-based and population-based approaches to mental health promotion are those that have moved health systems beyond individualized responses toward action on a range of structural barriers and inequalities (social determinants) that negatively affect mental health.

Inadequacies of the biomedical paradigm

The first cluster of papers documents some of the inadequacies of the current reductionist psychiatric biomedical paradigm. This approach to mental health is preoccupied with excessive biomedical interventions, including psychotropic medications and reliance on non-consensual measures that have contributed to the exclusion, neglect, coercion, and abuse of people with intellectual, cognitive, and psychosocial disabilities. In their paper, Linda Steele and colleagues draw on data from focus groups and interviews with people living with dementia, care partners, aged care workers, and lawyers and advocates to identify the daily facilitators that contribute to the confinement of people with dementia in Australian care homes. They argue that micro-level interrelated factors contribute to human rights abuses of people living with dementia by limiting their freedom of movement and community access. Petr Winkler and colleagues report on a nationwide study in which multidisciplinary teams using the World Health Organization's QualityRights toolkit conducted interviews, analyzed internal documents, and observed practices to evaluate the quality of care in Czech psychiatric hospitals. The study concluded that none of the CRPD articles was fully adhered to in these hospitals and that substantial investments are required to reach a more adequate adherence to the CRPD.

Other papers explore the causes of inadequacies in mental health services. Faraaz Mahomed focuses on the underprioritization and underfunding of mental health because it is a neglected priority of policy makers and funders at the national and international levels. He also cautions that as policy makers seek to "scale up" mental health and reduce "treatment gaps" in the wake of COVID-19, there is a need to ensure that increased funding does not replicate the current overemphasis on the biomedical model.

Jenifer Wogen and Maria Teresa Restrepo discuss the stigmatization, discrimination, and negative stereotypes that individuals with mental health problems, including those with drug dependence, suffer and how stigma affects their treatment and health care. They look at the roles played by policy change and the decriminalization of drugs in addressing and reducing stigma, and improving mental health. Lisa Cosgrove and Allen Shaughnessy are critical of industry's influence on psychiatry, for it has contributed to the current medical model that overemphasizes biomedical treatments and underappreciates the social and psychosocial determinants of health and the need for population-based health promotion. Their paper argues that a robust rights-based approach to mental health is needed to overcome the manipulative effects of commercial interests in the mental health field.

Learning from rights-based approaches

Another cluster of papers considers new approaches that are more consistent with human rights. A perspective contributed by Michelle Funk and Natalie Drew Bold introduces the World Health Organization's QualityRights initiative, and it is included in our special section as a useful resource for practitioners. This approach and framework for promoting mental health systems, services, and practices prioritizes respect for human rights consistent with the CRPD, and its use is demonstrated in the paper by Winkler and colleagues. Lucas Trout and Lisa Wexler's paper on youth suicide in indigenous Arctic communities identifies suicide as psychogenic on the one hand and as an index of social suffering on the other. The paper draws on structured interviews and ethnographic work with health professionals in the Alaskan Arctic to examine the inadequacies of the health systems that currently shape clinicians' practices of care. They recommend linking caregiving to the health and social equity agenda of social medicine in order to operationalize commitments to health as a human right. Ursula Read and colleagues draw on ethnographic and participatory research in urban and rural sites in Ghana to underscore the importance of social and economic rights, especially the right to work, in protecting the rights of persons with mental illness. The paper evaluates the challenges of implementing mental health, disability, and labor legislation and discusses the potential of practices of solidarity and social activism to promote the rights of people with mental illness.

Petr Stastny and colleagues, including guest editors Julie Hannah and Dainius Pūras, explore critical elements of rights-based support for individuals undergoing serious mental health crises. The paper proposes a set of nine critical elements underpinned by human rights principles to support a person experiencing significant emotional distress related to mental health problems of psychosocial disabilities. They urge that these nine elements be used as building blocks for designing services and systems that promote effective rights-based care and support. Despite the frequency of calls for a human rights-based approach to mental health, there are few documented attempts to use such approaches, nor assessments of their degrees of success. We therefore welcome Emma Broberg and her colleagues' evaluation of a pilot study of their human rights-based approach to psychiatry in Gothenburg, Sweden. They discuss the human rights principles used and are open about difficulties they encountered, such as realizing meaningful participation and challenging the hierarchies of different professions within care. Their paper reflects on ways to make human rights-based methods sustainable in a large organization.

New paradigms promoting reform

Civil society movements led by persons with disabilities have developed alternative treatment approaches and, by doing so, have contributed to a paradigm shift. The Hearing Voices Movement, an international grassroots movement that aims to shift public and professional attitudes toward experiences such as hearing voices and seeing visions—which are generally associated with psychosis—is one such example. Rory Neirin Higgs's paper argues that incorporating this perspective into mental health practice and policy has the potential to foster greater understanding and respect for consumers and survivors diagnosed with psychosis, while opening up valuable avenues for future research.

The reform agenda is also promoted by recognizing the importance of traditional health systems and cultures for the well-being of local communities—something often overlooked in contemporary health systems and models of mental health care. José Carlos Bouso and Constanza Sánchez-Avilés discuss the need for the global mental health movement to recognize the role of traditional medicines and healers, particularly in Global South countries where traditional healers are far more numerous than mental health workers and constitute the main health resource for local populations.

Some papers in this section describe the difficulties inherent in adopting new models more consistent with human rights. Jasna Russo and Stephanie Wooley examine the implications of human rights approaches that lack a theoretical framework when trying to counteract the hegemony of the biomedical model of mental illness.

They suggest that the task of implementing the CRPD requires not just reforming psychiatry but rather "an entirely different approach to madness and distress" and point to the indispensability of first-person knowledge in developing and owning a broader agenda for change. Laura Davidson addresses the difficulties of trying to adopt a complete prohibition on the use of coercion, consistent with the requirements of the CRPD. She proposes the need for interim mental health legislation that will facilitate a move toward a complete ban on psychiatric coercion. She also urges the UN committee overseeing the CRPD to issue a general comment providing "reluctant permission" for the progressive realization of respect for articles 12 and 14 of the CRPD. Article 12 recognizes the equal rights of persons with disabilities before the law and their right to exercise this legal capacity. Article 14 sets forth the rights of persons with disabilities not to be deprived of their liberty and security.

Finally, Bram Wispelwey and Yasser Abu Jamei's paper on the Great March of Return documents the ways in which the Gaza mass resistance movement protesting the Israeli blockade provides an opportunity to develop an understanding of the psychosocial consequences of community organizing and mass resistance. They comment on the need for holistic mental and physical health care for community members affected by the events of the Great March of Return and the ongoing dire situation in Gaza.

Conclusion

The 15 papers in this special section give us reason for cautious optimism. Optimism in that globally, mental health is emerging slowly from a Dickensian past, tarnished with human rights violations, to a more enlightened era where human dignity, equality and justice, and empowerment are increasingly central to reform efforts and advocacy. Cautious and vigilant we must remain as calls for mental health reform and expansion become live and viable political issues, thanks in part to the global mental health movement. This cautious optimism is equally critical today, as the demands of social justice movements, including Black Lives Matter, to decarcerate and divest from corrupt criminal justice systems are finally (and rightfully) receiving political attention. While such calls to decarcerate and reinvest public spending toward community services, including mental health, are an essential response to racist and coercive criminal justice systems, it is vital to remember that mental health systems around the world emerged from and retain that same racist and coercive patina.

While COVID-19 didn't create inequalities or racism, much like natural disasters and disease outbreaks before it (such as Ebola and HIV), it has exposed the toxic foundations and institutions of our society: racist, classist, sexist, and intolerant. This legacy, which places our collective well-being under strain every day, has produced an infrastructure of exclusion, coercion, and incarceration that breeds systemic and widespread human rights violations. This special section aims to illuminate the human rights dimensions of this context—and though we have fallen short of exposing more explicitly the racial and gender dimensions, we hope that this is merely the beginning of an ongoing scholarly conversation.

In the wake of COVID-19 and the remarkable worldwide community activism of Black Lives Matter, questions are emerging about how to decolonize our broken systems and reimagine something different. Mental health is part of that discussion and must be part of a reimagined future. The global debates around mental health—including the often competing visions of activists, governments, Big Pharma, psychiatry, and persons with lived experience—will shape our post-pandemic future in many ways. As the editors of this special section, we believe that these debates could not come at a more important time. All governments are presently having to design and implement policies to support people, especially poor and marginalized people, who have suffered huge personal and financial losses. Here is their chance to reduce the mental health distress arising in an unfair world. We believe that the human rights lessons from the papers in this special section offer much guidance.

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1. See, for example, D. Pūras, Report of the UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/35/21 (2017); D. Pūras, Interim Report of the UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/73/216 (2018); D. Pūras, Report of the UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/41/34 (2019); Human Rights Council, Res. 32/18, UN Doc. A/HRC/RES/32/18 (2016); Human Rights Council, Res. 36/25, UN Doc. A/HRC/36/25 (2017).

2. See D. Pūras, Report of the UN Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health, UN Doc. A/HRC/44/48 (2020).

3. "UN leads call to protect most vulnerable from mental health crisis during and after COVID-19," *UN News* (May 14, 2020). Available at https://news.un.org/en/story/2020/05/1063882; D. Pūras, "COVID-19 and mental health: Challenges ahead demand changes," *Health and Human Rights Journal* (blog) (May 14, 2020). Available at https://www.hhrjournal.org/2020/05/covid-19-and-mental-health-challenges-ahead-demand-changes.

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Human Rights and the Confinement of People Living with Dementia in Care Homes

LINDA STEELE, RAY CARR, KATE SWAFFER, LYN PHILLIPSON, AND RICHARD FLEMING

Abstract

This paper responds to growing concerns in human rights practice and scholarship about the confinement of people living with dementia in care homes. Moving beyond the existing focus in human rights scholarship on the role of restrictive practices in confinement, the paper broadens and nuances our understanding of confinement by exploring the daily facilitators of confinement in the lives of people with dementia. The paper draws on data from focus groups and interviews with people living with dementia, care partners, aged care workers, and lawyers and advocates about Australian care homes. It argues that microlevel interrelated and compounding factors contribute to human rights abuses of people living with dementia related to limits on freedom of movement and community access of people living with dementia, at times irrespective of the use of restrictive practices. These factors include immobilization and neglect of residents, limited and segregated recreational activities, concerns about duty of care and liability, apprehension of community exclusion, and pathologization and subversion of resistance. It is necessary to challenge the organizational, cultural, economic, and social dynamics that shape day-to-day, microlevel, routine, and compounding factors that remove the agency of people living with dementia and in turn facilitate entrenched and systematic human rights breaches in care homes.

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Competing interests: None declared.

Introduction

The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health has emphasized that confinement in health care settings can become a barrier to mental and physical health.[1] While the Special Rapporteur does not specifically mention care homes, his concerns align with growing awareness in human rights scholarship and practice of the impacts of confinement on the mental and physical well-being of people living with dementia in care homes. The Special Rapporteur on the rights of persons with disabilities has recently identified a range of human rights issues affecting people living with dementia, including "stigma and stereotypes," the absence of rehabilitation services, being "assumed to possess weak or even no agency," being at greater risk than other older people of "violence, abuse and neglect," and a lack of building accessibility.[2] She emphasizes the particularly concerning conditions in care homes:

> *Many of these facilities are in fact segregated institutions, where staff exercise control over the person's daily life and make decisions about the person's care, including their placement in segregated locked wards, the administration of chemical restraints such as psychotropic drugs and the use of other physical restraints.*[3]

An examination of confinement in care homes is timely because of growing international momentum to improve the human rights of people living with dementia. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) enshrines the rights to non-discrimination and equality, including in relation to deprivation of liberty, the exercise of legal capacity, and consent to medical treatment.[4] People living with dementia and their organizations, such as Dementia Alliance International, are advocating for equal rights for people living with dementia in care homes.[5] Scholars and practitioners in public health and dementia care, traditionally focused on individual quality of care, are also now engaging with human rights.[6] International civil society is taking up this issue as well; for example, Human Rights Watch recently reported on chemical restraint in Australia and the United States.[7] The ongoing development of a Convention on the Rights of Older Persons promises enhanced recognition of the rights of people living with dementia.[8]

Turning to Australia, our focus, in 2016–17 there were 902 providers of aged care offering 200,689 residential places in 2,672 facilities, at a cost to the government of AUD11.9 billion.[9] Moreover, "[s]ince 2008–09, the proportion of people entering residential care with a diagnosis of dementia has been consistently between around 43 per cent and 45 per cent of all permanent residents entering care."[10] These statistics alone indicate the increasing significance of care homes to the well-being and enjoyment of human rights of people living with dementia. However, a number of government reviews and inquiries have recently drawn attention to systemic shortcomings in the aged care system and have flagged their impact on human rights and people living with dementia (even if tangentially). Most notable in this respect is the current Royal Commission into Aged Care Quality and Safety ("Aged Care Royal Commission"), which states in its 2019 interim report that "[m]any people receiving aged care services have their basic human rights denied. Their dignity is not respected, and their identity is ignored. It most certainly is not a full life."[11] It should be noted that Royal Commissions present a particularly significant opportunity to explore systems; in this way, they differ from most legal mechanisms, such as courts, which are focused on specific justiciable issues concerning a particular individual's specific experience with a system. However, there is a long critique of government inaction on Royal Commission recommendations for systemic reform.[12] This is perhaps exacerbated in the context of aged care. While concepts such as "dignity" feature in Australia's new Aged Care Quality Standards, possibly suggesting promising leanings toward human rights in aged care service delivery, there is a disappointing absence of reference in these standards to individuals' access to avenues for enforcement or redress for breach.[13] In the Aged Care Royal Commission's terms of reference and interim report, there is a similar absence of mention of—let alone in-depth consideration and commitment to action on—matters of enforceable legal or human rights and recourse to redress. Despite the possibly limited impact of the Aged Care Royal Commission on human rights reforms to aged care policy and practice, the evidence coming out of the inquiry confirms the urgency of increased engagement by human rights scholars and practitioners with care homes as a site of widespread and profound human rights violations.

We begin this paper by discussing some of the existing literature on the confinement of people living with dementia in care homes. Next, we introduce methods and present key findings from focus groups and interviews, identifying a series of interrelated factors that contribute to human rights breaches pertaining to confinement. We then reflect on the findings in the context of human rights and offer some recommendations for human rights scholars and practitioners. Our reflections are also relevant and of benefit to aged care and health policy workers who might very well have more capacity to affect the legal, policy, and service delivery frameworks that directly shape the conditions in aged care.

The confinement of people living with dementia in care homes

People living with dementia have explicitly expressed the desire not to be confined in care homes. Drawing on results from interviews and online focus groups with people living with dementia, a recent book by Kate Swaffer (a dementia human rights advocate living with dementia) and Lee-Fay Low explains what people living with dementia want in residential care. They want non-institutionalized settings, no segregation or locked dementia units, and the absence of apparent barriers or walls. They also want ample space inside and outside, as well as access to outdoor recreational areas for walking, bird watching, and enjoying natural environments. Swaffer and Low explain that people living with dementia want re-ablement, rehabilitation, exercise, and recreational activities; the ability for the outside community to come in; the opportunity to have visitors stay overnight; and strategies to enable independence.[14] However, as documented by the literature on aged care, care homes commonly employ a wide range of physical and environmental barriers to movement, including locked doors, lap sashes and belts, bed rails, and segregated wards.[15] Having a secured perimeter is often taken for granted as necessary for a care home where people living with dementia reside. While there is ample evidence that obvious "safety" features such as high fences can increase depression and agitation and provoke attempts to escape, staff and families continue to defend their use as being necessary to provide protection from the perils of access to the outside of the care home and getting lost. In addition, medications are overused in care homes, sometimes as a means of restraining people with dementia without consent.[16]

Human rights scholars' and practitioners' exploration of the confinement of people living with dementia in care homes has focused largely on the deprivation of or restriction on liberty through the use of restrictive practices such as those described above. However, a more nuanced examination of the dynamics within aged care settings resonates with the observation made by the Special Rapporteur on health (in the context of the right to health) that "[a] structural assessment … of the 'climate' of prison, detention and confinement, that is, how people experience life and survive once inside, how power is structured and organized and the structural factors that enable practices and institutions to persist, would help to broaden such responses."[17] He elaborates on the systemic cultures that shape spaces of confinement:

> *Centres of … confinement often concentrate people from the most vulnerable situations, including those who are medically vulnerable. The centres are often characterized by inhumane physical and psychosocial environments and unequal structures of power frequently rooted within racist and violent pasts. The unpopularity and powerlessness of those deprived of liberty and confined leave them with no voice and few defenders to advocate for their dignity. These factors shape an ecology of deprivation that*

> *significantly compromises the ethical and effective organization and delivery of health care.*[18]

In the course of grappling with the ethical, legal, and practical challenges to providing high-quality care to people living with dementia in care homes, health sciences research implicitly points to some less tangible means through which confinement occurs.[19] This research indicates that some of the most common forms of indirect restriction are seating a person in a deep chair that they cannot get out of, placing a table in front of their chair, leaning a wheelchair back, and otherwise ensuring that the person is "parked."[20] As with fences, these techniques are frequently defended as necessary to protect the safety of residents and to enable daily care tasks to be performed.[21] Yet sociological scholarship emphasizes the socially constructed nature of risk, in particular the riskiness of people with dementia "wandering."[22] Several scholars have argued that the extent to which doors are locked and the movement of people living with dementia is restricted, particularly with regard to outside spaces and beyond care home perimeters, varies depending on an institution's philosophy, approach to risk, and understanding of dementia.[23] Frances Tufford et al. point out that the prevalent prioritization of risk management over residents' choice and well-being indicates a cultural attitude of devaluing older people.[24]

Mark Skinner et al. argue that the social inclusion of people with dementia requires "supporting the rights for full participation with resources and services in relationships and activities across economic, social and cultural spheres," including for those people living in institutional settings.[25] The health sciences literature, however, documents decisions made by care homes not to include people living with dementia in social and recreational activities. Research on residents' access to community beyond the perimeter of a care home suggests that facilities often provide only very limited opportunities.[26] Underlying the lack of provision of such opportunities, Sherry L. Dupuis et al. identify resource limitations, as well as staff concerns about the suitability of the community for residents, and vice versa.[27] People with dementia in residential care are accordingly less likely to have opportunities for community access. Restrictions on movement into care homes of family and friends also contribute to the sense of confinement experienced by residents. Jessica E. Thomas et al.'s research shows that a care home's environment and location can be a barrier to family and friends visiting.[28] Unsurprisingly, a lack of continuity with the broader community is associated with depression among residents.[29]

Methods

This paper reports on the findings of an Australian project that involved interviews and focus groups with people living with dementia, care partners, care home workers, and lawyers and advocates. Taking insights from health sciences literature and observations of the Special Rapporteur on the right to health as a point of departure, this paper aims to deepen human rights scholars' and practitioners' understanding of the drivers and facilitators of confinement in care homes, with the ultimate aim of enhancing the human rights of people living with dementia.

The project researchers constitute an interdisciplinary team traversing law, public health, dementia design, psychology, and science and technology studies, and include a leading international advocate on the rights of persons living with dementia who herself has younger onset dementia (Kate Swaffer). Our project was guided by an advisory group that included people living with dementia, care partners, care home professionals, and lawyers and advocates for people living with dementia.

Recruitment

We recruited a convenience sample of participants by promoting our research to organizations whose members or staff identify with the relevant participant groups (people living with dementia, care partners, care home professionals, and lawyers and advocates). Promotion occurred via email, websites, Facebook, and Twitter. All those who responded were provided with the participant information statement and consent form and were required to provide written consent to participate. Our recruitment targets are outlined in Table 1.

Following extensive recruitment efforts, our final sample of participants consisted of 5 people living with dementia, 19 care partners, 12 care home professionals, and 9 lawyers and advocates. Overall, this was consistent with our targets, with the exception of the low numbers of participants living with dementia. We were unable to recruit any aged care regulatory officials.

Data collection

We gave respondents the choice of participating in an individual interview (via Zoom or phone) or an in-person focus group. Participants were asked questions about their current awareness and experiences of community access and freedom of movement in relation to care homes (commonly referred to in Australia as "aged care facilities"), as well as questions about their views on human rights (the latter is reported in a separate paper).[30] Questions about current awareness and experiences of community access and freedom of movement included the following:

- Do you know if people living with dementia in aged care facilities have access to the community? How does community access occur?
- Do you know if people living with dementia in aged care facilities have access to the full range of recreational and social spaces and activities in the aged care facility?
- Do you know of anyone who has been restricted in their ability to move around or beyond an aged care facility through the built environment? How did this occur?

Interviews ran for approximately 40–60 minutes, and focus groups ran for 1.5–2 hours. To maximize participants' comfort and freedom, the two focus groups with a mixture of participant groups were conducted in two stages. The first stage, on current practice, separated participants with dementia and care partners from those who were care home professionals. For the second stage, all participants came together to discuss human rights.

Analysis

The data was thematically analyzed. Initial coding was undertaken manually by three of the authors. Each engaged in iterative coding of a small sample of transcripts. Following a discussion of emerging themes, a coding schema was applied to identify barriers to a wide range of CRPD rights relevant to freedom of movement and community access. This approach was taken in order to ensure that the analysis drew out the human rights implications of the data (with particular attention to the material, legal, and cultural dynamics affecting day-to-day experiences of restricted movement and community access). The broad range of rights utilized in coding enabled a more nuanced understanding of the dynamics of confinement, notably a shift away from a focus on the deprivation of liberty toward one that includes rights related to various facets of the care home experience whose breach can indirectly give rise to confinement. For example, attention to the right to participation in cultural life, recreation, leisure, and sport highlighted the impact that segregated bus trips have on confinement (a point we elaborate on below)—a finding that would not have emerged if we had concentrated only on the use of locks, lap belts, and so forth as is the focus of the right to liberty and security of the person. Transcripts were uploaded into NVivo 12 to

Table 1. Recruitment targets

Participant group	Target sample size
People living with dementia	15
Care partners	10
Care home professionals	15
Lawyers and advocates	10
Total	50

support systematic coding by one of the authors. Another author then identified themes emerging from and cutting across the codes for discussion in this paper, choosing those themes that were particularly relevant to enhancing human rights scholars' and practitioners' engagement with confinement in care homes.

Findings

Interestingly, while participants mentioned physical and environment restrictions on liberty (predominantly locked doors and gates) and ways in which people living with dementia had limited or no access to community activities or spaces, they generally did not perceive these as forms of confinement or restrictions on liberty or, indeed, even as problematic or unusual. As an overarching observation, this suggests that those involved in the day-to-day support and advocacy of people living with dementia are largely oblivious to significant human rights violations. We now turn to draw out some of the dynamics that contribute to restricted freedom of movement and limited community access and, we argue, systemic, day-to-day practices of confinement in care homes.

Locks and other material features of restraint

Many of the participants identified material features of restraint that restrict the movement of people living with dementia in care homes. However, participants generally mentioned these features only after being specifically asked about them by the interviewer, suggesting that they are unquestioned aspects of care home culture. One care home professional described these circumstances and attributed them to safety:

> *Across all of our sites where we have dementia units, they're behind an access-control door. But it's always done because of the residents' safety, so they don't wander out onto the street, so they don't go … It's for their safety. (focus group 2, care home professional)*

Locked doors can also affect the ability of people living with dementia to receive visitors, as described by one care partner who has a friend in a dementia care unit (DCU) "cottage":

> *All the cottages are locked so there's, the facility, itself, just has a white picket fence but it's double locked everywhere. Each cottage has its own little back yard and that's got high bars et cetera … So, it really is—this particular friend is really going through psychological distress. Feeling locked in … So, if I go to visit him, I have to call ahead to the cottage and tell them that I'm coming and then I get to the cottage and knock or ring. And then I say who am I coming to see and then they open the door. (focus group 1, care partner)*

Participants also observed forms of physical restraint. One person living with dementia who had visited care homes noted:

> *I've seen them sat with the tray tables and they were*

TABLE 2. Initial coding schema and final cross-cutting themes

Primary node	Initial codes	Cross-cutting themes
Human rights for community access	• Accessibility • Choice • Family relationships • Freedom from violence, abuse, and neglect • Freedom of expression • Habilitation and rehabilitation • Health • Independent living and community inclusion • Inherent dignity • Liberty • Mobility • Non-discrimination • Participation in cultural life, recreation, leisure, and sport	• Locks and other material features of restraint • Immobilization and neglect • Limited and segregated activities • Apprehending community exclusion • Duty of care and liability • Pathologization and subversion of resistance

> *still sitting there hours later with the tray table in front of them. (interview 5, person with dementia)*

As we discuss further below in relation to the subversion of resistance, some care partner participants had knowledge of chemical restraint in relation to their spouses or parents with dementia. These findings illustrate that restrictive practices are used in care homes and clearly affect mental well-being. However, as we now turn to show, the picture of confinement in care homes is much more complex and can occur in more subtle or unexpected ways.

Immobilization and neglect

The most commonly mentioned factor affecting freedom of movement was the removal of means of mobility. This includes not providing mobility aids, opportunities for physical exercise, or meaningful activities to prevent decline and distress.

> *The first thing they do with people with walking frames is take the walking frame away from them and put them in a wheelchair because they don't have the staff to support them while they're walking. And they sat in the wheelchair, and then they just … they're parked. (focus group 1, care partner)*

Several participants mentioned people being seated ("parked") in front of televisions:

> *They're parked … No, I'm not talking about them being restrained. I'm talking about them being put in an area like the common area, where the TV's on, and, essentially, just left there. And they're supposed to occupy themselves, I suppose, by looking at the TV for endless hours. Or, alternatively, they're left in their room, perhaps in their bed or in their chair, but with no real way of them getting up and being able to move about and interact. (interview 3, lawyer)*

These indirect means of restricting people's movement can have profound impacts on people's physical and mental well-being. They not only prevent immediate movement by residents with dementia but may reduce their capacity for mobility over time, in some instances physically disabling them.

Limited and segregated activities

While some care partners spoke positively about the opportunities for family and friends to enter the care home to visit residents with dementia and opportunities for the broader community to frequent cafes operating commercially on the care home site, many participants mentioned the limited opportunities for people living with dementia to move freely and spontaneously in the community, instead being restricted to excursions in groups that generally involved pre-determined activities and destinations. A common example offered was a bus trip:

> *Well, actually, where the sister is, they do occasionally have external activities, bus trips to places. (focus group 2, person with dementia)*

> *My experience is … that the bus trips go out, but the residents don't get off the bus. They maybe go for an ice-cream or view of the coastline. (focus group 1, care home professional)*

A participant living with dementia who lives in a care home (but not in a DCU) elaborated on the bus trip they regularly participate in:

> *Yes, so there are outings and then there's a bus that goes on a Friday … It's only three quarters of an hour, but it just goes for a tour around the area and you see, you know, interesting points, history in the area because there's lots … Being in the gold fields, there's lots and lots of history in the area, you know. So I know I enjoy going out on that … we just sit in the bus because it's only about three quarters of an hour, that one. (interview 10, person with dementia)*

While some care partners spoke positively of the recreational and social opportunities available to residents with dementia within the care home, some participants noted that people living with dementia were not always included in the *full range* of external activities on offer to other residents. One participant living with dementia (focus group 2) said that people in the DCU were taken out on separate bus trips and these trips were "far rarer" and "more limited." This was corroborated by another professional:

> *They don't really have the full range of the activities*

> *that the other residents in the main nursing home have. (focus group 1, care home professional)*

Individualized community access (in the dual sense of going out by oneself and choosing the timing and activities) was rare and contingent on staff availability and access to transportation. Given the limited resourcing of care homes, it thus depended on individuals' access to family or friends who could help them.

Some people are denied access to the full range of social and recreational opportunities, being restricted to specific sections of the care home designated for people living with dementia. These areas are not always of the same quality as other areas:

> *They have opportunities to do activities in a certain area, a communal area where they would have music or people to visit them, community visitors and whatnot ... that isn't like the dementia unit ... the rest of the facility have more open plan areas, gardens they can go and sit at. Although there are little gardens in the dementia unit but it's not as—what's the word?—fancy versus the other non-dementia unit areas. (interview 12, advocate)*

A care partner similarly described the lack of stimulating activities and spaces in the DCU where her husband had lived:

> *There was a very, very basic garden around the cottage with a little path that walked round the perimeter of the cottage. And there were 14 residents in each cottage. So, some of them seemed to get into a habitual behaviour of walking round and round on this path around the perimeter of the cottage, which had a high fence around it. So, my husband eventually joined the walk. Which they do on their own volition, just going round in circles on this pathway. (interview 6, care partner)*

Thus, people living with dementia can come to be confined through exclusion from opportunities to venture outside of the care home or to even traverse the care home itself, and through reduced opportunities for social interaction and meaningful activities. These means of confinement are striking in their segregating and discriminatory character, yet the majority of participants, across all groups, took these as normal or at least inevitable and unchangeable.

Apprehending community exclusion

Many care home professionals and care partners noted that the lack of understanding of dementia in members of the community caused fear, which can lead to residents with dementia being prevented from having access to the community:

> *Somebody has got a disability and he's got a wheelchair; the public is aware that this one, we can help them in this way. But with dementia, there's lack of awareness on how they present and the help that they need. (focus group 2, care home professional)*

Participants also noted that public spaces outside of the care home might not be physically accessible for people living with dementia.

In this way, people living with dementia are effectively fenced in by both the stigma around dementia and the staff perception that negative community experiences are too difficult to manage. Yet, at the same time, the segregation of people with dementia cuts off opportunities for the whole community to develop a better understanding of living with dementia, thus reinforcing the "need" for confinement.

Duty of care, risk, and liability

Perceptions of duty of care play a significant role in shaping care home staff's decisions about where in the care home people with dementia live, the circumstances in which they live, and whether they are included in excursions. Staff in some care homes quickly classified these residents' riskiness, as noted by this care partner:

> *In terms of restriction or access to community services, the only one that was accessed ... in the normal community ... was to the local bowling club ... In the minibus, which was once a week under supervision. For a small group of suitable residents. My husband participated in that on one occasion not long after he went there but was deemed to be a person who would be at risk after that one*

> *outing. That he was always looking at the horizon as though how he might escape, was their view, so he was banned from all future outings. (interview 6, care partner)*

Lawyer and advocate participants, as well as some care partner participants, thought that duty of care toward residents with dementia was interpreted narrowly and arbitrarily by some care home staff as the physical safety of the individual. There was little consideration of the extent to which the duty of care pertained to emotional well-being or a duty to protect people's rights and freedoms and to recognize personhood. Moreover, comments by some participants suggested that it is potentially directed toward concerns about protecting the care home from liability, rather than concern about the well-being of residents with dementia. For example, lawyers and advocates noted that fear of litigation may press care homes into risk-averse restrictions:

> *Now, when you run a nursing home you want to keep the people who live there safe because you have a duty of care, and also, you could be sued if you don't do that. So, to really make sure people are safe and not in any danger, you completely remove risk, but when you do that you remove people's rights and the quality of their lives. (interview 14, lawyer)*

The lawyer explained how physical confinement and chemical restraint are central practices to the pursuit of this so-called duty:

> *To minimise that liability and have that duty of care, what a lot of aged care facilities do, will they heavily medicate the older person. That's a form of restraint. They've got them drugged up all day. Then their behaviours are not going to come out, they're not going to do much. You're not going to have staff who have to, kind of, chase after them. (interview 14, lawyer)*

Some care home staff noted the role played by family members in asserting a stringent focus on duty of care as physical safety. They highlighted the need for community education to teach people that being diagnosed with dementia should not automatically equate with people having their choices taken away from them:

> *And we're seeing … that shift … in terms of litigation in response, as a sector… to "Mum fell" or that "Mum breaks her hip and dies." Well, actually … they have a duty of care so Mum shouldn't fall. But, in actual [fact], Mum's choice was to actually get up and move and want to be free and not restricted. So I think there's that whole balance there.*
> *It's really about educating the broader community around a diagnosis that doesn't mean to say you don't have the same rights as any other human being … I think it's just about people understanding that just because Mum or Dad or Aunt or Uncle have a diagnosis of dementia doesn't mean that they can't make decisions about some things. (interview 16, care home professional)*

These findings illuminate both misconceptions about the legal content of duty of care and a fear of liability for breach of duty in which considerations of the well-being and agency of the resident are largely absent. However, one care home professional (interview 18, care home professional) did recognize that "behaviors" of dementia that resulted in confinement for one's purported safety were most likely the care home's failure of its duty to provide residents with dementia with more stimulation.

The dominance of liability considerations in the choices made by care home staff about the movement and living circumstances of people living with dementia might inform the use of restrictive practices and, if an individual is not locked up or restrained, hinder individuals' ability to practically *realize* their freedom of movement (for example, by receiving practical support from staff in order to be able to leave the care home or even leave their bed).

Pathologization and subversion of resistance

Some lawyers, advocates, care partners, and care home professionals expressed assumptions that people living with dementia cannot know and express their own views and needs. Such assumptions supported care homes denying people living with dementia the opportunities to make their own choices, rather than recognizing a basic desire for freedom. One person living with dementia stated:

> *So it was just a matter of, you know, there's reasons that people go walking, if you know the history that they were up at dawn and they walked for five*

> *kilometres as the sun was coming up, well, that's what they're going to do. And so, you need to look at it with a, from outside of the square, why is this person doing this, why. (interview 5, person with dementia)*

These assumptions also meant that attempts by people living with dementia to leave the care home were framed as subversive acts of escape or absconding. It is striking that behaviors that might be viewed as resistance or distress in response to the living circumstances of residents with dementia were pathologized as challenging or a clinical symptom of dementia, thus legitimating these individuals' being locked away or excluded from community access.

> *I think the really telling thing is the number of people who are restrained because they object to the way they're being treated. And, in fact, in many cases people don't get the chance to say what they would like, they're told what they're supposed to do and then their reaction is, no. And so, if you react with no, it's BPSD [behavioral and psychological symptoms of dementia], give you a shot, sit you in a chair, lap belt, whatever. Shut up and behave. (focus group 1, care partner)*

Attempts to express distress and resistance in relation to one's circumstances can simply sustain and legitimate the continuation of those circumstances. This was reflected in one care partner's experiences in relation to her husband:

> *He wasn't as well placed as he would've been in the past to discuss, explain, comment on how he was feeling about, for example, being confined to the cottage. So, you had to go by his behaviour, his expressions. And he subsequently made a few attempts to escape over the fence at different times in the following months. And was, of course, eventually caught and brought back ... He did subsequently decline because they put him on anti-psychotics and that had a terrible effect on his capacities and, I think, just really accelerated his decline, rather rapidly from there ... it certainly wasn't discussed with me what the side effects were likely to be, and I don't know whether people even knew or cared, perhaps, you know? It wasn't 'til sometime afterwards that I realised the decline we were seeing in him, both physically and mentally, was attributed to the anti-psychotics. (interview 6, care partner)*

This participant's husband was then moved to a locked cottage, which she noted she had not authorized:

> *They didn't consult with me before doing that. The incident of him scaling the fence and trying to escape and he was caught. So, they brought him back and immediately transferred him and notified me afterwards. So, they seemed to consider … it was within their rights for the safety of the patient and for the safety of staff. (interview 6, care partner)*

The pathologizing and subversion of resistance is a deeply concerning dynamic of confinement because it effectively prevents individuals from challenging the power relations within care homes.

To conclude our discussion of the findings, restrictive practices might be integral to the confinement of people living with dementia, yet they are just the "tip of the iceberg" of confinement, with multiple, less visible, and more diffuse dynamics at play. These dynamics could very well be present in relation to an individual or an entire care home free of restrictive practices. Indeed, our findings highlight indirect factors of restriction of liberty that are interrelated and compound one another in a negative spiral. The cultural understandings of dementia and people living with dementia is what threads together or interlocks the various facilitators of restriction, informing day-to-day choices made by care home staff and family members. If we envisage these compounding factors in terms of concentric circles, then at the very core sit profoundly troubling views about the ontology and epistemology of people living with dementia—who they are and can be, and what they can know and want. Our findings also reveal an aged care sector that is, at its heart, risk averse and procedural in nature. It is a sector that sustains a culture committed to minimizing risk, which is viewed through a narrow lens, at the expense of residents with dementia enjoying equality, autonomy, dignity, freedom, and other aspects integral to their physical and mental well-being.

Implications for human rights scholars and practitioners

Human rights scholars and practitioners have demonstrated increasing interest in the rights of people living with dementia, and the recent Aged Care Royal Commission has provided a forum through which to draw attention to these issues in the Australian context. The findings discussed in this paper suggest how the work of scholars and practitioners advocating for the human rights of people living with dementia can be broadened and enriched. The points we make here are also relevant to aged care and health policy makers, particularly because of their engagement with recommendations of the Aged Care Royal Commission. We conclude by identifying four key implications.

First, human rights scholars and practitioners can supplement their focus on restrictive practices and other legally ordered or regulated modes of deprivation of liberty with more microlevel dynamics affecting movement and agency in order to counter multifarious practices of confinement of people living with dementia. Restrictions occurring in the mundane, day-to-day provision of care can arise irrespective of formal restrictive practices and might not be associated with the kinds of decisions that care homes require from substituted decision makers. These issues might continue even if legal frameworks for restrictive practices are reformed. Confinement in care homes can so easily and systematically occur irrespective of the presence of legal authority or physical restraint (as compared to prisons, immigration detention facilities, or mental health facilities, where there are clearer legal and physical boundaries to confinement). One particular step that human rights practitioners and scholars can take is to argue for care homes to be classified as "places of detention" for the purpose of monitoring for torture under the Optional Protocol to the Convention against Torture. Australia has recently ratified this optional protocol, although it has yet to deem care homes (or locked units within them) as "primary places of detention" for monitoring, as advocated by civil society and legal scholars.[31] In Australia's neighboring jurisdiction, New Zealand, locked dementia wards have been deemed places of detention and are now subject to the same scrutiny as jails.[32]

Second, human rights scholars and practitioners can advocate on issues relating to community access, social and recreational inclusion within care homes, and physical mobility. Lawyers and advocates providing support to people living with dementia in care homes should consider the extent to which existing laws and policies that might directly or indirectly pertain to these issues can be creatively utilized to challenge confinement.

Third, human rights scholars and practitioners should challenge the current interpretations and misappropriations of duty of care in relation to people living with dementia, and advocate for legal reforms that re-center people living with dementia as subjects of duty of care and see "duty of care" as requiring care homes to uphold freedom of movement and a full range of human rights. It would also be useful for all lawyers who work in elder and disability law to be made aware of the problems with the current narrow (mis)understandings of duty of care and to consider how they can shift community attitudes through their legal advice and advocacy.

Fourth, while it is important for human rights scholars and practitioners to advocate, in accordance with article 19 of the CRPD, for improved circumstances of those living inside care homes, there is a bigger, more long-term aim that requires their attention: deinstitutionalization, desegregation, and a transformation of the fundamental ways in which we provide housing and support to people living with dementia. For an increasing number of people with dementia, even current initiatives such as Dementia Friendly Communities and dementia villages run the risk of reinforcing ideas of dementia as "different" and of supporting inequality and, in turn, segregation and confinement. Indeed, the UN Special Rapporteur on the rights of persons with disabilities has noted this, stating, "Of particular concern is the emergence of dementia villages in developed countries, which represent a systemic form of disability-based segregation and isolation."[33] While deinstitutionalization of the aged care system might seem an impossible and incomprehensible task, the child welfare and disability systems provide examples of the closure of large-scale institutions and movement of individuals into smaller-scale residences in the community. While these have not necessarily been wholly successful in addressing cultural, social, political, and legal drivers of oppression, they show that change is possible and provide case studies from which we might learn about how to garner policy and community momentum toward change (and the possible unintended consequences and risks we need to be alert to along the way).[34]

Ultimately, human rights scholars and practitioners (and aged care and health policy makers), mindful of principles of equality and personhood for all, should challenge the cultural logics around dementia that sustain confinement. One of these logics is that dementia is feared and needs to be hidden from the community. Another logic is that people living with dementia lack their own subjectivity and ability to articulate their needs and experiences. All of these logics speak to a profound tolerance of the inequality and dehumanization of people living with dementia. It is vital to foreground the voices and experiences of people living with dementia in human rights scholarship and advocacy, support and amplify the work of consumer-led organizations such as Dementia Alliance International, and challenge the pathologization and subversion of their acts of resistance into further bases for confinement.

Acknowledgments

We thank members of the project advisory group for their insights, guidance, and support. This paper is part of the “Safe and Just Futures for People Living with Dementia in Residential Aged Care” project funded by the Dementia Australia Research Foundation – Victoria.

Ethics approval

This study was approved by the University of Technology Sydney Human Research Ethics Committee (approval no. ETH18-2508).

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Health and Human Rights Journal

Adherence to the Convention on the Rights of People with Disabilities in Czech Psychiatric Hospitals: A Nationwide Evaluation Study

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Abstract

This study sought to evaluate the quality of care in Czech psychiatric hospitals and adherence to the Convention on the Rights of Persons with Disabilities (CRPD). Each psychiatric hospital was evaluated by a team comprising a service user, a psychiatrist, a social worker, a human rights lawyer, and a researcher, all trained in using the World Health Organization's QualityRights Toolkit. We conducted content analysis on internal documents from psychiatric hospitals, observed everyday practices, and conducted 579 interviews across public psychiatric hospitals between 2017 and 2019. We found that none of the CRPD articles as assessed by the QualityRights Toolkit was fully adhered to in Czech psychiatric hospitals. We recommend both facility- and system-level interventions to improve CRPD adherence in the Czech context and in the wider region of Central and Eastern Europe. To achieve this, substantial investments are required.

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Competing interests: None declared.

Introduction

Psychiatric hospitals have been associated with violations of the human rights of service users all over the world.[1] In many countries, this has triggered a deinstitutionalization of psychiatric services, which is understood as shifting the locus of care from psychiatric hospitals to care in the community.[2] Deinstitutionalization began in the 1950s and has been successfully pursued in many countries worldwide, but not in the region of Central and Eastern Europe.[3] Evidence from Scandinavia suggests that deinstitutionalization has led to both a decrease in suicide and a lower mortality gap between people with mental disorders and the general population.[4]

Mental health care systems in Central and Eastern Europe—despite a significant development of community services, increased participation of service users, and stronger emphasis on human rights over the last three decades—remain hospital based and inefficiently funded.[5] The *Strategy for Mental Health Care Reform* published by the Ministry of Health of the Czech Republic places a strong emphasis on human rights and includes deinstitutionalization as a major aim for reform.[6] The strategy has been translated into implementation projects funded by European structural and investment funds. One of these projects is entitled "Deinstitutionalization" and is focused on the transformation of Czech psychiatric hospitals. Increased adherence toward the human rights of people with mental health problems is one of the primary aims of this project.

The Convention on the Rights of People with Disabilities (CRPD) was adopted by the United Nations in 2006 to "promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[7] The CRPD has introduced new challenges for mental health care legislation and practice, and it is now considered a milestone in safeguarding the human rights of people with mental health problems.[8]

In 2017, the World Health Organization (WHO) used its QualityRights Toolkit to evaluate adherence to the CRPD in selected European long-term residential institutions for people with psychosocial disabilities.[9] We aimed to follow up on this initiative and assess adherence to the CRPD in all Czech psychiatric hospitals.

Methods

Participating psychiatric hospitals

The Institute of Health Information and Statistics of the Czech Republic registered a total of 21 psychiatric hospitals in the Czech Republic in 20Of those, three care specifically for children and adolescents, three are primarily for people addicted to alcohol and other substances, and one is for people with organic mental disorders. The remaining 15 psychiatric hospitals provide long-term care for various groups of people with mental illness, including long-term care (six months and longer) for adults with severe mental illnesses. Eighteen psychiatric hospitals are public and belong to either the Ministry of Health or a Czech administrative region; three psychiatric hospitals are private.

Two Czech psychiatric hospitals participated in the aforementioned 2017 WHO survey assessing adherence to the CRPD.[10] For our study, we invited all but one of the Czech Republic's public psychiatric hospitals to participate in a nationwide evaluation of adherence to the CRPD in 2018 or early 20One smaller public psychiatric hospital was not included because it was already assessed within the 2017 WHO survey. We did, however, invite the other psychiatric hospital that participated in the 2017 survey because only a portion of the hospital's approximately 30 wards had participated in the WHO survey.

In total, 16 of the 17 public psychiatric hospitals we invited participated in our study. The one public hospital that declined our invitation is a relatively small institution, with 70 beds, and belongs to one of the Czech administrative regions. This paper synthesizes the findings from our study, as well as the results from one of the hospitals that participated in the 2017 WHO survey, in order to present results for 17 of the country's 18 public psychiatric hospitals.

Instrument

The WHO QualityRights Toolkit is divided into five basic themes, each focused on specific articles of the CRPD: (1) articles 12 and 14 (the right to exercise legal capacity and the right to personal liberty and the security of person); (2) articles 15 and 16 (freedom from torture and cruel, inhuman, or degrading treatment or punishment and freedom from exploitation, violence, and abuse); (3) article 19 (the right to live independently and be included in the community); (4) article 25 (the right to enjoyment of the highest attainable standard of physical and mental health); and (5) article 28 (the right to an adequate standard of living). The themes are divided into standards, which consist of different criteria. The instrument allows each criterion to be scored as follows: "not initiated," "achievement initiated," "achieved partially," "achieved in full," and "not applicable." Under the tool, criteria are evaluated first. Then, a score is assigned to individual standards, based on both the scores of all criteria belonging to a given standard and on a discussion among team members. Therefore, the score for a standard is not a mere arithmetical mean of its criteria, nor is the score for a given theme. As a result, the evaluating team provides descriptions and justifications for the scores it awards to each criterion, standard, and theme, especially when adherence is considered to have only been initiated or not initiated at all.

Assessment

Our evaluation teams consisted of five evaluators: a psychiatrist, a social worker, a human rights lawyer, a service user, and a researcher. All evaluators, with the exception of substitutes, were trained in the use of the WHO QualityRights Toolkit by WHO experts during two-day workshops. Evaluation team members were encouraged to avoid any conflict of interest—that is, to dismiss themselves from assessments where a conflict of interest could arise, for example, because they were previously admitted to or employed by a hospital or because they had professional ties with a given hospital.

Evaluation visits were initiated by the Ministry of Health and planned in cooperation with management from each hospital. Visits lasted two or three days (according to the size of the psychiatric hospital) and included interviews with service users, relatives and close friends of service users, and hospital staff; an analysis of internal documents; non-participant observations; and participant observations (for example, participation in selected therapeutic activities). Overall, we conducted 579 interviews with 308 staff members (72 members of management, 224 staff who provide direct care, and 9 in other positions), 250 service users, and 21 family members and friends.

All members of the evaluation team were present during visits. Evaluation reports were produced following each visit. These reports included a basic description of the facility; the team's assessment methodology and a basic description of the sample; scores and justifications for each standard, criterion, and theme; context surrounding the institution; discussion surrounding the five themes; and recommendations for improving CRPD adherence. Evaluation scores were determined by consensus—in other words, based on discussion and agreement among the evaluation team. The evaluation team considered all available information, including observations, documentation, and interviews with service users, professionals, and family members. Interviews were guided by the WHO QualityRights Toolkit, which provides a set of questions for each standard.[11] In the case of ambiguity, the team conducted additional interviews. Rarely, when team members were unable to reach consensus, they voted in order to arrive at a final score.

Analyses

The data are presented anonymously and graphically, using clustered bar charts. One chart presents the results for adherence across all five themes, and five individual charts present the results for individual standards within each theme. In order to identify priority areas for improvement across psychiatric hospitals, we further analyzed the standards and themes that were least frequently adhered to according to the charts. To do this, we extracted qualitative descriptions and justifications provided by evaluation teams' reports across priority themes and standards for individual institutions and across all assessed institutions. Narrative discussion surrounding each of the five themes and recommendations for improving adherence are provided for both individual institutions and Czech psychiatric hospitals generally. The recommendations are our own and do not necessarily reflect the views of the evaluation teams.

Ethical considerations

All members of our evaluation teams signed a nondisclosure agreement. All interviewees received information about the study and provided written informed consent. Ethical approval for this study was provided by the Ethical Committee of the National Institute of Mental Health in 2017 (ID 188/17) and the Ethical Committee of the Ministry of Health in 2018 (ID MZDRP011FZ5B).

Results

Theme 1: The right to an adequate standard of living (CRPD art. 28)

In regard to overall adherence to theme 1, only one hospital was not actively initiating changes to assure an adequate standard of living for patients. However, no hospitals fully met the criteria of this standard. The hospital buildings were found suitable for usage following some technical adjustments. Almost one-third (5 of 17) of the hospitals were not wheelchair accessible, and only two psychiatric hospitals were fully barrier free. While most of the hospitals were investing in building reconstruction, only three hospital buildings provided a sufficiently adequate standard of living according to CRPD standards.

The evaluation teams found serious shortcomings in the area of comfortable sleep conditions and privacy, as well as room capacity discrepancies between buildings and hospitals. In newly reconstructed buildings, rooms usually accommodated two to three beds; however, some wards had fourteen-bed rooms. A strict daily regime was followed in most of the hospitals, and half of them allowed patients to choose when to get up and go to bed. Patients' rooms had non-locking doors, and lockers were not provided for personal belongings. Additionally, mobile phones, personal documents, and other personal belongings were usually kept in the nurses' office.

Patients' overall right to privacy was not fully respected within the hospitals. The majority of the hospitals we evaluated had not fully achieved CRPD-compliant conditions regarding facility sanitation. Patients shared common toilets with non-lockable doors and open showers. Regarding the food served, the dietary preferences of hospitalized patients were not considered, but minimum dietary requirements were fully adhered to.

Evaluation teams agreed that the food served should contain more fresh fruit and vegetables, legumes, and dairy products. However, most patients did not complain about the quality of their diet. Most of the hospitals (12 of 17) fully respected the patient's right to choose their clothing.

The evaluation teams found significant shortcomings in terms of the communication technologies available to patients. Time restrictions were applied to private mobile phone use, Wi-Fi connections were rarely available, and few wards employed a point reward system as a condition for using the facility phone. There also was a lack of privacy for personal communication, with insufficient or no rooms for personal visits, and no sound barriers for facility phones. Some hospitals (3 of 17) had no measures in place to meet adherence to this standard.

Consistent with the state of buildings, room furnishings required significant remodeling. Rooms were scarcely equipped, usually consisting of only a bed, bedside table, and closet. Some wards lacked a common room, which significantly limited social life within the facility, since patients, personnel, and visitors could not come together in a common setting. Staff rooms were sometimes located outside of the ward, separating personnel and service users and decreasing the sense of community. Leisure time activities usually took place in the eatery or hallways. Only a third (5 of 17) of hospitals fully met CRPD adherence in providing an environment conducive to active participation and interaction.

None of the hospitals we assessed fully

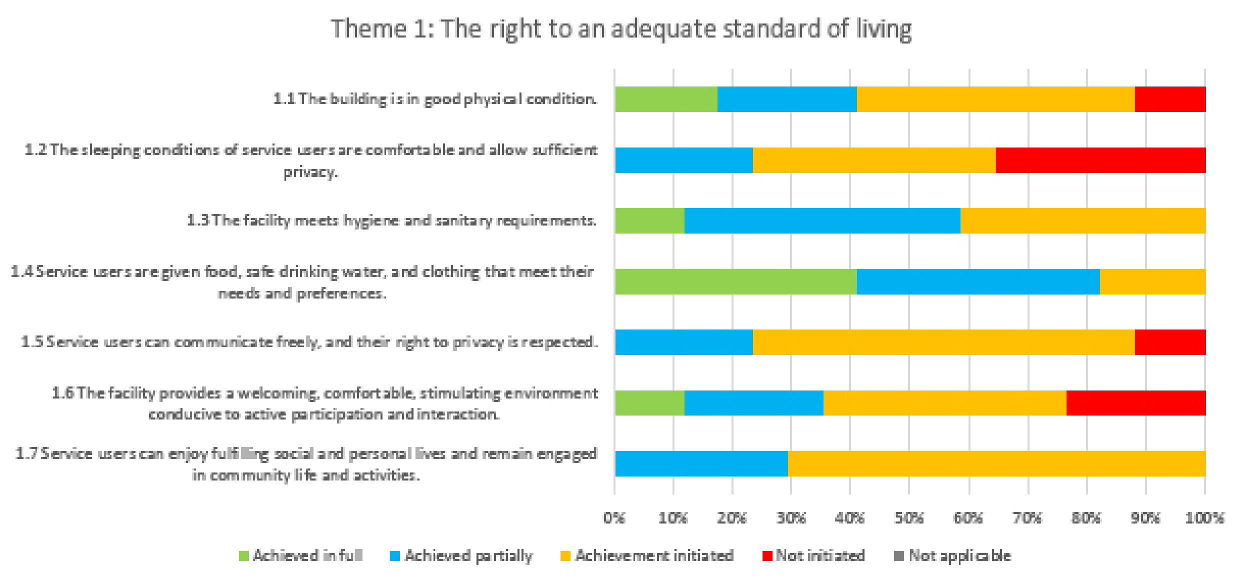
achieved the CRPD standard for patients' engagement in the community. Patients could meet with patients of the opposite sex only through gaining permission to leave their department. However, personnel in most psychiatric hospitals (12 of 17) proactively provided assistance for patients' personal affairs (for example, attending a wedding or a funeral). All psychiatric hospitals at least initiated organizing and providing information about social events within the hospital facility. On the other hand, none fully respected the CRPD recommendation to build an interactive environment between hospital and community.

Theme 2: The right to enjoyment of the highest attainable standard of physical and mental health (CRPD art. 25)

While adherence to theme 2 was fully achieved in only one psychiatric facility, all of them had at least initiated changes toward fulfilling the theme. Almost all psychiatric hospitals at least partially met the standard of providing adequate treatment and support to everyone in need. However, treatment for foreigners and people with disabilities fell short. A lack of translation services acted as a barrier to non-Czech speaking patients' participation in talking therapy. Additionally, the inaccessible state of hospital buildings detailed in theme 1 limited the scope of care provided to people with physical disabilities. No cases were uncovered where treatment was denied to anyone based on economic or social status, race, sex, religion, or political or philosophical opinions. Additionally, service users often remained hospitalized for non-health-related reasons, usually a lack of transitionary and follow-up services or inadequate financial security of service users.

Facility staff demonstrated significant knowledge gaps in terms of patients' rights—11 of the 17 hospitals had no rights-based trainings. Trainings on how to adequately support patients in social and community integration and independent living were largely lacking, with only a third of psychiatric hospitals training their staff in the benefits of multidisciplinary treatment and community-based care models. Some wards lacked adequate numbers of mental health professionals, though patients had adequate access to individual consultations with a psychiatrist. Most psychiatric hospitals had at least initiated mechanisms for service users to express their opinions on service provision and improvements. Areas for improvement identified by patients included the establishment of independent

FIGURE 1. Adherence to CRPD article 28 in Czech psychiatric hospitals: Results for individual standards



* 100 % = 17 psychiatric hospitals

commissions and the introduction of anonymous complaint processes that are accessible and understandable to patients.

The evaluation teams identified various deficits surrounding recovery plans. According to service users, a third of the hospitals (5 of 17) had initiated no efforts toward the preparation of recovery plans. Of the remaining facilities, only two at least partially met the criteria stated by standard 2.3. Patients' individual preferences were not considered because of the strict regime of treatment. In the majority of hospitals (11 of 17), individual recovery plans did not exist; and in three, individual plans existed but lacked complexity, excluding the patient from the process of developing the plan. A few psychiatric hospitals had guidelines regarding the development of either recovery plans or "previously expressed wishes," but the development and implementation of such documents was lacking, and neither patients nor staff were acquainted with these guidelines or documents.

Psychosocial therapeutic programs were available and systematically incorporated into individual treatments in all psychiatric hospitals except one; however, these programs were not accessible to all patients. Patients were not sufficiently supported in keeping social contact with family and close ones. The strict regime in psychiatric hospitals (including limited outings, visiting hours, ward visits, mobile phone usage, and Wi-Fi connections), scarce communication between hospital staff and patients' families, and insufficient staff capacity prevented adequate support networks for patients. About a third of the hospitals (5 of 17) had fully developed systems for follow-up services, including health (outpatient psychiatric clinics and somatic services) and social (mental health community care and social-based inpatient facilities) services. The remaining facilities had a shortage of integrated social-health professionals, resulting in social services being dependent on external providers.

About a quarter (4 of 17) of the hospitals fully met the standard on availability, affordability, and adequate usage of psychopharmaceutic drugs. Generally, psychopharmaceuticals were widely available. About half of the hospitals (7 of 17) used modern medications and conducted regular reviews of prescribed medications. According to the CRPD, patients in psychiatric hospitals should be adequately informed about the purpose and potential side effects of prescribed medications, as well as attainable alternatives to medications, which was not adhered to. Service users occasionally did not know which medication they were on and were generally uninformed of the drug's purposes, side effects, and alternative treatments. Service users' lack of knowledge of alternatives to medication (such as psychotherapy) is worth considering, especially in the context of the unavailability of these alternatives in the majority of psychiatric hospitals (10 of 17).

Services for physical health were accessible in all of the psychiatric hospitals. Specifically, physical health screening was available upon admission, and no deficits were found in the provision of surgical or medical procedures provided outside of the facility. However, preventive education programs on general health and reproductive health were not systematically provided in the vast majority of hospitals, apart from smoking reduction programs.

Theme 3: The right to exercise legal capacity and the right to personal liberty and the security of person (CRPD arts. 12 and 14)

All 17 psychiatric hospitals had at least initiated changes toward fulfilling patients' rights regarding legal capacity and personal liberty and security. However, patients' preferences concerning the place and form of their treatment were not prioritized.

According to the CRPD, treatment should be based on patients' free and informed consent. In general, fulfilment of this standard had been at least initiated in all of the psychiatric hospitals. However, treatment-related communication was not always fully understandable to patients, and the document containing "previously expressed wishes" was used in only 3 of the 17 hospitals. There were no cases of neglecting a patient's right to refuse treatment or of inappropriate involuntary treatment found within the health records we reviewed. On the other hand, the opportunity to appeal involuntary treatment was not clearly or adequately communicated or detailed to service users.

While 13 hospitals had taken measures toward adhering to the exercise of patients' legal rights, a paternalistic approach to service users remained dominant in most facilities. Education on rights and treatment was lacking, and supported decision-making was not systematically incorporated into services.

Service users' right to access personal health information was respected, and access to one's own medical records was available to all patients. Service users were also permitted to add supplemental information to their records; however, most patients were not aware of this option. Personal health information was treated as confidential.

Theme 4: Freedom from torture and cruel, inhuman, or degrading treatment or punishment, and from exploitation, violence, and abuse (CRPD arts. 15 and 16)

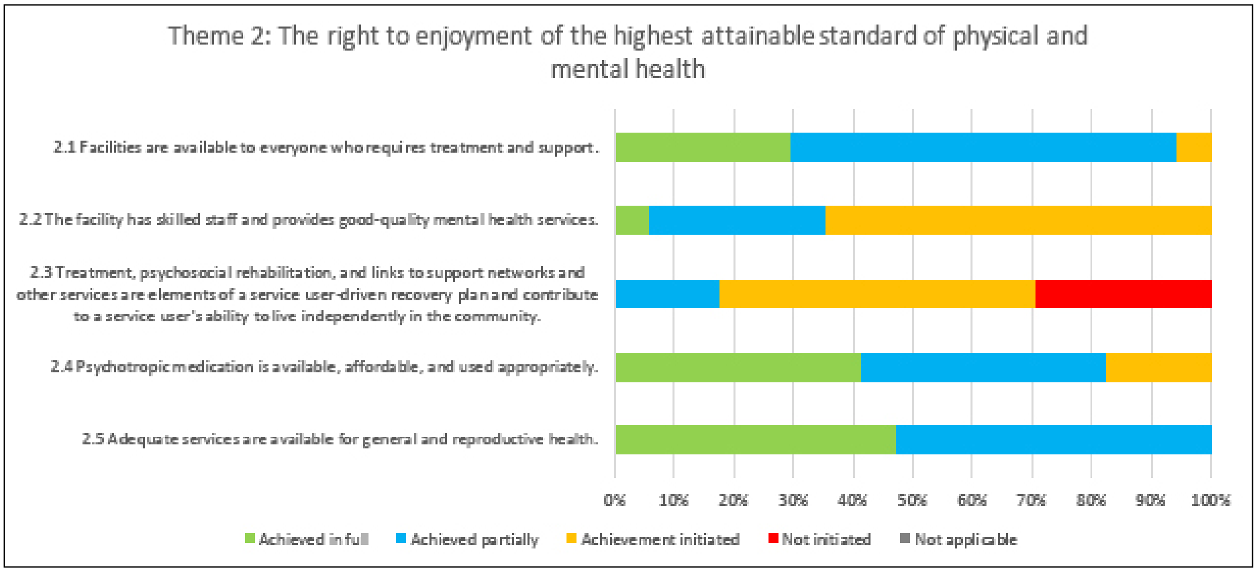
While none of the psychiatric hospitals fully adhered to this theme, more than half had at least initiated efforts toward its achievement. In 13 of the 17 hospitals, the use of medical restraints was in line with Czech legislation, and such instances were reported consistently to the head of the facility. Alternative methods to seclusion or restraint (such as de-escalation methods for potential crises) were often not in place. In 11 psychiatric hospitals, de-escalation methods were not used, nor were potential trigger factors for crisis evaluated. Emergency plans and personal recovery plans were missing across all of the psychiatric hospitals.

Insufficient access to legal representation was found in 8 of the 17 hospitals. Service users were not given information on independent legal authorities (such as the Ombudsman's Office). Additionally, when service users' communication was perceived as inappropriate (for example, shouting), punishments were in place (for instance, transfer to a closed department). Bullying among users was also noted as an issue.

Theme 5: The right to live independently and be included in the community (CRPD art. 29)

Service users were supported in securing a place to live in the community. However, the lack of staff, especially social workers, prevented service users from being adequately informed about all available options. Additionally, only two hospitals provided patients with sufficient access to education. The hospitals did not prevent users from participating in political, public, or community life, but they did not actively support or promote it.

FIGURE 2. Adherence to CRPD article 25 in Czech psychiatric hospitals: Results for individual standards



* 100 % = 17 psychiatric hospitals

Summary of results

In general, Czech psychiatric hospitals are in poor physical shape, are suboptimal for quality sleep, lack comfort and room for interaction, and do not meet many hygiene and sanitary requirements. Nutrition and clothing are mostly up to standards, except for some shortcomings with respect to the preferences of service users. Freedom of communication is low because of censorship, a lack of privacy, and service users' restricted access to facility premises. The social life of patients is also limited, especially with regard to social and cultural events outside of the hospital. The availability of medical care in psychiatric hospitals is very good, however provision of multi-sectoral services and human rights training for staff lack.

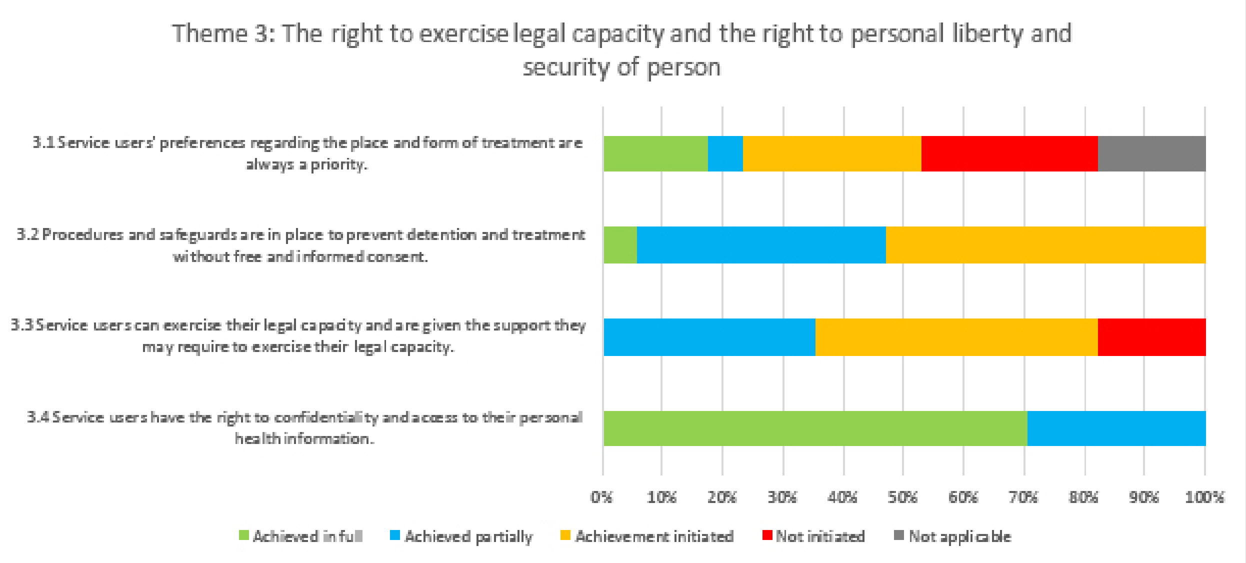
Individual recovery plans are scarce, and treatment and rehabilitation do not sufficiently take into account service users' preferences. Psychopharmaceuticals are widely available, but service users receive little information related to psychopharmacological treatment. Physical and reproductive health care is available, but again, service users receive little information about health care options.

Across the psychiatric hospitals, service users enjoy marginal participation in deciding their treatment and lifestyle, advanced directives are not utilized, and service users are provided with minimal support for decision making. Although the maintenance of patient records is good, service users have very little opportunity to add their comments, opinions, and perspectives. Patients are generally treated with dignity, but help and support are not optimally provided in cases of adverse events. Protection against inappropriate treatment is also suboptimal.

A major problem is the use of constraints, both in the context of crisis management and in the context of subsequent evaluation of crisis; and again, service users' preferences are often not taken into account. The use of special medical procedures, such as electroconvulsive therapy, is generally good, with the exception of one hospital that, according to the electroconvulsive therapist, applied such treatment to young people aged 16–17 approximately 10 times over the past five years. All research studies in psychiatric hospitals practice adhere to the CRPD.

Service users are provided with good support for life in society in terms of assistance with housing and income. However, access to education and employment, as well as support for participation in

FIGURE 3. Adherence to CRPD articles 12 and 14 in Czech psychiatric hospitals: Results for individual standards



* 100 % = 17 psychiatric hospitals

public life, is very low.

From the perspective of service users, boredom and limited opportunities for independent living are major problems. This is illustrated in the following excerpts from our interviews with service users:

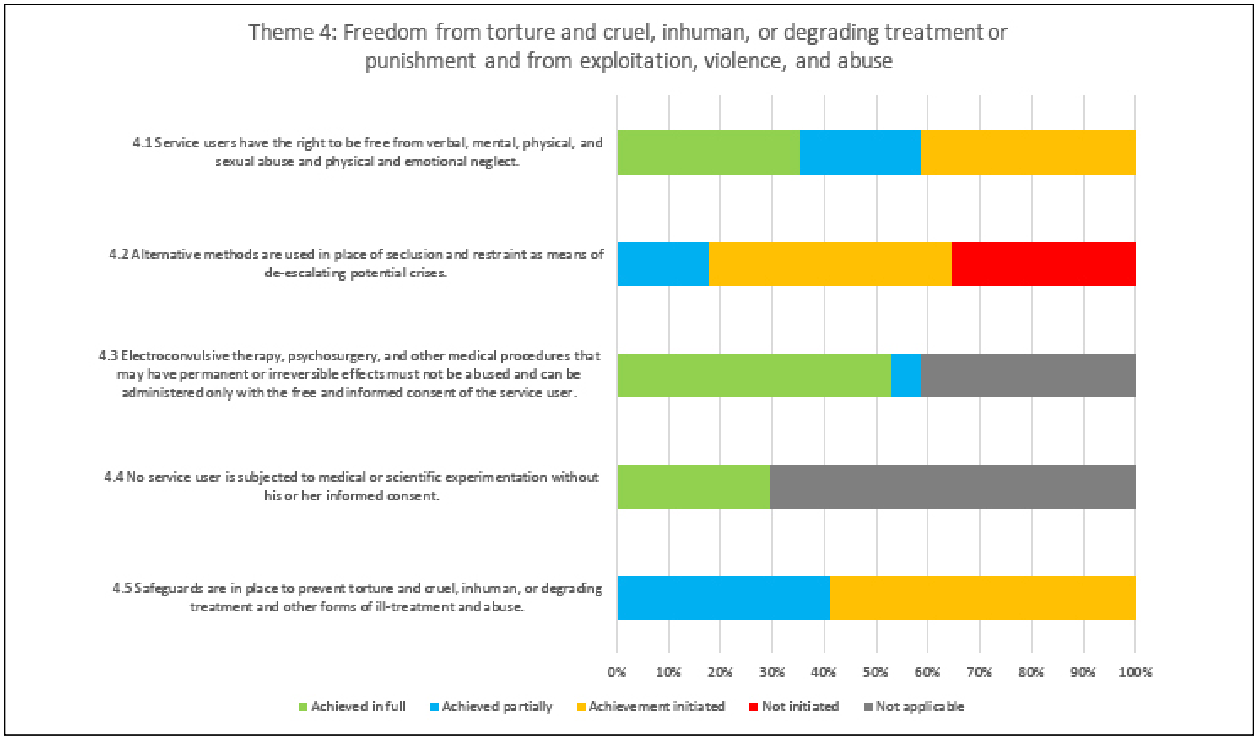
> *People here have low moods, everyone is just sleeping. As soon as 7 p.m. comes, after pharmaceuticals, all go to bed, because there is nothing they would enjoy. Smoking, sleeping, smoking, sleeping—this is the rhythm of this ward.*
>
> *They close bedrooms for the whole midmorning, they say it's so they can be ventilated. So we lay around on the ground. We have pharmaceuticals that make us sleepy, but we cannot go to bed.*
>
> *They close bedrooms for the whole midmorning, they say for cleaning purposes, but the reason is to not allow us to lie in beds. At least they do not close the smoking room.*
>
> *We cannot have any money—we have a card which we can use just in one shop [located on the hospital premises]. There they note what we buy, and a social nurse discounts this from our account.*
>
> *I have been here since I was 18, and now I am 81, which is 63 years. It is such a certainty for me. Actually, I spend all my time in one room, where there are a total of seven people. I am used to it now. I have been here longer than most of the doctors or nurses.*

Recommendations based on our study's results are outlined in Box 1.

Discussion

Our systematic assessment of the quality of care and adherence to the CRPD in Czech psychiatric hospitals revealed serious shortages in almost all themes within the WHO QualityRights Toolkit. The majority of shortcomings are linked to the unsatisfactory state of buildings, the lack of qualified and thoroughly trained staff, insufficient support for service users' decisions and preferences, and insufficient emphasis on service users' integration

FIGURE 4. Adherence to CRPD articles 15 and 16 in Czech psychiatric hospitals: Results for individual standards



* 100 % = 17 psychiatric hospitals

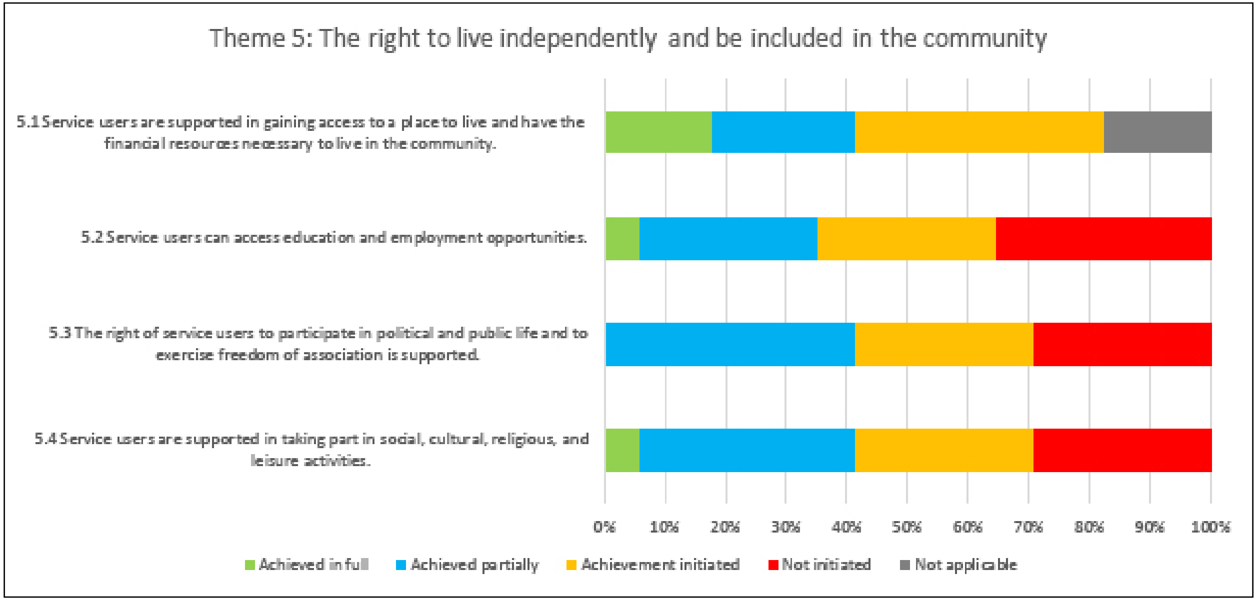
into society.

These results are notably worse than the results of the 2017 WHO study assessing European long-term residential institutions for people with psychosocial disabilities.[12] Discrepancies may be partially explained by the fact that participating institutions from the WHO study were chosen by countries' ministries of health or social affairs and thus may not have been nationally representative. The WHO study also included countries from all over Europe, with various historical, cultural, and political contexts. Our study confirms some of the findings from the WHO study, including the restriction of service users' communication, lack of staff knowledge about consent for admission and treatment, lack of supported decision-making for service users, lack of individualized treatment and recovery plans, and lack of access to supported community housing.[13] However, unlike the WHO study, our study did not reveal the potential exploitation of service users' labor as a problem in the Czech Republic.

Psychiatric hospital buildings in the Czech Republic are in a profound state of disrepair and require extensive renovations to create an environment suitable for CRPD adherence. From an economic point of view, community-based care has been found to be highly cost-effective when compared to psychiatric hospitals both in "old" European Union member states and in the Czech Republic.[14] Taking into consideration that there is an overlap between service users in psychiatric hospitals and those in community care, the pursuit of deinstitutionalization of mental health services is supported by both a human rights perspective and an economic one.

The use of restraint and seclusion measures is particularly problematic. Most staff lack training in de-escalation techniques, and patient-preferred methods of intervention during crisis are not taken into account. Following this finding, a workshop for staff from Czech psychiatric hospitals on alternatives to restrictive interventions was organized by the "Deinstitutionalization" project team in collaboration with WHO in February 20Further workshops and training activities will follow within the course of reform. Regardless, deinstitutionalization needs to be pursued to achieve full adherence to the CRPD and hopefully also to improve other important outcomes, such as suicide and mortality rates, which are particularly high among people hospitalized in Czech psychiatric hospitals.[15]

FIGURE 5. Adherence to CRPD article 19 in Czech psychiatric hospitals: Results for individual standards



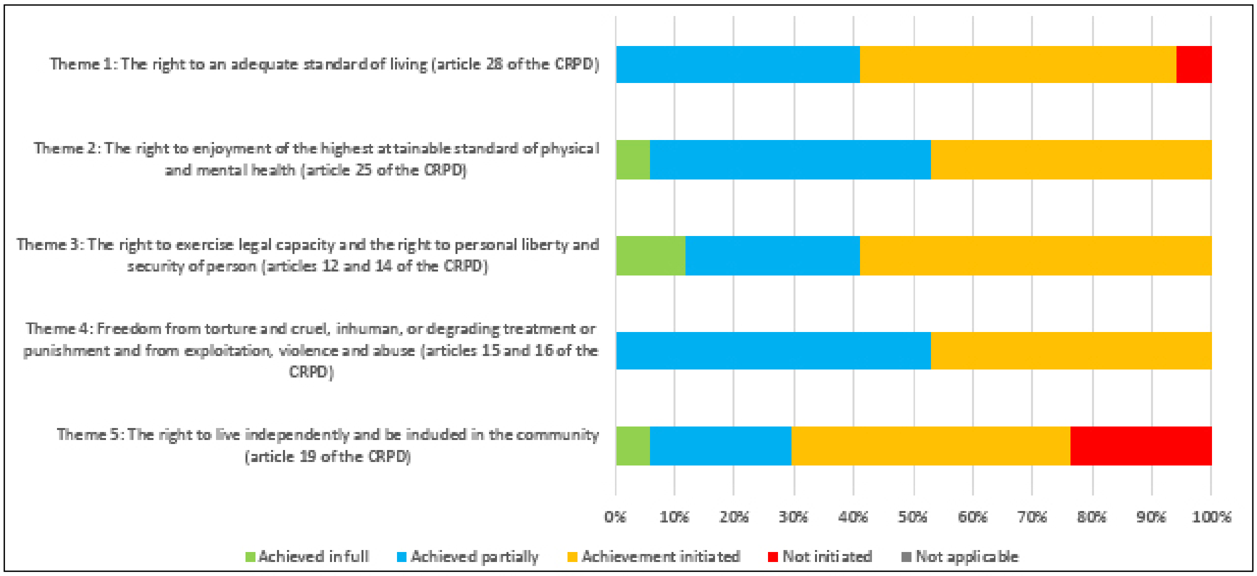
* 100 % = 17 psychiatric hospitals

The strengths of our study include a high participation rate (17 out of 18 psychiatric hospitals participated in the evaluation); thoroughly trained evaluation teams; the use of a comprehensive WHO QualityRights Toolkit instrument; and a high number of interviews. All of these factors contributed to a detailed assessment of facilities' adherence to the CRPD. Some noteworthy limitations exist, including the fact that only a few wards in each of the participating hospitals were assessed, which might have influenced the representativeness and consequently the generalizability of our results. Indeed, evaluation teams reported that the quality of the wards from the same psychiatric hospital may differ substantially, depending, for instance, on staff training and traits. Furthermore, evaluation teams were ambivalent when scoring in areas that were felt to mirror specific cultural values. This was the case, for instance, with regard to dietary requirements and, perhaps even more importantly, the issues of freedom of movement, sexual needs, and freedom of choices. In these instances, psychiatrist team members often expressed the opinion that it is necessary or normal for users, for example, to be woken up around 5 a.m. because hospitals' regimes require this. In these cases, discussions occasionally ended up with disagreements, and voting had to be used to arrive at a final score for a given criterion. Additionally, evaluation teams occasionally reported that some of the interviewed patients might have been afraid to speak openly because of the anticipated negative rewards from hospital personnel. Despite being somewhat worried, service users were notably more critical than professionals. Professionals were often convinced that the living standards in the hospitals were "not that bad" and that there was no reason for complaint. Frequently, there was no alignment between the views of patients and those of professionals.

The results of our nationwide study are in line with previous findings from the Czech ombudsman and are considerably worse than the results of the 2017 WHO survey.[16] Despite current efforts to improve the quality of care in Czech psychiatric hospitals, such as the "System of Integrated Psychiatric Rehabilitation" project, treatment and rehabilitation does not sufficiently follow recovery principles.[17]

The 2017 WHO European study synthesized overarching priorities for improved CRPD adherence, including (1) continuous assessments and monitoring of progress; (2) staff training; and (3)

FIGURE 6. Adherence to CRPD articles 12, 14–16, 19, 25, and 28 in Czech psychiatric hospitals: Results for individual themes



* 100 % = 17 psychiatric hospitals

exchange of knowledge and learning in pursuit of CRPD adherence in Europe.[18] Taking into consideration these and the priorities emerging from our study, we developed specific recommendations for improving the quality and safety of care in psychiatric hospitals at both the facility and the system level (Box 1). The results from our study not only provide justification for the continued reform of psychiatric care in the Czech Republic but also offer a resource to help motivate and inform rights-based mental health initiatives in neighboring countries in Central and Eastern Europe, which share a history of communist and socialist influences on their sociopolitical and economic state and, in turn, on the development and provision of mental health services.[19] Based on the results of our study, some important steps to improve the quality and safety of care in Czech psychiatric hospitals, such as the recent WHO-led training of staff to reduce the use of restrictive measures, have already been launched. Hopefully, other countries in the region will follow suit.

Funding

We were supported by the project "Sustainability for the National Institute of Mental Health" (grant LO1611), funded by the Ministry of Education, Youth and Sports of the Czech Republic; and by the project "Deinstitutionalization of Mental Health Care" (CZ.03.2.63/0.0/0.0/15_039/0006213), funded by the European Structural and Investment Funds

Box 1. Recommendations for improving the quality and safety of care in Czech psychiatric hospitals

FACILITY-LEVEL INTERVENTIONS
Increase patients' privacy through low-capacity impassable rooms, room dividers, lockable cabinets, curtain showers, and lockable toilet doors.
Enhance room quality by providing adequate lighting, barrier-free sanitary facilities, and room dividers.
Improve nutrition by providing a variety of food for patients with dietary restrictions and by offering different food choices, consulting with nutritionists to ensure high-quality nutritional dishes and offering consultations for patients who struggle with weight as a side effect of medications; reduce the use of metal and plastic dishes except for specific cases (for example, patients with dementia).
Improve access to amenities by ensuring that any required fees are established in accordance with patients' income or benefits; provide waivers for patients who are unable to afford amenities.
Promote and provide alternatives to medication, especially psychotherapy.
Foster patients' agency by developing and implementing individual recovery plans and documents stating patients' express wishes.
Follow supported decision-making of patients and staff, modeled by specialized in-house training or internships.
Offer legal support to patients through cooperation with independent legal authorities and by establishing legal offices in wards.
Establish independent complaints commissions for service users, and reform services accordingly.
Regularly review medications prescribed to patients.
Educate patients about medications and their possible side effects.
Train hospital staff on modern approaches to care, human rights, de-escalation, and other interventions for diffusing tense and conflictual situations.
Make external supervision available to all helping professionals working in a psychiatric hospital.
Prevent bullying among patients.
Improve access to social life by collaborating with local social services and cultural organizations and offering and supporting leisure time activities (for example, access to books, board games, and courses).
Develop and raise awareness of reintegration programs and resources available to patients within the community after discharge.
Task-shift patient-recovery responsibilities (such as communication with family and the discharge process) from doctors to social workers and peer workers.
Offer inclusive educational opportunities—ideally integrated into the community—to all patients (children and adults alike); hire private teachers when necessary.
Loosen daily regimes to allow patients agency in time management and daily activities.

SYSTEM-LEVEL INTERVENTIONS
Increase and redirect funding to projects that enable the above facility-level recommendations.
Develop multisectoral collaboration among local governments and other psychiatric services through regular meetings among psychiatric hospital management to discuss aims and planned measures of psychiatric care reform.
Provide follow-up services to patients at discharge (such as social services that address financial stability).
Provide care to foreigners and improve forensic treatment.
Provide regular human rights trainings organized by a national governmental authority (such as the Ministry of Health).

as administered via the Ministry of Labor and Social Affairs of the Czech Republic. The funding bodies had no role whatsoever in the design of our study, methodology used, data collection, data analysis, data interpretation, or writing of this paper.

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Addressing the Problem of Severe Underinvestment in Mental Health and Well-Being from a Human Rights Perspective

FARAAZ MAHOMED

Abstract

Throughout the world, mental health remains a neglected priority, low on the agenda of policy makers and funders at the national and international levels. While this is shifting somewhat, there remains a considerable need to address the underprioritization of mental health and well-being, perhaps even more so in the wake of the COVID-19 pandemic. However, given the history of mental health interventions—which have overemphasized the biomedical model and have thus resulted in coercion, denial of life in the community, and unnecessary pathologization of human experience—there is also a need to ensure that increased funding does not simply replicate these mistakes. This is particularly true in the current landscape, where efforts to "scale up" mental health and to reduce "treatment gaps" are gaining momentum and where post-pandemic responses are still being formulated. As the potential for global mechanisms for funding mental health increases, national and international funders should look to practices that are rights affirming and contextually relevant. In this paper, I explore the current landscape of mental health financing, in terms of both national resource allocation and development assistance. I then outline the momentum in global mental health that is likely to materialize through increased funding, before considering ways in which that funding might be utilized in a manner that promotes human rights.

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Competing interests: None declared.

Introduction

Around the world, financial investment by national governments, international development organizations, and United Nations (UN) agencies in mental health and psychosocial support is extremely inadequate to meet demand. Laura Asher and Mary De Silva, for example, suggest that "the dire shortage of mental health specialists, coupled with chronic underinvestment in mental health services by both governments and international donors, are key reasons for poor access to care."[1]

Far from being a developing country problem, underinvestment in mental health is a global phenomenon, despite the apparent significant need for people to access mental health and psychosocial support services and often despite legislative and policy mandates for parity between physical and mental health. Moreover, the quality and efficacy of services funded is a fundamental question that needs further reflection. This is particularly true when one considers the need for interventions to focus on the fundamental rights of people with mental health conditions because this is an area where myriad rights violations have been recorded.[2]

Applying a human rights lens to global mental health means recognizing that the glaring neglect of mental health as a policy and resourcing priority is unacceptable, but it also requires critically examining the manner in which efforts to address that neglect are undertaken. The replication of systems that have thus far been responsible for the oppression and abuse of people with mental health challenges can, however, be problematic. According to numerous scholars and practitioners, traditional biomedical approaches rely heavily on coercion and a disease framing, and addressing this overemphasis on a purely biomedical view of etiology requires a shift in established mental health systems as well as efforts to build new systems.[3] Therefore, in normative terms, increased funding for mental health must be aligned with fundamental human rights principles as determined by international instruments, most notably the UN Convention on the Rights of Persons with Disabilities (CRPD), which has been ratified by 181 countries and which protects and promotes the rights of people with disabilities, including psychosocial disabilities. Another such instrument is the International Covenant on Economic, Social and Cultural Rights (ICESCR), which has been ratified by 170 states and which requires states to protect and promote the right to health, with a dedication of the "maximum available resources" to do so.[4] It is important to note that these instruments obligate states to implement policies and programs that are in keeping with principles such as dignity, autonomy, and life in the community.[5] This means that the rollout of rights-oriented programming for mental health and well-being need not necessarily be predicated on the assumption of the availability of financing; instead, financing ought to be determined by the needs and obligations arising out of the CRPD and other rights instruments.

With these factors in mind, this paper seeks to reflect on the current landscape with regard to financing for mental health, both in relation to domestic health spending and in relation to development assistance for mental health (DAMH). In addition, I examine the nature of services provided when resources are available, and what their human rights implications might be. I then consider current global efforts to promote mental health, seeking to illustrate the crucial moment that policy makers, service users, and advocates find ourselves in, including in light of the COVID-19 pandemic. In doing so, I argue that a significant contribution can be made by adopting a rights-oriented, well-being-focused approach to mental health financing as efforts to "scale up" mental health gain momentum.

The current landscape of mental health financing

Research related to mental health financing is extremely limited and rarely clear. The World Health Organization (WHO) notes that just 40 countries were able to report on their domestic budget for mental health in 2014.[6] This number rose to 80 countries in 2017, representing something of an improvement but nonetheless constituting less than half of WHO member states.[7] Even where budgets are available, these are often not disaggregated beyond a distinction between hospital-based and community-based services.

With regard to international aid for mental health, a 2016 report by the Overseas Development Institute "highlights how little information there is on what donors are spending on mental health globally, [and] what types of activities are funded."[8] This is illustrative of the significant challenge that exists in putting together a complete picture of the funding landscape for mental health.

There is another inherent problem in any analysis relating to development assistance for health (DAH) research, as highlighted by Jessica Mackenzie and Christie Kesner.[9] Larger projects might have a mental health component but are often dealing with a larger range of health concerns (including HIV/AIDS and gender-based violence). In such cases, it is rare that mental health interventions are separate line items, making it impossible to accurately state what proportion of funds goes to these services. This raises the risk of over-reporting and should be borne in mind when considering the figures presented.

Recognizing the constraints mentioned above, I utilized already-published data from the academic literature and institutional reports such as those of WHO, the Overseas Development Institute, the South African Human Rights Commission, and Lion's Head Partners. Similarly, to track global DAMH, I utilized the Creditor Reporting System of the Organization for Economic Cooperation and Development and the Development Assistance for Health Database of the Institute for Health Metrics and Evaluation.[10]

The results of this secondary data analysis are expanded on below. It should be noted, however, that changes to flows of aid and domestic health spending are expected in the wake of the COVID-19 pandemic. Therefore, these results provide a useful baseline for "what has been" as the world begins to reconsider "what should be."

Domestic funding for mental health

Domestic funding for mental health by governments is low despite many calls for parity between physical and mental health services.[11] In 2013, WHO noted that, globally, the average percentage of national health spending devoted to mental health was about 0.5%.[12] Some high-income countries devoted more spending, but this amounted to only about 5% of total health budgets on average.[13] In pure monetary terms, WHO reported in 2017 that there was a strong association between higher per capita gross domestic product (GDP) and per capita expenditure on mental health. However, it also noted that with regard to mental health spending as a percentage of the total health budget, there was not a strong association with GDP per capita.[14] This suggests that some low- and middle-income countries dedicate a larger proportion of their health budget to mental health than some high-income countries. In terms of individual out-of-pocket expenditures, WHO reported that in 17% of countries, people pay entirely or mostly out of pocket for access to mental health services.[15]

Average annual health expenditure around the world amounts to US$141 per person, while the median government spending on mental health per capita in 2017 was US$2.50.[16] Despite the fact that some low- and middle-income countries might spend more on mental health than some high-income countries, overall the gap between high-income and low-income regions is stark, with countries in Europe dedicating US$21 per capita while those in Africa dedicate just US$0.10 per person per annum.[17] This disparity represents a significant challenge in its own right, because estimates suggest that simply raising the annual per capita expenditure in low-income countries to US$1 annually would require an investment of some US$30 billion globally.[18] Yet in light of the fact that the majority of signatories to the CRPD are low- and middle-income countries, the obligation to provide appropriate care and support services for those affected suggests that financing ought to be determined by service needs as opposed to the corollary and status quo of access and quality being determined by available resources.[19] As noted by the UN Economic and Social Council, a "lack of resources cannot justify inaction or indefinite postponement of measures to implement those rights."[20] The council further notes that international cooperation and funding are key and necessary mechanisms to ensure equitable and sufficient service provision. This suggests that adequate financing for appropriate, quality services is both a national concern and an international one.

Interventions and approaches funded

In high-income countries, 43% of all spending on mental health is dedicated to hospital-related infrastructure, maintenance, and service provision.[21] In low-income countries, this figure is 80%. Even where budgets for community-based services are allocated, these tend to be medical in nature, referring to the delivery of psychotropic medication in primary health care settings. Addressing mental health needs from this perspective does not fully account for the social, political, legal, and economic determinants of well-being (see below for further detail), and risks undermining human rights principles. Box 1 provides insight into some of the complexities of domestic mental health financing, including issues of devolution of financing decisions to local governments.

These case studies illustrate the point that mere allocation of funds is not sufficient for the provision of mental health and psychosocial support services. The nature of the services provided and the governance of those services are equally important considerations. The emphasis on well-being in New Zealand's budget is encouraging, although it is clear that there remain some obstacles to a fully rights-based approach, while the South African case illustrates the need for more than simply allocation or reallocation of funding to attain a rights-oriented model. I will return to these topics after exploring the landscape of international development assistance as a source of financing for mental health.

Development assistance for mental health

According to the Institute for Health Metrics and Evaluation's DAH database, total spending by bilateral donors, UN agencies, and philanthropies on mental health amounted to roughly US$162 million in 2018.[22] As demonstrated by Figure 1, this represents a substantial increase in spending from previous years, assuming that all data are accurate and complete. Even so, the total amount of global DAH in 2018 was US$38.9 billion, demonstrating that funding for mental health represents just 0.4% of total DAH.[23] This, too, is illustrative of the substantial lack of prioritization of mental health as a global health concern.

A few countries stand out with regard to their spending on DAMH. The United States is the largest bilateral donor, followed by the United Kingdom and Germany.[24] In recent years, Canada has been viewed as a champion of global mental health, with Grand Challenges Canada reportedly spending US$42 million in 31 countries between 2011 and 2017.[25] However, the data from the Institute for Health Metrics and Evaluation for 2018 do not reflect significant spending. This may be because mental health is no longer a priority, or it may be because of any number of concerns with regard to classifying funds as DAMH. In any event, the governments of Canada, United Kingdom, and Australia have collectively founded the Alliance of Champions for Mental Health.[26]

Notwithstanding the funding from bilateral donors, the single largest source of DAMH is from private foundations, corporations, and campaigns. The Institute for Health Metrics and Evaluation estimates that total flows of financial investment into mental health services from all private sources amounted to US$65.7 million in 2018.[27] Organizations such as the Wellcome Trust, Comic Relief UK, CBM International, Fondation d'Harcourt, the National Lottery Community Fund, the Novo Foundation, the Disability Rights Fund, the Catholic Overseas Development Agency, the Leonard Cheshire Disability Trust, and the Mariwala Health Initiative are funders of mental health and psychosocial services and research in developing countries (though their sizes and geographic scopes differ considerably).[28] Corporate sponsors of mental health-related services include Johnson and Johnson and Sanofi.[29] It is worth noting, however, that commentators and scholars have cautioned that investment in mental health by pharmaceutical companies can be a source of substantial bias in terms of research outputs and even policy decisions, because of potentially profit-driven motives aimed at increasing market sizes for consumers of psychotropic medications.[30] Investment in developing countries by pharmaceutical corporations may therefore present many of the same challenges that have thus far been identified in developed-country settings, where policymaking related to mental health has, through strong and sustained lobbying, been heavily influenced by a biomedical model that

Box 1. Case studies for domestic mental health budgeting

New Zealand

In 2019, New Zealand made headlines by adopting the world's first "well-being budget," with one of its key priorities being to "take mental health seriously."* This budget contained US$1.2 billion for mental health services over the next five years. This is indeed a significant commitment, but in real terms represents a contribution of just 0.006% of GDP annually.† The well-being budget is of interest also because of its approach to holistic support for communities, paying attention to social protection and poverty reduction. It therefore seeks to address not only the biological determinants of well-being but also the social and economic determinants, an approach that has been shown to be increasingly necessary to undo the overmedicalization of mental health.‡ The approach to mental health is somewhat progressive in that it supports mental health from various cultural perspectives, engaging with traditional Maori practitioners as well as medical practitioners. In addition, there is an emphasis on the prevention of serious or acute distress, seeking to support people at all points on the spectrum of symptoms in community health settings.§ Nonetheless, the budget also seems to focus heavily on locating mental health services in clinics and substance abuse recovery facilities, and dedicates funds to the construction of new such facilities. It also emphasizes the role of clinicians over other non-medical interventions.**

South Africa

The tragic deaths of 140 people during a maladministered process of deinstitutionalization in 2016 in South Africa (now commonly referred to as the "Esidemeni tragedy," named after the facility from which patients were discharged) brought to light more systemic concerns regarding the treatment of people with mental health conditions.†† Widespread neglect of mental health services has since been uncovered. Despite the adoption of the National Mental Health Policy Framework in 2013, which requires parity between mental health and physical health services, spending on mental health services is estimated by the National Treasury to be roughly 2.6% of the national health budget.‡‡ However, according to the National Department of Health, accurate data regarding resource allocation for mental health is difficult to obtain, as each province decides on its own allocations from the provincial health budget. Of South Africa's nine provinces, just two have fully costed and budgeted mental health plans.§§ The South African Human Rights Commission has reported that none of the provinces is able to provide a detailed budget for mental health services and just one province is able to estimate funding for mental health services in primary health settings (primarily providing outpatient medical interventions), amounting to 19% of the total mental health budget.*** The largest allocation of resources is reserved for psychiatric institutions, which the National Treasury estimates at 5 billion rands, or 2.2% of the national health budget.††† Efforts to reform the national mental health system have been largely at a standstill since the Esidemeni tragedy unfolded, but South Africa is embarking on an ambitious universal health coverage project—the National Health Insurance—due to be completed in 2026.‡‡‡ Mental health services are included in the National Health Insurance, but the allocation of resources and the actual quality and content of services remain unclear.

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* Government of New Zealand, The wellbeing budget (Wellington: Government of New Zealand, 2019). Available at https://www.budget.govt.nz/budget/pdfs/wellbeing-budget/b19-wellbeing-budget.pdf.

† Ibid.

‡ D. Puras, The role of the determinants of health in advancing the right to mental health, UN Doc. A/HRC/41/34 (2019).

§ Government of New Zealand, The wellbeing budget.

** Ibid.

†† "Life Esidemeni case goes back to court," Maverick Citizen (September 19, 2019). Available at https://www.dailymaverick.co.za/article/2019-09-19-life-esidimeni-case-goes-back-to-court.

‡‡ South African Human Rights Commission, Report of the national hearing on the status of mental health care, March 2019 (Johannesburg: South African Human Rights Commission, 2019). Available at https://www.sahrc.org.za/home/21/files/SAHRC%20Mental%20Health%20Report%20Final%2025032019.pdf.

§§ Ibid.

*** Ibid.

††† Ibid.

‡‡‡ Personal communication with former official from the South African Department of Health, September 14, 2019.

favors the pharmaceutical industry.[31]

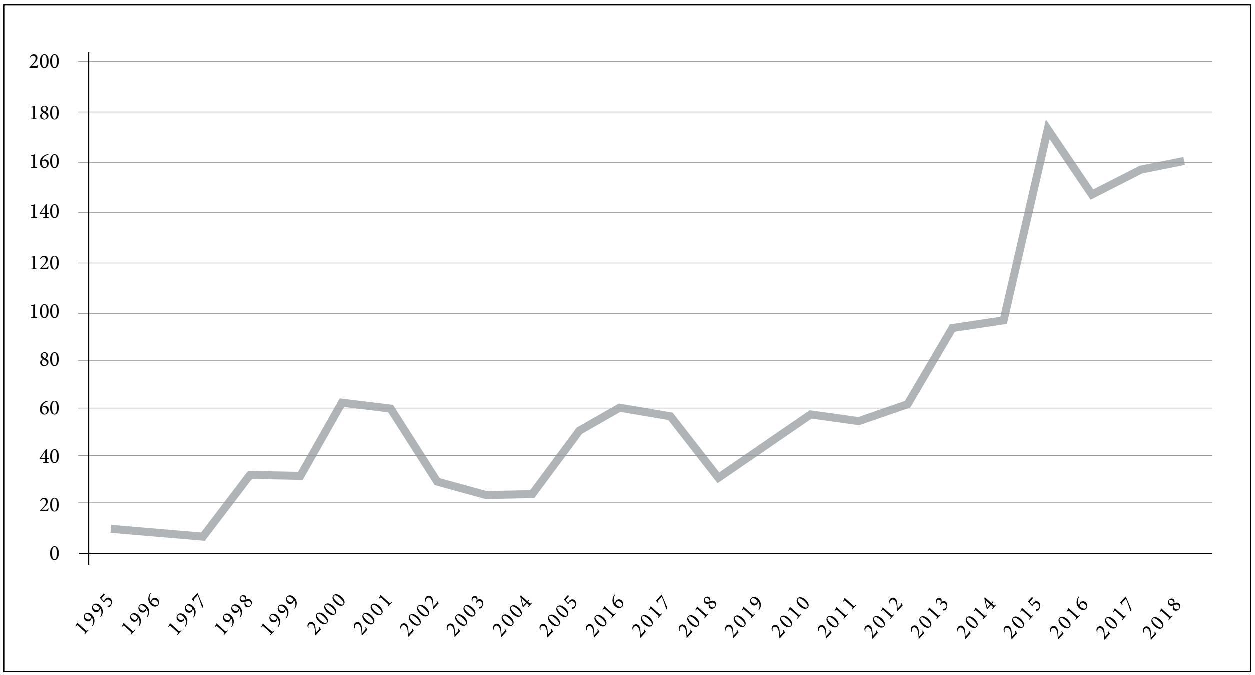
According to the Organization for Economic Cooperation and Development, the largest recipients of DAMH are in the Middle East and Africa. Countries where humanitarian emergencies are underway receive the largest amounts of funding, while other recipients reflect more "protracted" challenges. Figure 2 provides an overview of where DAMH funding flows are most commonly directed.

While there is limited and somewhat dubious data regarding flows of DAMH, to date, no report or database accurately captures the nature of mental health funding or the interventions supported, leaving open the question of what the already-meager resources devoted to mental health and psychosocial support are actually promoting. Further research is urgently needed to examine the trends in this field not only with regard to aid flows but also with regard to the content of that aid.

Current trends in global mental health

The lack of a sufficient response to mental health concerns around the world is perhaps best demon-

Figure 1. Total development assistance for mental health from all sources (in millions of US$)



Source: Institute for Health Metrics and Evaluation

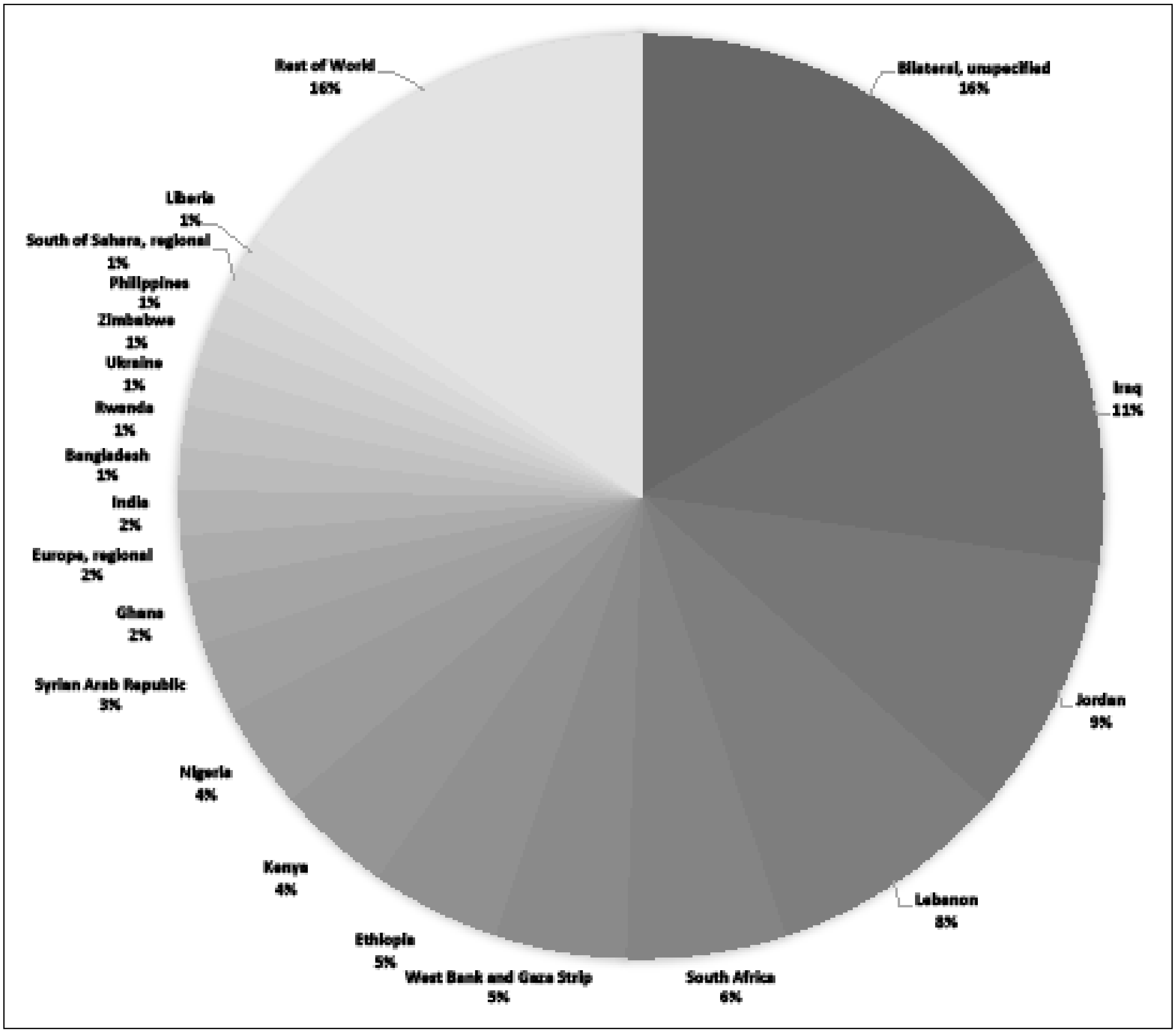
Table 1. Largest funders for mental health interventions globally (2018)

Australia	$51,106
Bill and Melinda Gates Foundation	$1.4 million
Canada	$852,160
France	$3.6 million
Germany	$9.5 million
Other	$29 million
United Nations	$9.4 million
Private foundations and corporate donors	$65.7 million
United Kingdom	$13.1 million
United States	$19.6 million

Source: Institute for Health Metrics and Evaluation strated by the fact that large-scale health surveys such as the Global Burden of Disease list mental health conditions as some of the most prevalent "diseases" worldwide.[32] According to estimates, mental "disorders" will affect one in four people in their lifetime, and depression is considered the single-largest cause of disability in the world.[33]

There are inherent challenges with regard to the language and framing of mental health in instruments such as the Global Burden of Disease that proffer a "disease" model of mental health, that rely heavily on diagnostic criteria that are increasingly considered inadequate, and that view mental health challenges as monolithic in terms of their effects on individuals (see further exploration of this subject below).[34] Notwithstanding these concerns, they do offer insight into the sheer lack of proportion between public health responses to physical health challenges and public health responses to mental health conditions, as well as the glaring unmet need for spending to promote mental health. The COVID-19 pandemic has also served to further highlight the substantial need for resourcing for mental health, as the public health crisis, social isolation, and economic hardship pose significant challenges for individual and community well-being.

FIGURE 2. Destinations for development assistance for mental health (2017)



Source: Organization for Economic Cooperation and Development Creditor Reporting System Database.

Efforts to counter the mental health "treatment gap" have been gaining momentum. In 2015, the UN adopted the 2030 Agenda for Sustainable Development, more commonly known as the Sustainable Development Goals, marking the first time that a major global development instrument included the promotion of mental health and well-being as an objective.[35] Commentators have also referred to the goal relating to the strengthening and prevention and treatment of substance abuse as a mental health-related goal, suggesting that the nexus between mental health and development had finally been acknowledged at an unprecedented level and scale.[36]

In 2016, the World Bank and WHO organized a conference entitled "Out of the Shadows: Making Mental Health a Global Development Priority," which noted the need for improved financing for mental health to support efforts to close the "treatment gap."[37] Similarly, the World Bank has noted the substantial developmental and economic costs of the "mental health burden," highlighting the need to help states recognize the human capital-related costs of unattended mental health conditions.[38]

Substantive engagement around global mental health has also taken the form of a Lancet Commission on Mental Health and Sustainable Development, whose report was launched in 2018 at the First Global Ministerial Mental Health Summit.[39] Both of these initiatives have called for increased attention to mental health in global policy and financing spaces and have recognized the substantial need for states, particularly those where there is a lack of clinical treatment options, to address vast "treatment gaps." As part of states' commitments to the SDGs, monitoring will be undertaken under the auspices of Countdown Global Mental Health 2030. The initiative will focus on three domains for monitoring and accountability, namely mental health determinants, mental health system and service components, and mental health outcomes and risk protection.[40]

It is clear that momentum is building in the field of mental health, an important development given the abject exclusion of mental health care and psychosocial support in health budgets and in international instruments. Indeed, the inclusion of language relating to mental health in the UN Political Declaration on Universal Health Coverage is seen as a major victory for many who have advocated strongly for mental health to not be ignored in discussions on universal health coverage.[41] Similarly, there is increasing recognition of the mental health implications of the COVID-19 pandemic, which suggests that more attention could—and should—be paid to mental health in future. As with current funding, however, the nature of interventions funded is an equally fundamental question as the level of resourcing available. This is the subject turned to next.

Applying a human rights lens to global mental health and well-being and resource allocation

As noted, the largest proportion of financing for mental health in domestic health budgets is often devoted to supporting psychiatric institutions. Community-based mental health services are usually poorly funded, and the lack of coordination and governance means that non-financial resources and infrastructure are not forthcoming. Non-clinical interventions and interventions not rooted in the biomedical paradigm are still not the norm, meaning that the community-based services which are funded are focused on access to clinical treatment without focusing on the numerous non-biological determinants of mental health. With regard to DAMH, data relating to the content of what is funded are very limited, so it is virtually impossible to state accurately what is or is not supported.

Increasingly, evidence is emerging of approaches to mental health that are community oriented and not over-reliant on the biomedical disease model. These approaches have demonstrated utility in multiple contexts with varying cultural precepts and variable resource availability. Efforts to support people with lived experience of mental health challenges that align with human rights principles often incorporate peer support because there is substantial benefit in engaging with peers with similar experiences, in developing communities that allow for connection and support, and in building self-efficacy rather than relying on the intervention of a clinician.[42] Similarly, rights-based approaches incorporate efforts to prevent coercion and to respect the right to legal capacity, focusing on supported decision-making and utilizing various measures such as the open dialogue approach, the circle of support model, and interlocutors such as the "personal ombudsman" or the "guarantor of personal autonomy."[43] Their viability and efficacy is increasingly recognized, and their applicability in contexts as diverse as India, Sweden, and Costa Rica is indicative of their utility. Box 2 examines some models of mental health interventions that are respectful of human rights and that have demonstrated efficacy.

Recent efforts to close "treatment gaps" and to "scale up" access to treatment suggest that there is not sufficient emphasis on approaches to mental health and well-being dedicated to addressing the social, economic, political, and legal determinants of mental health.[44] Scholars are increasingly interested in a framing of "mental health and well-being" as opposed to mental health alone. This broader conception focuses not only on the "health" component of mental health but also on the numerous ways in which health interacts with other forms of well-being, such as economic, social, and cultural well-being.[45]

This conception remains somewhat underutilized, but it highlights the notion that mental health is intrinsically linked to numerous other factors at the individual and at community levels. Interventions that ascribe to such a framing are therefore concerned with recognizing these linkages and promoting all of these forms of well-being as matters of social justice. As noted by the UN Special Rapporteur on the right to health, mental health interventions should be geared primarily toward removing barriers to well-being.[46] Support for the realization of civil, political, economic, social, and cultural rights may thus be thought of as mental health interventions. This may require measures and initiatives that have not traditionally been seen as mental health programming, such as actions focused on income generation, education and vocational training, legal support, and stigma reduction in family and community systems. Holistic approaches to well-being that recognize the person's psychosocial health as a product of their interaction with their environment are thus prioritized over narrow biomedical thinking. This is highlighted by the current COVID-19 pandemic, wherein the public health challenges posed by the virus are mirrored by social isolation brought about by physical distancing and financial hardship brought about by economic inactivity. The mental health implications of these myriad concerns are not likely to be addressed through exclusively biomedical interventions and will instead require a more holistic focus on well-being.

The well-being approach suggests that a similar framing of mental health and well-being in budgets for national and international financing can also incorporate such a conception in their own allocations. Necessarily, what this calls for is a reorientation of policy to provide holistic and cross-cutting supports. This might be difficult for funders and policy makers to conceive of, as it suggests a far more substantial outlay of resources. However, it is possible that the opposite is true in that a well-being focus incorporates various social protection and social upliftment mechanisms in a way that is holistic rather than fragmented and bureaucratically challenging. Moreover, when weighed against the cost of investing in other methods with limited utility and often lacking in clinical validity, these investments in whole-person approaches may very well be more cost-effective.[47] Regardless of cost, states, bilateral funders, and others will need to recognize the human rights obligations that arise out of instruments such as the CRPD and ICESCR and appreciate that the mere provision of services, when those services do not promote social justice, does not constitute meeting those obligations. Box 3 highlights some organizational approaches to mental health and well-being that proffer a more holistic understanding of the relationship between mental well-being and economic, social, cultural, and political well-being.

Increased attention being paid to financing mental health

As numerous new initiatives are taking shape to galvanize action to improve access to mental health services globally, there have also been increasing efforts aimed at ensuring the financial viability of those efforts. A study commissioned by the Global Campaign for Mental Health published in June 2018 highlights numerous potential options for the devel-

Box 2. Models of effective mental health interventions that are non-coercive and supportive of human rights

Circle of Care[*]

In the city of Pune in India, the Bapu Trust focuses a significant portion of its mental health interventions on the promotion of inclusion. Recognizing that stigma, discrimination, and social exclusion are important contributors to distress, and that opportunities for connection and community interaction are important, the circle of care model eschews the need for biomedical intervention and has substantial benefits not only for individuals but also for broader communities.

Open Dialogue[†]

Open Dialogue refers to a model that has been adapted in multiple contexts. The model originated in Western Lapland in Finland and then continued to develop elsewhere. Working with families and social networks, as much as possible in their own homes, open dialogue teams engage with people in crisis situations to provide support and stimulate dialogue regarding treatment options. As a result of the success of this model, it now constitutes the "normal" mental health approach in Western Lapland and receives direct funding from the national government. The region now has the best documented mental health outcomes in the Western world.[‡]

Friendship Bench[§]

Developed in Zimbabwe with the initial purpose of bridging the "treatment gap," the friendship bench has gained international acclaim as a model that relies on peer supporters and lay workers to provide informal and easily accessible support to people experiencing mental health challenges. Anyone needing support can utilize the bench, located in their community. Friendship benches have been shown to be both effective and scalable, and their utility has led to replication in developed-country contexts such as the United States and Canada.[**]

Soteria[††]

Soteria houses were first developed in California in the United States. The model uses the principles of recovery, safety, and community to reduce distress and to build social networks within mental health residential facilities. Restraints are not used, even during periods of "acute psychosis," and antipsychotic medication is rarely utilized. The Soteria model has been shown to have equal or better outcomes than traditional biomedically oriented approaches to schizophrenia spectrum conditions.[‡‡]

Hearing Voices Networks[§§]

Hearing voices networks are peer support mechanisms that eschew biomedical interventions in favor of experiential and peer-oriented processes aimed at recovery, while also recognizing the value of what are typically referred to as "hallucinations." With numerous networks in more than 20 countries, this approach has shown to have positive clinical outcomes.[***]

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[*] B. V. Davar, "Social inclusion of persons with psychosocial disabilities: Bapu Trust experiences" (paper presented at the Department of Psychology, University of Allahabad, Seminar on Social Exclusion and Mental Health, September 21–22, 2014). Available at https://www.academia.edu/8404515/Social_Inclusion_of_persons_with_psychosocial_disabilities_Bapu_Trust_Experiences.

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[**] T. Rosenberg, "Depressed? Here's a bench. Talk to me," New York Times (July 22, 2019). Available at https://www.nytimes.com/2019/07/22/opinion/depressed-heres-a-bench-talk-to-me.html; Strategic Group, Riaz Mamdani unveils first public Friendship Bench in Canada. Available at https://www.strategicgroup.ca/news/riaz-mamdani-unveils-first-public-friendship-bench-in-canada.

[††] T. Calton, M. Ferriter, N. Huband, and H. Spandler, "A systematic review of the Soteria paradigm for the treatment of people diagnosed with schizophrenia," Schizophrenia Bulletin 31/4 (2008), pp. 181–192.

[‡‡] Ibid.

[§§] Intervoice, The International Hearing Voices Network. Available at https://www.intervoiceonline.org.

[***] J. Dillon and G. A. Hornstein, "Hearing voices peer support groups: A powerful alternative for people in distress," Psychosis 5/3 (2013), pp. 286–295.

opment of funding mechanisms for mental health.[48] These include "innovative funding" mechanisms derived from multiple sources, along with an international financing facility, an international capital account, and a global mental health giving pledge.

Similarly, a 2019 article published in *Lancet Psychiatry* calls for a "partnership for transforming mental health globally," stating that

> *the Sustainable Development Goals and the Universal Health Coverage agenda provide new impetus for the global mental health field … Established networks, such as the Movement for Global Mental Health and the Mental Health Innovation Network, and emerging efforts such as the Global Campaign for Mental Health offer the foundations of a partnership and indicate that the time is ripe for establishing a multipolar and inclusive partnership to address the challenge of financing a global scale-up of mental health services.*[49]

The article explores several options for the development of a global funding mechanism for mental health, including a public-private partnership model akin to the Global Fund to Fight AIDS, Tuberculosis and Malaria and a mechanism located in the World Bank, modeled on the Global Financing Facility. These discussions are indicative of a growing momentum around the need for a global entity that will direct funding toward mental health services.

An emphasis on well-being in a broader sense (that is, apart from a purely health orientation) is somewhat absent in these discussions, suggesting

Box 3. Organizational approaches to mental health and well-being that support human rights

Basic Needs[*]

Basic Needs combines health, socioeconomic, and community-oriented solutions to support people with mental health challenges. The organization's goal is to combine effective and affordable mental health services with livelihoods approaches in order to address some of the root causes of distress, namely social exclusion, poverty, and lack of access to opportunities. To date, Basic Needs has supported over 600,000 people with mental health challenges in low- and middle-income countries in Africa and Asia.

The Banyan[†]

The Banyan is a psychosocial support organization located in three states in India. It provides emergency and acute medical, psychiatric, psychological, and social care through street-based services, hospital settings, shelter-based services, community-based outpatient care, and inclusive long-term care options for persons with high-support needs. The Banyan's community-based work includes interventions to address the determinants of distress, including social exclusion, poverty, and homelessness. The organization conducts training, peer support, and outreach activities in addition to clinical interventions.

Kamili Mental Health Organization[‡]

Kamili provides free community-based mental health services across Kenya. In addition to providing clinical services, the organization conducts educational and awareness-raising activities. Kamili also engages with service users to support microenterprises and micro-loans in an effort to reduce the contribution of economic hardship to mental distress.

La Collina Social Cooperative[§]

La Collina Social Cooperative is part of the Italian social protection system, whose development followed the dismantling of the county's institution-based mental health infrastructure in the 1970s. The cooperative system focuses on community integration through employment and the development of social enterprise. Based in Trieste, La Collina Social Cooperative employs people with lived experience of mental health challenges to work in various industries, such as hospitality, tourism, and business administration. By addressing barriers to social inclusion and promoting self-efficacy, this model has been shown to lead to significantly improved outcomes.

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[*] Basic Needs, What we do. Available at http://www.basicneeds.org/what-we-do/.

[†] Banyan, About us. Available at https://thebanyan.org/aboutus.

[‡] Kamili Organization, About us. Available at https://www.kamilimentalhealth.org/copy-of-about-us.

[§] La Collina Social Cooperative, Social inclusion. Available at https://www.lacollina.org/presentazione-inserimento-lavorativo.html.

that any envisaged mechanism might not pay sufficient attention to the numerous determinants of mental health and well-being. For advocates of a well-being approach, this represents a significant opportunity to engage with the conception and framing of mental health and well-being as a social justice consideration and as a product of social, economic, cultural, and political factors.

Additionally, it is important to note that global health financing has been the subject of criticism on human rights grounds in the past, suggesting that any form of consolidated funding mechanism for mental health will need to consider these critiques, or indeed, consider whether such a mechanism is desirable at all. One such criticism has centered on the absence of the participation of affected individuals and communities—particularly those in the Global South—in decision-making spaces.[50] Participatory decision-making in the planning of health funding mechanisms, and the mainstreaming of mental health and well-being into existing mechanisms, can be a useful tool to recognize the cross-cutting nature of mental health and well-being and the importance of a plurality of approaches to address underfunding and underprioritization. Multiple funding mechanisms and institutional frameworks have the potential to support such plurality, but these can be bureaucratically burdensome, so the harmonization of such mechanisms and locally driven governance and oversight measures can enhance effectiveness.

Where new mechanisms are instituted, it is also necessary to consider some of the critiques of the "rights approaches" of existing global funding mechanisms in the health field that have over-emphasized the input of large civil society bodies over that of smaller organizations which more directly represent communities.[51] Similarly, tokenistic approaches that merely utilize civil society organizations as implementers of projects without recognizing their value as custodians of accountability have also been critiqued.[52] Donor conditionality that is removed from local context and therefore lacks an understanding of social, cultural, and political factors is an additional challenge, and one that can be mitigated through increased flexibility and direct transfers.[53] This then requires some reflection as to whether such direct bilateral funding ought to be the preferred approach, and the perspectives of advocates and people with lived experience of mental health challenges can add substantial value to such deliberations.

It should be noted that while there is strong momentum around the development of a financing facility for mental health, the obligations arising out of the CRPD and ICESCR recognize that states have a responsibility to maximize their own ability to cater to the needs of their inhabitants. Therefore, global impetus can also be galvanized to support states to do so, through measures such as progressive taxation, debt restructuring and cancellation, and technical assistance.[54] These mechanisms lend themselves to similar critiques regarding stakeholder participation, local knowledge prioritization, and civil society governance and accountability mechanisms.[55] Addressing these concerns is vital if financing is to be human rights focused.

The strong impetus around mental health in numerous global spaces is indeed quite promising and may well represent a considerable shift from the neglect that has plagued mental health systems around the world for so long. Even so, there are some important questions relating to whether rhetoric is actually matched by financial commitment, particularly as the public health agenda is dominated by the COVID-19 pandemic. Additionally, this moment is illustrative of the fact that an approach to mental health that does not take into account social, economic, and political factors is likely to recapitulate many of the criticisms that have been leveled at mental health systems in the past and is likely to undermine efforts to address the numerous challenges that individuals and communities are facing. Pandemic response funding should recognize the significance of mental health and well-being and avoid redirecting mental health funding to other priorities. This would be counterproductive for societal well-being and contrary to the obligation to promote and protect the right to the highest attainable standard of physical and mental health.

Conclusion

The underprioritization of mental health and well-being is a global problem that spans domestic investment and international development assistance. This is compounded by a significant lack of accurate data on spending and resource allocation. What little data there is suggests that spending on mental health continues to emphasize institution-based services, despite guidance from bodies, including WHO, that speaks to the need for community-based services, and despite the assertion of the right to life in the community in the CRPD. National budgeting for mental health is complex and requires accurate data capturing and the implementation of existing calls for parity. Moreover, it requires a reorientation from a framing of mental health as a purely public health concern to one that recognizes the ways in which well-being is affected by access to livelihoods, freedom from discrimination, belonging in a community, and numerous other factors. This offers the potential to utilize resources more holistically and to make decisions that do not see health as separate from, for example, social protection or education. Increased oversight of national-level resource allocation should be a fixture in all countries, and the involvement of people with lived experience in decision-making is an essential addition.

Similar concerns abound with regard to DAMH. At present, there is very little governance or oversight of international funding for mental health and well-being, and the perspectives of people with lived experience of mental health challenges seem to be absent in decision-making settings.[56] Likewise, additional data regarding DAMH would be useful, particularly in relation to the nature of the efforts funded. Research and advocacy around DAMH funding flows can substantially alter the way in which investments in mental health and well-being are made, and efforts to engage with the subject of holistic models of financing that are contextually relevant and participatory in nature can be of substantial value. These considerations should take into account the numerous critiques of international health financing mechanisms, many of which have created hierarchies of participation, have institutionalized conditionality, and have at times resulted in ineffective and inefficient delivery.

While it is encouraging to see the shifts evident in global decision-making spaces with regard to investment in mental health, this also presents substantial dangers if coercive and stigmatizing practices are to be "scaled up" in an effort to close "treatment gaps" without any emphasis on the numerous social, economic, political, legal, and cultural determinants of mental distress and mental well-being. This is particularly worrying as indications of profit-motivated interests determining mental health policy are increasingly being uncovered. However, as demonstrated above, there are numerous interventions and models of support that do not simply replicate institution-based and coercive practices, that do not recapitulate Western-oriented or Global North-developed practices in the Global South, and that do not promote a narrow biomedical framing of mental health. Supporting these models can significantly alter the way that all social support services are delivered, but it can do more than that. It can also reverse the stigmatization of people with lived experience of mental health challenges by shifting the disease framing that contributes to their marginalization.[57] Rights-based approaches—which engage with the social, economic, cultural, and political determinants of mental health and well-being—are both effective and necessary, and a strong evidence base is developing to demonstrate their utility and their applicability. Arguably, these approaches are rendered even more relevant and necessary in the current context, in which the COVID-19 pandemic is having a substantial impact not only on physical and biological well-being but also on social and economic well-being.

This moment represents a truly singular opportunity for advocates and policy makers. The momentum that is building around mental health can be an unparalleled catalyst for change. In addressing the barriers to mental health and well-being, a focus on social, economic, political and legal factors can be substantially helpful. The recognition of the mental health implications of the COVID-19 pandemic demonstrates a need for investment in holistic approaches to well-being if these implications are to be effectively addressed, and it requires that financing for mental health and well-being not be rendered "secondary" to other funding needs if the right to the highest attainable standard of physical and mental health is to be realized. In keeping with the principle of participation as enshrined in the CRPD, the voices of those affected must be centralized in policymaking and resource allocation decisions. Addressing the various biological, social, economic, cultural, and political determinants of mental health and well-being admittedly requires substantial investment, beyond even the increases that are already being seen. Even so, it is clear that there is both an obligation and a need for increased attention and increased funding for the promotion and protection of mental health. Perhaps more pointedly, there is an urgent need for attention and resourcing for the promotion and protection of well-being.

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HHR
Health and Human Rights Journal

Human Rights, Stigma, and Substance Use

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Abstract

The primary purpose of political, civil, socioeconomic, and cultural rights is to protect the dignity of all human beings. Good mental health and well-being is defined by the "social, psychosocial, economic, and physical environment that enables individuals and populations to live a life of dignity, with full enjoyment of their rights and in the equitable pursuit of their potential."[1] Stigmatization, discrimination, and negative stereotypes are barriers to mental health and well-being.[2] Individuals with mental health problems, including those with drug dependence, suffer stigmatization, which is a direct affront to dignity and may have enduring health impacts. This paper discusses the implications of stigma for a human-rights based approach to improving mental health among those with drug dependence, with a focus on the opioid epidemic now ravaging the United States. It explores the public health burden of stigma related to substance misuse, including stigma in the context of treatment and health care. It also discusses the role of policy initiatives—including decriminalization—in addressing stigma related to substance misuse.

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Competing interests: None declared.

We begin by emphasizing the need to consider the impact of stigma and discrimination for persons who experience substance use problems as a violation of their human rights and dignity. Although the literature on mental health stigma has grown significantly in recent years, it is critical to apply what we have learned on stigma specifically to substance use. In 2016, a report by the National Academies of Sciences, Engineering and Medicine concluded that the body of research on stigma related to substance use is sparse compared to the much larger evidence base that has amassed for mental illness.[3] In 2017, a series of papers evaluated the status of the current evidence base for stigma related to mental illness and drug dependence. The authors identified four systematic reviews of substance use-related stigma in the published literature representing approximately 200 published studies, compared to 49 systematic reviews of mental illness-related stigma representing more than 1,000 empirical studies.[4] In the United States specifically, given the opioid-driven overdose crisis, low rates of treatment among populations with opioid dependence, and the lack of a robust evidence base related to the impact of stigma, there is an urgent need to identify strategies to reduce the stigma associated with both self-identification of opioid dependence and use of medication-assisted treatment for opioid dependence. Effective strategies to reduce stigma could foster increased access to treatment for substance use problems.

In this paper, we explore some of the connections around human dignity, human rights, language, and stigma. Recognizing that there is extensive work being done around the concept of human dignity and its relationship to human rights from different perspectives, we embrace in this paper the notion of human dignity as the ethical core value and justification for human rights, and the idea that human rights are the means to realizing human dignity.[5] In the international human rights context, human dignity is considered inherent to every person and the basis for equal and inalienable rights. In its first article, the Universal Declaration of Human Rights declares that "all human beings are born free and equal in dignity and rights."[6] Similar references to human dignity are inscribed in several other international legal instruments. This notion of human dignity emphasizes an egalitarian belief in the sense that all persons are guaranteed dignity by virtue of their intrinsic value or worth as human beings, or "inherent dignity."[7] The foundation of this notion relies on Kantian ideas of human beings as autonomous entities with the capability of making their own decisions and determining their destinies. Human dignity defined as egalitarian and inherent necessarily implies that every person should be treated with respect and have their rights respected, protected, and fulfilled. To make this possible, societies need to ensure that every person has the opportunity to exercise their rights.

Along these lines, we need to be critical of the language used to refer to individuals who use substances. The growing body of literature on this subject shows us that language frames what the public thinks about substance misuse and dependence, and treatment and recovery, and it can affect how individuals think about themselves and their own ability to recover.[8] Language is one of the key mechanisms for reinforcing beliefs about persons with substance use problems that impair their dignity as human beings and interfere with the protection of their human rights. For example, the use of pejorative or condemnatory language (such as "junkie" and "addict") to refer to an individual with substance use problems may foster or perpetuate stigma. This is not simply about "political correctness"—it is about taking into consideration scientific evidence showing that certain terminology commonly used in the addiction field is associated with implicative cognition biases against the human dignity of persons with substance use problems.[9] Person-first language emphasizes the person instead of her condition (for example, a person who uses drugs or a person with a substance use problem or condition, as opposed to an "addict" or "drug abuser"). The use of person-first language is a way to deter the use of language that undermines human dignity and to protect the rights of individuals who use substances; thus, health care providers in particular have an obligation to use person-first language when referring to individuals with substance use problems.[10] Stigmatizing language in a health care setting may influence medical care and provider perceptions of individuals with drug dependence.[11]

Mental health and substance use problems

Since both mental distress and substance use problems are prevalent conditions and frequently co-occur, strategies to understand and address stigma have implications for the mental health of populations. In the United States, an estimated one in four individuals will experience mental or substance use problems during their lifetime.[12] In 2017, approximately 47 million US adults reported a mental illness, while 20 million persons aged 12 and older reported having a substance dependence problem; furthermore, almost one-fourth of adults (23%) with serious mental illness report past-year substance use problems.[13] About half of persons with serious mental illness report discrimination due to mental health status, physical disability, substance use, and ethnic or sexual minority status.[14] These figures likely represent underestimates, as stigmatization may contribute, in part, to underreporting in population-based surveys.[15] Worldwide, alcohol and illicit drug use is a leading cause of death. In 2017, approximately three million persons died from alcohol use, indirectly or directly, while the number of people deceased due to illicit drug use was approximately 800,000.[16] Additionally, mental health and substance use problems combined are the leading cause of years lost to disability, and the associated global burden of disease continues to grow, as evidenced by an increase of 37.6% between 1990 and 2010.[17]

What is stigma?

We can trace the term "stigma" to the ancient Greeks, who used this word to refer to the skin mark they left on the bodies of criminals, slaves, and traitors to identify them as immoral—"a blemished person, ritually polluted, to be avoided, especially in public places."[18] According to Erving Goffman in his seminal text on stigma, stigma embodies tribal identities (for example, race, ethnicity, religion), physical characteristics or conditions (for example, obesity, disability), and "blemishes of individual character." In this sense, stigma relates to personal characteristics, or cues, that are socially considered shameful. Goffman's discussion of stigma helps us understand that when we stigmatize others whom we perceive as different from ourselves, we assume that they are bad, dangerous, or weak. In addition, by stigmatizing an individual who is different, we are invalidating her whole personhood and diminishing her to a lesser status. Consequently, a person who is being stigmatized may perceive that she is not accepted or considered equal, engendering feelings of inferiority, shame, and self-loathing.[19]

Persons with mental health and substance use problems are exposed to an array of stigma components that interact to endanger their mental health. These components include stereotypes, prejudice, and discrimination.[20] Stereotypes are the over-generalized social beliefs we have about groups of people. For instance, persons with substance use problems may be perceived as untrustworthy, weak, and unwilling to stop using substances. Prejudice is an emotional response (for example, anger, irritation, pity, fear) among those who agree with the stereotype. Discrimination refers to behavior resulting from stereotypes and prejudices; for example, a person with drug dependence may be denied housing on the basis of these characteristics.

Types of stigma

To understand the mental health impact that stigma can have on people with substance use problems broadly, it is important to distinguish how stigma works at different levels of society and the individual. Furthermore, the use of different types of substances may be associated with the level at which stigma manifests and the intensity of that stigma. We will discuss five types of stigma: public, courtesy, structural, self, and multiple stigma. Each type of stigma entails specific challenges and responses in the protection of rights for persons with substance use problems.

Public stigma refers to the collective public's prejudice and discrimination toward a specific group of individuals—in this case, individuals with substance use problems. These prejudices and discriminatory actions are founded on cognitive representations that "perceivers" have about persons with the stigmatized condition ("targets"), which elicit negative emotional and behavioral responses.[21] Mental health conditions, including substance use problems, are more highly stigmatized than physical health conditions, regardless of the specific condition or severity.[22] High levels of perceived personal responsibility for a condition may elicit public anger and stigmatizing behavior, while low levels may induce sympathy and willingness to assist; higher levels of severity of the condition may evoke more public sympathy.[23] Among people with mental health conditions, those with substance use problems tend to experience more stigma because of the perceived personal responsibility often associated with this condition. Cognitive representations explain, in part, the greater public stigma associated with substance use as compared to mental illness, as substance use may be viewed as more controllable and a more egregious norm violation.[24] Despite research suggesting widespread understanding of the neurobiology of both mental illness and substance use problems, public beliefs related to substance use problems tend to blame the individual.[25] Research has demonstrated less willingness to socially include people with substance use problems than those with mental health conditions and more unfavorable reactions to persons with substance use problems.[26] Thus, public stigma creates obstacles for persons with substance use problems when other members of the community prevent their access to basic needs such as housing, food, education, and employment. In addition, stigma does not affect all individuals with mental illness or problematic substance use equally. For instance, individuals with psychosis are more stigmatized than those with depression or anxiety.[27] In addition, people who use intravenous drugs and crack cocaine are more highly stigmatized than those who use other substances by both the general public and people who use drugs.[28]

Within the realm of public stigma is the stigma experienced by associates of stigmatized groups, including treatment professionals, family, and friends, labeled as *courtesy stigma*.[29] This type of stigma may serve to further isolate stigmatized individuals, since associates may distance themselves from the individual to avoid such stigma. Family stigma may involve societal blame for some conditions.

Structural stigma refers to policies or institutional actions that restrict—whether intentionally or not—the opportunities of targeted groups.[30] Examples of structural stigma include discriminatory behaviors or overtly negative attitudes manifested by individuals acting as institutional representatives, such as those working in health care or within the criminal justice system.[31] Unintentional structural stigma encompasses both public and private sector policies, with consequences that restrict opportunities for those with drug dependence in unintended ways and may restrict access to and diminish the quality of care.[32] For instance, a review of legislation found some degree of legal restrictions for persons with mental illness in all 50 US states related to rights to serve on a jury, vote, hold political office, have parental custody, and engage in marriage.[33] One of the more serious issues with this type of legislation is the broad language used—which refers to people with any diagnosis of mental illness—instead of specific metrics of functional impairment; this reflects the stigma associated with persons with mental illness and substance use problems as dangerous and untrustworthy.[34] Consequently, persons with mental health and substance use problems may experience limitations and the infringement of their civil and political rights.

Another critical violation of the human rights of persons with mental health and substance use problems arises from policies established by the United States' war against drugs. It has been estimated that 65% of the US prison population has an active substance use diagnosis, while an additional 20% have been incarcerated for a crime involving drugs, including drug use.[35] The disproportionate representation of people with substance use problems in the criminal system may be an indication that the laws have been designed with the implicit intention of targeting such people. As a society, we have preferred a punitive approach to deal with persons with substance use problems instead of responding from a more humanistic perspective that considers drug dependence as a chronic mental health and medical condition that needs to be treated as such. Decriminalization could play an important role in reframing substance use problems as chronic health conditions rather than criminal activities. Within society, the illegal status of specific substances engenders structural stigma, and individuals who use illegal substances may thus experience greater effects of stigma than those who use licit substances.

Self-stigma occurs when a member of a targeted group internalizes a public stereotype or prejudice. Much of stigma's impact is a consequence of self-stigma, as it encompasses low self-esteem and alienation of self and has been associated with recovery orientation, empowerment, and perceived devaluation.[36] It has been suggested that self-stigma may mediate the relationship between structural stigma and poor health.[37] Self-stigma may result in lower self-efficacy, decreased motivation, and reduced quality of life, and it has been associated with increased depression risk.[38] Related to the impact of self-stigma on mental health is *label avoidance*, which occurs when a person avoids activities that reveal his or her condition or mental distress.[39] Label avoidance may manifest in a reluctance to seek care, as persons may avoid entering treatment or taking medication to avoid a stigmatic label. In general, individuals with mental health conditions, including those with substance use problems, may be more likely to conceal their diagnosis than those with a physical one. Because of label avoidance, persons with substance use problems may experience isolation and a reduction of social support, which may prevent them from the self-identification needed to benefit from protections afforded by anti-discrimination legislation.[40] Self-stigma and label avoidance may prevent persons with substance use problems from obtaining the health care services needed to attain complete physical, mental, and social well-being.

Public stigma, courtesy stigma, structural stigma, and self-stigma work together in an interrelated multilevel system, and public stigma, as a societally shared idea that a specific condition is devalued, is at the core of the interrelated domains.[41] However, other stigma domains may serve to increase (or decrease) effects of other domains. This systems understanding of stigma takes into account reciprocal relationships between individuals, their social networks, and larger social structures.[42] For example, higher levels of structural stigma related to substance use may result in higher levels of public stigma, courtesy stigma, and self-stigma; higher levels of public stigma may work to foster more structural stigma, as public opinion is incorporated into policy. Thus, the potential for stigma to infringe on individuals' human rights is not limited to the socioeconomic and cultural rights of persons with substance use problems and can also affect their political and civil rights. This framework also suggests that researchers should consider that stigma interventions at one level may have additive, enduring effects across the entire system.[43]

The concept of *multiple stigma* is particularly relevant to understanding the additive impact of stigma for many individuals with substance use problems. Among individuals who identify with multiple stigmatized groups, the accumulative distress of multiple stigma may result in more severe manifestations of mental distress and thus make discriminatory treatment by others more likely.[44] The tendency of substance use and mental illness to co-occur, and to also be associated with other stigmatized states (such as homelessness and poverty), is thus critically important from the perspective of multiple stigma.

The burden of stigma related to substance use

Understanding the burden of stigma related to problematic substance use must guide effective approaches to improve population health and individual health outcomes, which are intimately related to the protection and promotion of people's human rights; this, in turn, may foster the realization of certain human rights, such as the right to the highest attainable health. In a nationally representative survey of the US general adult population, which evaluated public stigma associated with specific mental health conditions (such as major depressive disorder and schizophrenia) and alcohol dependence, more than 80% believed that treatment for mental illness and alcohol dependence is effective, and this proportion increased over time, as did the proportion who attributed mental health disorders to neurobiological causes.[45] However, measures of social distance and perceived danger associated with individuals with mental illness and alcohol dependence did not decrease over the time period studied. Furthermore, 62% of respondents were unwilling to work closely with, and 52% were unwilling to socialize with, individuals with schizophrenia; 47% and 74% were unwilling to work closely with individuals with major depressive or alcohol dependence, respectively. Despite endorsing treatment overall, one in two adult respondents said that treatment for a mental health disorder would result in discrimination and, among children with mental health disorders who are treated, long-term harm to a child's future. These findings highlight the pervasiveness of public stigma within the United States that is associated with mental health conditions and substance misuse, as well as a continued resistance to change despite increased knowledge; they also suggest that understanding the neurobiological component of drug dependence may not be sufficient to preclude or address stigma or discrimination. Research has also highlighted the pervasive effects of internalized self-stigma and its impact on individual well-being across multiple domains among those experiencing mental distress. For example, research conducted among a population with serious mental illness demonstrated that expectations of discrimination prevented 64% from applying for employment or educational opportunities and 55% from entering into interpersonal relationships, and about one-third reported anticipating discrimination in situations where no discrimination was subsequently experienced.[46]

Stigma and treatment for substance use problems

Stigma influences the entire continuum of care for individuals with substance use problems—including treatment seeking, choice of treatment, treatment retention, and treatment adherence—which results in poorer individual and population health. The majority of individuals with drug dependence do not receive treatment. Fewer than 1 in 10 who need treatment for substance misuse or dependence receive any treatment.[47] Furthermore, less than half of individuals who meet diagnostic criteria for opioid misuse or dependence engage in treatment.[48] Stigma is a barrier to seeking treatment among affected individuals and may exacerbate preexisting health disparities by deterring health-seeking among affected persons.[49] Stigma prevents individuals from seeking the care needed to obtain a diagnosis, as those with a condition may be motivated to hide the condition to avoid public stigma (label avoidance).

Stigma is also a barrier to treatment seeking among individuals with alcohol or drug dependence. For example, among a nationally representative sample of adults with alcohol dependence, those who perceived higher stigma toward individuals with this disorder had lower odds of treatment utilization.[50] Among those with drug dependence who do enter treatment, the effects of stigma on their treatment (including treatment choice, adherence, and retention) may negatively affect treatment outcomes. For example, medication-assisted treatment (MAT) with buprenorphine or methadone is considered the current gold standard for treatment for opioid dependence, since its use is associated with reduced risk of relapse and mortality, yet stigma may present a barrier to its use, including stigma associated with MAT use within sectors of the treatment community. Stigma has been identified as a factor associated with individuals' desire to use a lower dose of methadone than may be necessary to prevent opioid cravings.[51] Further, self-stigma has been implicated in early MAT discontinuation, thus increasing individuals' risk of relapse and overdose.[52] Some peer-led support groups and 12-step recovery support programs may not support MAT use, and consequently individuals in recovery who are being treated with MAT may experience stigma from peers or group facilitators or, perhaps unintentionally, be persuaded to discontinue MAT use.[53]

Within the health care and substance use treatment systems, the use of pejorative diagnostic labels such as "addict," "drug abuser," and "psychotic" may perpetuate stigma. Health care systems may provide inferior care and reduced access to care for individuals with stigmatized conditions. A recent literature review identified 28 studies between 2000 and 2011 that assessed health care professionals' attitudes toward patients with substance use problems and concluded that providers' negative attitudes directed at such patients contribute to suboptimal care.[54] In addition, this review highlighted that surveyed providers lacked education, training, and support that specifically addressed substance misuse or drug dependence.

Structural stigma, ethics, and implications for policy and public health

Structural stigma encompasses policies within corporations, the judicial system, government, professional groups (including health care), schools and universities, and social service agencies, which may affect health care, employment, and educational opportunities.[55] Structural stigma may endorse discrimination and foster self-stigma and public stigma. An example of structural stigma is the lack of mental health parity in the United States, as historically mental health treatment infrastructure, workforce capacity, and insurance coverage has been less comprehensive than physical health.[56] Both the Mental Health Parity Act (2008) and Affordable Care Act (2010) represent policy responses to structural stigma that expand insurance coverage for mental health services; however, disparities persist, and not all persons and mental health conditions have equal access. Multiple components of the stigma process are unable to be directly addressed by policy; legislation cannot directly alter public attitudes toward those with mental health conditions, including substance use problems, but it can address the discrimination component of stigma, and the legislative protection of stigmatized groups may help change cultural norms.[57] Anti-discrimination policies may indirectly improve components of public and self-stigma (stereotype and prejudice) by upholding the standard that persons with mental health conditions should not be subject to discrimination, and they represent a mechanism for addressing stigma-related outcomes in arenas such as health care, education, and employment; however, legislative reform to combat discrimination must be accompanied by anti-stigma programs (for example, media campaigns) that directly address other components of stigma to improve such outcomes.[58]

Ethical consideration of structural stigma related to mental health conditions should contemplate whether society has an obligation to arrange social institutions to ensure that all citizens are equally protected from disease as much as possible.[59] Universal, equal access of all persons to appropriate health care and educational opportunities is an imperative for distributive justice and for the protection and fulfillment of the right to the highest attainable standard of health. Self-respect requires the respect of others, which is undermined by stigma, and in a just society, institutions respect every individual equally; structural stigma opposes these principles. Policy considerations differ for mental and substance use disorders, in large part due to the widespread criminalization of substance use. In the United States, federal legislation generally protects the rights of individuals with mental illness, while anti-discrimination protection for persons with substance use disorders is more tenuous. This differentiation, from an ethical perspective, is contrary to the principle of distributive justice, since fewer health care resources and legal protections are available to persons suffering from substance use problems than other mental health conditions.[60]

The decriminalization of drug use and possession has been proposed as a public health strategy for the United States' current overdose crisis. It is also a strategy to protect the human rights of those with substance use problems. Related to the use of illegal substances, the Joint United Nations Programme on HIV/AIDS (UNAIDS) asserts that "decriminalization of drug use and possession for personal use reduces the stigma and discrimination that hampers access to health care, harm reduction and legal services … people who use drugs need support, not incarceration."[61] UNAIDS maintains that states should "[p]rotect and promote the human rights of people who use drugs by treating them with dignity, providing equal access to health and social services, and by decriminalizing drug use/consumption and the possession, purchase and cultivation of drugs for personal use," and that taking action to end stigma and discrimination experienced by individuals who use drugs, including as related to health, legal, education, employment, and social protection services, is of paramount importance. There is some evidence that Portugal's decriminalization of all illicit drugs in 2001 may have resulted in reduced stigma around substance use, with downstream public health benefits.[62] Subsequent to decriminalization, drug-related incarceration plummeted, and significant reductions were observed in drug-related morbidity and mortality; the role of reduced stigma in increased treatment entry and service seeking may have played a role. Decriminalization could pave the way for expanded harm reduction and evidence-based public health approaches used in other countries, such as supervised injection facilities, that could curb the United States' current overdose crisis.

While this paper has adopted a US focus to specifically address the opioid overdose crisis, addressing substance use-related stigma in all societies is important regardless of geographic boundaries. Indeed, addressing stigma may be more imperative in low- and middle-income countries, where individuals with substance use problems may be forcibly institutionalized or otherwise involuntarily restrained and where pharmacological treatments may be unavailable.

Conclusion

Stigma related to substance use problems is a direct affront to the dignity and human rights of affected individuals, and it presents a barrier to individuals' attainment of the highest possible standard of physical and mental health. Stigma influences the entire continuum of care for individuals with substance use problems, including treatment seeking, choice of treatment, treatment retention, and treatment adherence, negatively influencing individual and population health. Public stigma, structural stigma, courtesy stigma, and self-stigma are interrelated in a multi-level system, which must be considered as a whole, and interventions or other changes specific to one component of substance use-related stigma may affect the entire system. Policy initiatives, including the decriminalization of substance use, could play a significant role in reducing discrimination and stigma associated with drug misuse and dependence. Such targeted anti-stigma initiatives could play a critical role as part of an armamentarium of policy and other initiatives to address the United States' opioid overdose crisis.

Acknowledgments

We thank Audrey Chapman for her helpful comments on an earlier draft of this manuscript.

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Mental Health as a Basic Human Right and the Interference of Commercialized Science

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Abstract

Although there is consensus that a rights-based approach to mental health is needed, there is disagreement about how best to conceptualize and execute it. The dominance of the medical model and industry's influence on psychiatry has led to an over-emphasis on intra-individual solutions, namely increasing individuals' access to biomedical treatments, with a resultant under-appreciation for the social and psychosocial determinants of health and the need for population-based health promotion. This paper argues that a robust rights-based approach to mental health is needed in order to overcome the effects of commercial interests on the mental health field. We show how commercialized science—the use of science primarily to meet industry needs—deflects attention away from the sociopolitical determinants of health, and we offer solutions for reform.

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Competing interests: None declared.

Introduction

> *Mental health and well-being cannot be defined by the absence of a mental health condition, but must be defined instead by the social, psychosocial, political, economic and physical environment that enables individuals and populations to live a life of dignity, with full enjoyment of their rights and in the equitable pursuit of their potential.*[1]

Human rights are not only entitlements that have a legal and ethical force but also "fundamental pillars of justice and civilization."[2] The United Nations (UN) Committee on Economic, Social and Cultural Rights adopted its general comment on the right to health 20 years ago. Officially adopting this comment solidified states' obligation to make the right to health a priority. Over the last two decades, mental health has become recognized as a critical component of the right to health and one that must be addressed for this right to be realized. As the first director-general of the World Health Organization (WHO) noted, "without mental health there can be no true physical health."[3]

However, there are numerous challenges to bringing a rights-based approach to mental health to fruition. This approach necessitates a critical evaluation of the assumptions about mental illness and traditional models of care. The hegemony of the medical model and the over-reliance on organized psychiatry as the main policy maker has undermined the development of mental health policy "as a robust cross-sectoral issue."[4] As a result, there has been an over-emphasis on biomedical interventions aimed at the individual rather than at population-based health promotion, even though the latter is just as important as individual health treatment.[5] The focus on biomedical interventions is particularly disconcerting because of the ways in which industry influence has compromised the scientific evidence base in medicine.

This paper argues that a rights-based approach to mental health is needed in order to overcome the effects of commercial interests on the mental health field. Specifically, we show how commercialized science—the use of science primarily to meet industry needs—deflects attention away from the psychosocial and sociopolitical determinants of health and undermines several key elements of a rights-based approach to mental health, such as the right to participation, the right to acceptable health care, and the importance of population-based health interventions.

Commercialized science: Why it undermines a rights-based approach

> *The mix of science and commerce continues to erode the ethical standards of research and diminish public confidence in its results.*[6]

Collaborations between academe and industry are credited with sparking innovation and have resulted in benefits to overall health (for example, treatments for malaria and the vaccine to prevent meningitis). However, the pressures of capitalism have resulted in a corrupting of the scientific evidence base, the medical education system, and even the lens through which human wellness and illness are viewed. Indeed, research has consistently shown that commercial influence is a pernicious problem in all of health care.[7] Although there is disagreement about the extent of bias, there is consensus among researchers, clinicians, scientific communities, and medical organizations that the scientific evidence base has been compromised.[8] Research has consistently shown that financial conflicts of interest shape prescribing practices, medical education, guideline recommendations, and editorial decisions.[9] In 2009, the Institute of Medicine (IOM, now the National Academy of Medicine) published *Conflicts of Interest in Medical Research, Practice, and Education*, which offered recommendations for restoring integrity in medicine. A decade later, an international group of researchers and clinicians assessed the progress made and concluded that there is continued "widespread financial dependence on industry [which] brings commercial bias into research evidence, medical education and clinical practice."[10]

The public health implications of the bias resulting from undue industry influence, especially when taken in aggregate, are staggering.[11] Although all medical specialties have to grapple with commercial bias and its resulting harm to patients, psychiatry is particularly vulnerable because of the lack of biological markers for any mental health disorders. In the field of psychiatry, commercialized science crowds out an appreciation for epistemic diversity (that is, an appreciation of diverse idioms of distress) by reinforcing a reductive biomedical disease model. In turn, this results in the "professionalization of suffering" that sustains the authority of psychiatrists and other mental health professionals over people with lived experience.[12] The right to participation and autonomous decision-making, including the right to refuse a proposed treatment, are all too easily glossed over in the service of enhancing "adherence to treatment." The heavily marketed disease model of mental illness has contributed to a range of systemic measures that have inadvertently entrenched discrimination in health care services, such as forced hospitalization when there is no immediate danger to one's self or others. Disease rhetoric and disease measures (for example, the disability-adjusted life year) are used to emphasize the economic burden of mental illness, particularly in low- and middle-income countries. The following section briefly discusses the commercialization of psychiatric science in four key areas: psychiatric taxonomy, psychotropic drug trials, clinical care guidelines, and medical education.

How has commercialized science resulted in biased research, practice, and education in psychiatry?

Limiting mental distress to a biomedical model

> *There is a boundary between the normal and the sick. There are discrete mental illnesses … It is the task of scientific psychiatry, as a medical specialty, to investigate the causes, diagnosis, and treatment of these mental illnesses.*[13]

The early versions of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) were heavily influenced by the prevailing psychoanalytic zeitgeist of the early 20th century. As a result, *DSM I* and *DSM II* had a descriptive focus and did not make clear demarcations between specific disorders. However, a paradigm shift occurred in 1980 with the publication of the *DSM III*, when the American Psychiatric Association, the book's developer, adopted a medical framework and used a "symptom checklist" approach. The conceptualization of emotional distress (and mental health conditions such as schizophrenia) codified in the third edition and continuing with each new iteration of the *DSM* encourages a view of people as patients with identifiable, quantifiable mental illnesses. This paradigm shift facilitated standardization (for example, are symptom criteria met for a mental illness?), but it also deflected attention away from asking questions about how structural interventions at the population level could enhance emotional well-being. Moreover, embracing a disease model solidified organized psychiatry's status within the mental health field.

The *DSM's* categorical approach, with its focus on identifying discrete symptomatology and expansion of diagnostic boundaries, reinforces the logic of "a pill for every ill." Although it was not the intention of organized psychiatry to develop a diagnostic taxonomy that was an industry-friendly instrument, Robert Spitzer, the chair of the *DSM III*, later acknowledged that "[t]he pharmaceuticals were delighted" with the medical model adopted by the *DSM*.[14] The fact that the majority of *DSM IV* and *DSM V* panel members had financial ties to the manufacturers of psychotropic medications used to treat the disorders described in the manual has raised concerns about industry exerting an undue influence on it.[15]

Setting the agenda and swaying the evidence via psychotropic drug trials

In addition to aligning the very definitions of mental illness with its commercial needs, the pharmaceutical industry also controls much of the current evidence base. Although the US National Institutes of Health and government agencies in other countries fund basic science studies, much of the clinical research relied on by clinicians and policy makers is funded by industry. This "ghost management" not only sets the research agenda but also normalizes academic-industry relationships.[16]

This entanglement affects the interpretation of the data and research that is produced.[17] For example, in all fields of medicine, it has been shown repeatedly that published outcomes of industry-sponsored studies "tend to favour sponsors' products, creating a 'sponsorship bias'."[18] In psychiatry, studies that reported financial conflicts of interest were almost five times more likely to report positive results.[19] The use of disease-oriented outcome measures and a reliance on statistical—rather than clinical—significance contribute to this "funding effect." Indeed, industry funding of phase III randomized clinical trials for psychotropic drugs consistently results in the publication of pro-industry findings, overestimation of efficacy, and underreporting of harms.[20] The funding effect can be manifest in subtle but powerful ways. For example, Veronica Yank et al. found that trial authors with financial conflicts of interest tend to write favorable conclusions even in the absence of positive trial results.[21] This finding demonstrates that the commercial interference is likely to be rooted in implicit bias and in the development of "pro-industry habits of thought."[22]

Spreading the agenda via clinical care guidelines

Commercial influence over guideline development occurs when authors have financial conflicts of interest or when the pharmaceutical or medical device industry funds the development process (directly or indirectly). Guild interests can also exert an influence when the development group is not sufficiently multidisciplinary and when the group does not include methodologists who can help ensure that the interpretation of the evidence is not influenced by a professional society's interests. The fact that 90% of the authors of three major guidelines produced by the American Psychiatric Association for major depressive disorder, bipolar disorder, and schizophrenia had ties to the companies that manufactured the medications recommended as treatments for these disorders raises questions about undue industry influence.[23] More recently, a new guideline for the treatment of depression was published in a peer-reviewed psychiatric journal and heavily marketed to physicians and psychiatrists (for example, it was featured on Medscape and as a continuing medical education course).[24] The authors of this guideline recommended expensive on-patent medications even though generic options were available and did not provide empirical support for their recommendation. An independent review of the guideline found that it *did not meet a single IOM standard* for trustworthy guidelines and that most of the guideline authors had ties to the manufacturer whose product was recommended as a first-line treatment.[25]

Solidifying the hegemony via medical education

In addition to supporting great swaths of research in medical schools, the pharmaceutical industry starts early in medical training to create a non-critical, welcoming atmosphere among medical students. Most medical students will interact with the pharmaceutical industry at some point, with these interactions ranging from meals to gifts to books or study aids. As a result, favorable attitudes toward industry are cultivated.[26] Cultivation of either indebtedness or entitlement continues in residency training and follows physicians into their practices, where relationships with industry are further developed, resulting in the prescribing of new medicines with little or no advantage over older, less expensive ones.[27]

Commercial support of continuing medical education (CME) is also a pernicious problem. Despite efforts by the accrediting body to minimize the influence of industry on content, almost three-fourths of the top 500 providers of CME receive commercial support.[28] Not surprisingly, industry-funded CME has been criticized for containing marketing messages that are neither balanced nor accurate.[29] The Accreditation Council for Continuing Medical Education sets standards in an attempt to "ensure that CME activities are independent and free of commercial bias," but there is still a need for greater oversight and transparency. For example, physicians should be told that despite the council's oversight, it is possible that there will still be commercial interference in terms of the content of the educational activity.[30] Because of the concern that medical education has effectively become a marketing tool, the National Academy of Medicine has called for a complete severing of ties between industry and CME providers.[31] Unfortunately, this call has gone unheeded.

Solutions for reform

> *Will we have to wait for someone to run a randomised controlled trial with an economic evaluation to support the intervention of befriending, supported decision making, inclusion in the work-place, or decent housing before we acknowledge these as being worthy investments for health-care systems? Moral arguments continue to be dismissed or undervalued in priority setting in global health … [and] the primary locus of interventions for healthcare problems is narrowly defined technological fixes.*[32]

Using a human rights lens to understand emotional suffering revives ethical discussions about mental health because the impetus for addressing well-being is grounded in a moral and not economic argument. As Gillian MacNaughton and Diane Frey note, framing a right as an economic good "undermines its content and positions it as a component in an economic equation rather than as part of a fulfilling life."[33] In contrast, casting well-being in a moral framework facilitates a deeper understanding of the relationship between human rights and the social determinants of health, for we must consider the immediate psychosocial context out of which symptoms emerge. A robust human rights approach can thus address key aspects of this relationship in order to enhance the well-being of populations. Indeed, Amartya Sen's capabilities approach—a moral framework that understands that the opportunity to develop capabilities is central to human freedom and dignity—clearly shows that rights and capabilities must be seen as interdependent entities.[34] In an attempt to respond to that interdependence and ensure that access to care and health equity are not conflated, we offer the following suggestions.

First and foremost, greater inclusivity of individuals who have been assigned psychiatric diagnoses or who identify as individuals with psychosocial disabilities is needed in order to develop policies, programs, and standards of care that appreciate diverse idioms of distress. Participation must be seen not as an add-on but as an "efficient and effective strategy to improve health care systems and services"; such participation will help expand proposed solutions beyond the biomedical realm.[35] That is why people with lived experience should play a central role in the decision-making, design, and dissemination of mental health research and practice standards. Such inclusion will also help ensure that commercial interests do not compromise the integrity of guidelines.

Also, in terms of addressing stigma, the enhanced participation of stakeholders will help us better understand and challenge the *institutional* structures through which the stigmatization of individuals with psychosocial disabilities is perpetuated.[36] In order to avoid what Flick Grey has termed a process of "benevolent othering," anti-stigma approaches must be rooted in a more nuanced sociological understanding of stigma that sees it as social, relational, and structural.[37] For example, in Australia, the Queensland Mental Health Commission analyzed legislation and identified laws that were potentially stigmatizing, described why, and made specific recommendations for their revision or elimination.[38] A rights-based orientation can thus interrupt the stigmatizing process because it is premised on the universality of human dignity.[39]

Moreover, assessments of states' and duty bearers' compliance with a rights-based approach should not be limited to the availability of psychotropic medications. Interventions that fail to consider the social determinants of health would thus not be compliant with the right to health and not aligned with scientific evidence.[40] Population-based health must be put on equal footing with intra-individual treatments because improvements in the mental health status of populations cannot be improved simply by increasing access to medical and psychological treatments and services.[41] For example, the Special Rapporteur on the right to health has consistently urged action on structural factors that produce distress and has called on states to fund health promotion activities and not simply focus on scaling up access to psychiatric diagnosis and treatment.[42] Certainly, addressing structural violence (that is, the ways in which institutions and social arrangements hurt populations and individuals) will undoubtedly be an uphill battle: population-based interventions do not serve industry the way biomedical interventions do.[43] However, as the Special Rapporteur has urged, we should not remain wedded to a narrow metric of an essential medicines list when evaluating states' human rights compliance; we need to expand assessments of compliance to include psychosocial interventions.[44]

Finally, we need analyses that deepen our understanding of the constitutive role of power in the broader determination of health. The current Special Rapporteur on the right to health pointed out early on in his tenure that there needs to be a shift in conversations and policies about mental health—from talking about chemical imbalances to addressing power imbalances.[45] The resulting power asymmetries that occur because decision-making power remains concentrated in financially conflicted organized psychiatry and industry disempowers the people who need the care the most.

Conclusion

> *Scaling up of psychiatry in low income countries risks becoming scaled down to an "administrative psychiatry" whose primary objective is the prescription of psychotropic drugs and the reduction of symptoms rather than addressing the social and psychological factors which contribute to mental breakdown and recovery.*[46]

What are the conditions for the possibility of a robust human rights approach to mental health? While that question eludes easy answers, a necessary starting point is recognizing that the precarious epistemological foundations of psychiatry allow the mental health field to be manipulated by industry. Therefore, although it is clear that many people throughout the world are not getting the health care they need and deserve, it is also evident that the uncritical exportation of the biomedical disease model will not provide optimally effective mental health interventions at either the individual or population level. Indeed, scaling up mental health treatments in the absence of conceptual and structural competence may very well lead to unintended human rights violations (such as forced treatment).[47] Challenging though it may be, addressing the entrenched problem of commercial influence on the scientific evidence base is essential if we are to bring a rights-based approach to fruition.[48]

Acknowledgments

We would like to thank Chia Po Cheng for his editorial assistance and helpful feedback on earlier drafts and Justin Karter, Zenobia Morrill, Rebecca Troeger, Jackie Hogan, Evan Valdes, Michelangela Yusif, and Christine Tosti for their assistance, comments, and suggestions.

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PERSPECTIVE

WHO's QualityRights Initiative: Transforming Services and Promoting Rights in Mental Health

MICHELLE FUNK AND NATALIE DREW BOLD

This perspective essay introduces the World Health Organization's QualityRights initiative, which uses a multicomponent framework and strategies to promote mental health systems, services, and practices that prioritize respect for human rights, in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).[1] It describes how the initiative is working to provide practical solutions to promote inclusion, legal capacity, and non-coercive approaches in mental health.

Since the adoption of the CRPD in 2006, there has been considerable dialogue, debate, and concerns expressed around the applicability of the Committee on the Rights of Persons with Disabilities' interpretations of certain key provisions of the convention as they relate to the area of mental health. In particular, these concerns refer to the right to equal recognition before the law and to legal capacity (article 12), as well as the right to liberty and security of the person (article 14).[2] They are reflected in the declarations and reservations submitted by several countries in relation to these articles specifically and briefly summarized below.[3]

Article 12 of the convention states that all persons with disabilities, including persons with mental health conditions and psychosocial disabilities, must be allowed to exercise legal capacity—in other words, to make decisions for themselves on all aspects of their lives—on an equal basis with others.[4] This challenges and ultimately prohibits practices such as forced admission and treatment, guardianship, and other forms of substitute decision-making. Instead, article 12 recognizes and promotes the concept of "supported decision-making," wherein people are provided with access to a variety of support options, including the support of people they trust (for example, family, friends, peers, advocates, lawyers, and personal ombudspersons), in order to make decisions and choices for themselves. This approach recognizes that building on people's unique abilities and providing them with the support they require allows them to make their own decisions. A person may need support to understand the information, weigh different options, understand

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Competing interests: None declared.

Disclaimer: The authors are staff members of the World Health Organization. The authors alone are responsible for the views expressed in this article, and they do not necessarily represent the decisions, policy, or views of the World Health Organization.

the possible consequences of different options, and communicate their decisions to others.[5]

Article 14 on the right to liberty and security of the person states that persons with disabilities should not be deprived of their liberty unlawfully or arbitrarily and the existence of a disability shall in no case justify detention.[6] Applied in the mental health context, this means that persons with mental health conditions and psychosocial disabilities cannot be involuntarily detained in mental health services or other facilities such as institutions, prayer camps, sheds, or houses. Furthermore, detention on the basis of a diagnosed or perceived disability is not allowed, even when additional reasons or criteria are given for the detention, such as "need for treatment," "presumed danger," or "lack of insight."[7]

The main point of dispute for many professionals in the mental health field and beyond is that these provisions, in the context of "no exceptions," risk undermining the rights to the enjoyment of the highest attainable standard of health, to access to justice, to liberty, and to life.[8] They argue that "exceptional" measures such as guardianship and involuntary admission and treatment are necessary to prevent danger to one's self or others and to ensure that people receive the care and support they need.[9]

For example, Melvyn Freeman et al. argue that prohibiting involuntary admission or treatment "closes viable options for saving lives and is especially tragic where the suicidal ideation is directly linked with impaired decision-making capacity and could have been changed through admission or treatment."[10] Similarly, the authors go on to state that "in rare instances others might be harmed or their lives taken in select circumstances, whereas admission or treatment of a person with mental disability might prevent this" and that "when there is a conflict between different rights, the right to life should trump other rights."[11]

Paul Appelbaum, in a 2019 article, expresses concern that, under the CRPD, older persons with dementia who may be unable to care for their own needs or finances cannot be compelled to have a guardian manage different aspects of their lives. He also deplores the fact that people with major depression or who are experiencing psychosis and refuse to eat cannot be compelled to go to a hospital and that someone in "manic stage of bipolar disorder may be free to spend family savings or wreck the family business."[12] He further argues that "[i]n the name of protecting all these people from discrimination, they would be free to destroy their own lives and ruin the lives of their loved ones."[13]

Many other diverse groups—including mental health professionals, people with lived experience, people with psychosocial disabilities, lawyers, human rights advocates, and other stakeholders—point out that it is the "exceptions" in laws around involuntary admission, treatment, seclusion, and restraint and other coercive measures that, in reality, go on to become standard practice in countries everywhere.[14] Many call for the complete prohibition of all coercive practices, citing the absence of evidence of these practices' effectiveness and the available evidence demonstrating that coercive practices cause harm to physical and mental health, can lead to death, can undermine trust within therapeutic relationships, and are incompatible with the fundamental principles of dignity and autonomy.[15]

In an open letter to the World Psychiatric Association in relation to volume 18/1 of *World Psychiatry*, a consortium of users and survivors of psychiatry state that "the option of forced psychiatric treatment affects each citizen (although not equally) and has implications for anyone who comes into contact with the mental health system. The related debate can therefore not continue based on 'exceptional' cases and constructed scenarios only."[16]

For many, the focus now needs to center on putting in place creative responses in mental health care that respect people's will and preference and foster therapeutic relationships based on trust and empowerment, and in ways that avoid the pitfalls of the past.[17] In reality, however, laws and standard practice in all countries continue to adopt an "exceptions" approach and to authorize the use of coercive measures, including substitute decision-making, forced detention and treatment, and seclusion and restraint. With polarized opinions on these issues, resistance to adopting alternatives to coercive practices, and entrenched systems, mechanisms, and legal frameworks that keep them in place, mental health reform remains extremely challenging in all countries.

Fostering dialogue and action toward implementation of the CRPD

An important goal of the WHO QualityRights initiative is to provide practical solutions to promote human rights throughout countries' mental health and social care systems and in particular to support countries—the vast majority of whom have ratified the CRPD—to actualize the rights of convention.

The initial emphasis of QualityRights was on promoting sustainable change in attitudes and practices in the field of mental health and to ensure respect for the human rights of people with mental health conditions and psychosocial disabilities. Answering questions such as "How should practitioners be practicing in services in order to be compliant with the CRPD?" and "How should practitioners, families, and others respond to crisis situations in a way that respects the legal capacity and right to liberty of the person concerned?" became paramount in these efforts.

Following research on good practices in the literature and an extensive process of consultation with a wide variety of international experts on the types of practices on the ground that align with the CRPD, the next step was to develop strategies to integrate these practices into countries' mental health systems and services. This involved the development of three major areas of work, which are at the core of the WHO QualityRights initiative:

- building capacity among all stakeholders to improve attitudes and practices to address stigma and discrimination and promote human rights and recovery
- supporting countries in the creation of community-based services and supports that respect and promote human rights
- supporting national policy and law reform in line with the CRPD and other international human rights standards

Key to the initiative is the active engagement and support of civil society, in particular organizations of persons with lived experience, in all these areas of the work.

Strengthening knowledge and capacity on rights and recovery

On November 27, 2019, WHO launched its QualityRights training and guidance materials and tools.[18] These resources aim to support countries in transforming their health systems and services toward a person-centered, recovery-oriented, and human rights-based approach in line with the CRPD and the vision outlined by WHO Director General Tedros Ghebreyesus in the foreword to the QualityRights materials.

In order to maximize reach, WHO has also developed the QualityRights e-training on mental health, disability, human rights, and recovery. This platform has the potential to reach tens of thousands of stakeholders within and across countries.

The QualityRights resources are designed to build capacity on mental health, disability, human rights, and recovery among a full range of stakeholders, including policy makers, health and mental health professionals, social workers, people with lived experience, organizations of persons with disabilities, families and care partners, nongovernmental organizations, professional associations and organizations, academic institutions, and other key national actors.

The tensions, difficulties, and challenges highlighted earlier around involuntary admission and treatment, seclusion and restraint, and other coercive practices are addressed head on in the content of the QualityRights training modules. The modules build knowledge and skills on concrete strategies for promoting treatment, care, and support based on people's will and preference, even in the most challenging of circumstances. This includes a variety of strategies for promoting legal capacity, including supported decision-making, advance planning, best interpretation of will and preference, and Ulysses clauses.[19] The modules also build knowledge and skills in order to avoid coercion. They outline how to develop and use individualized plans that address a person's sensitivities and specific situations that can lead to distress and agitation. Furthermore, the modules provide techniques for de-escalating and resolving conflicts, creating a "saying yes" and "can do" culture, establishing supportive environments and comfort rooms, and setting up response teams to manage challenging and conflictual scenarios.[20]

Of course, conflictual situations are sometimes unavoidable, and even with the best of measures and strategies in place that align with the rights of the CRPD, coercive practices may occur on occasion. However, in these situations the QualityRights materials also provide guidance and training on how to learn from such incidents, understand what went wrong, and undertake measures to prevent them from recurring in the future.

A key ingredient to the effectiveness of the QualityRights materials and tools in changing attitudes and practices lies in their design and methodology. The materials use exercises, debates, discussions, case studies, and scenarios from countries around the world to engage people, on a personal and emotional level, with the concepts of human rights and recovery. People are encouraged to explore what rights and recovery means to them personally, in order to gain a more profound understanding of their importance to others, notably people with lived experience.

Through exercises and case scenarios, for example, people explore what it might be like to be denied the right to make decisions about all aspects of their lives—what to eat, what to wear, where to live, what kind of treatment to receive, how to handle personal and financial matters, and so on—as is the experience of so many people with psychosocial disabilities. In order to better understand concepts underpinning recovery, trainees are also encouraged to think about and discuss what has helped them recover from situations or events in their own lives—friendship, support, having hope, and finding purpose and meaning in life—in order to better understand that these are important for everyone in recovery, including people with psychosocial disabilities.

The face-to-face QualityRights training and guidance materials in their pilot form, as well as the QualityRights e-training platform, have already been extensively implemented in countries in all regions.

Support for transforming mental health and related services

Another area of work being undertaken as part of QualityRights is to support countries in promoting community-based and recovery-oriented mental health and related services that respect and promote human rights.

The WHO QualityRights assessment toolkit enables countries to assess their services against standards derived from the CRPD.[21] Furthermore, the recently published module on transforming services and promoting human rights also provides countries with the framework, guidance, and training required to address gaps and transform services in line with CRPD standards.[22] Some of the issues addressed in this "transformation" guidance tool include changing the service culture and the power dynamics, defining a shared vision for the service, and working on the specific priorities and actions for change.

In addition, as part of this area of work, the QualityRights initiative is developing a document that will showcase community-based mental health services being implemented in countries around the world that respect human rights, are person-centered and recovery-oriented, operate without coercion, and promote autonomy, participation, and inclusion in line with the CRPD. The document will encompass mental health services from all regions of the world, reflecting different socioeconomic and cultural contexts. The guidance document will discuss the applicability of services in different settings and underscore the importance of not importing models inappropriately into different contexts. Showing that these types of services exist and are effective is critical key to inspiring policy makers and other actors to spread these new and innovative approaches to mental health across the world.

Aligning policy and law with the CRPD

The third area of work that WHO has embarked on as part of QualityRights is the development of new guidance for countries on how to formulate and implement mental health-related policy and law in line with the CRPD.

Many countries rely on assistance and support from WHO to develop or reform their national laws and policies related to mental health. Previous WHO guidance in these areas were drafted prior to the coming into force of the CRPD and thus does not comply fully with the standards set by the convention.

Indeed, the lack of clear and concrete guidance on policy and law in the new CRPD era remains a major barrier to countries seeking to ensure that their mental health laws and policies comply with human rights standards. Policy makers are required to go beyond simply repealing provisions related to forced admission, treatment, and guardianship. They need clear legal and policy directions that provide practical solutions and strategies for upholding the rights of people with psychosocial disabilities and for ending coercion and abuse in mental health.

WHO's new policy and law guidance will answer critical questions such as "How can we safeguard people's rights, even in crisis situations?"; "What are the processes for respecting peoples will and preferences?"; "What concrete measures are needed to establish supported decision-making processes?"; and "How can policy and law facilitate the development of community-based services that promote recovery and rights?"

Creating strong policy and legislative frameworks that align with the CRPD will be critical to ensuring that practices and services on the ground respect and promote rights and recovery for people with psychosocial disabilities effectively and sustainably.

Country support

Implementation of the WHO QualityRights initiative started several years ago with small pilot projects in different countries. From 2014 to 2016, a comprehensive statewide implementation of QualityRights was undertaken in the state of Gujarat in India, led by the Ministry of Health and Family Welfare. As part of the study project, assessments of quality and human rights conditions were conducted in services throughout the state, and individualized improvement plans were developed at each of the services using the QualityRights tools and methodology highlighted above. Additionally, a comprehensive capacity-building program was undertaken to train health care staff, people using services, and their families using the QualityRights training modules.

The project evaluation demonstrated significant changes over the course of the three years, including substantial improvement in the quality of care, attitudes toward people using services, and satisfaction and empowerment among people using services.[23]

Since the initiative in Gujarat, QualityRights continues to gain momentum in countries in all regions of the world. During 2019, nationwide launches and rollouts of QualityRights were initiated in Ghana, the Philippines, Kenya, Turkey, Estonia, and Czechia; more launches are scheduled for 2020. QualityRights activities are also continuing on a wide scale in Lebanon, Armenia, Bosnia and Herzegovina, Romania, Slovakia, Croatia, and Lithuania. Although activities vary from country to country, activities include QualityRights service assessments, the implementation of transformation plans, face-to-face capacity building, the rollout of e-training, and policy and law reform. The actions taken to date and achievements are detailed country by country on the WHO QualityRights Country Implementation Portal.

This portal has been created to enable countries to document their activities and share information, strategies, experiences, and resources.[24] Documenting QualityRights reform in countries, and showing that real and impactful change is possible, will be key to inspiring other countries to take on the challenge and commitment of promoting human rights and recovery in mental health.

Although positive results are being achieved, there remain challenges in implementation and sustainability at the individual, service, and systems levels. At an individual level, not all staff are convinced of the need to change practices, and misconceptions and discriminatory attitudes persist. More time is required to reinforce new knowledge and skills in order to facilitate more sustained attitude change among larger numbers of staff working in mental health services, and this also needs to be reinforced by attitudinal change within the wider community.

Another key challenge concerns the types of services that are offered and the need to have all services be based in the community. In many of the countries engaging in the QualityRights initiative, psychiatric institutions and facilities remain the core of the services being provided. Facilities and institutions that are isolated from the community are breeding grounds for coercive practices, violence, and abuse and therefore need to be phased out. Furthermore, many services are under-resourced both financially and in terms of staff, which is an additional barrier to providing quality care and support in line with human rights standards. And finally, laws that legitimize coercive practices (even under exceptional circumstances only) will always remain a barrier to the full integration of a CRPD approach in mental health.

Conclusion

Mental health systems in countries around the world are far from reaching the obligations set out in international human rights conventions, in particular the CRPD. There are, however, a number of practical solutions, resources, and tools now available through the WHO QualityRights initiative that have been used in countries and have demonstrated that change is possible and can lead to better outcomes for people using services, professionals, policy makers, and communities. The new QualityRights tools that are currently being developed around good practice community-based services and on CRPD-aligned policy and law will also provide countries with much-needed guidance to achieve sustainable change.

Not all countries are ready or have the capacity to immediately take the multifaceted measures required to align their services and systems with the CRPD. A key motivating factor for many will be the availability of clear, documented evidence of good outcomes from other countries. This will demonstrate that change is possible and will hopefully convince them to embark on similar reform efforts. It will also be crucial for ensuring better research investment around the implementation of the CRPD.

Box 1. Links and resources

- QualityRights materials and tools: https://www.who.int/publications-detail/who-qualityrights-guidance-and-training-tools
- QualityRights self-help recovery tool for mental health and well-being: https://www.who.int/publications-detail/who-qualityrights-self-help-tool
- QualityRights Country Implementation Portal: https://qualityrights.org/
- WHO's feature story on WHO QualityRights: https://www.who.int/news-room/feature-stories/detail/mental-health-services-in-lebanon-an-approach-focused-on-recovery
- *QualityRights in Lebanon: A personal perspective* (video): https://qualityrights.org/wp-content/uploads/WHO-Mental-Health.mp4

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HHR
Health and Human Rights Journal

Arctic Suicide, Social Medicine, and the Purview of Care in Global Mental Health

LUCAS TROUT AND LISA WEXLER

Abstract

Youth suicide is a significant health disparity in circumpolar indigenous communities, with devastating impacts at individual, family, and community levels. This study draws on structured interviews and ethnographic work with health professionals in the Alaskan Arctic to examine the meanings assigned to Alaska Native youth suicide, as well as the health systems that shape clinicians' practices of care. By defining suicide as psychogenic on the one hand, and as an index of social suffering on the other, its solutions are brought into focus and circumscribed in particular and patterned ways. We contrast psychiatric and social explanatory models, bureaucratic and relational forms of care, and biomedical and biosocial models for care delivery. Within the broader context of global mental health, this study suggests steps for linking caregiving to the health and social equity agenda of social medicine and for operationalizing commitments to health as a human right.

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Competing interests: None declared.

What is the purview of care in global mental health, and what is the role of health workers delivering care in settings of morbific social inequality? The syncretic frameworks of social medicine and human rights—turning to the social, historical, and structural forces that produce illness and govern its care, while directing such care toward achieving the highest attainable standard of health—offer several converging points of guidance. Social medicine refers here to the constellation of fields working to understand and organize care around the non-biologic bases of illness and disease.[1] Social medicine is both an articulation of, and path toward realizing, human rights—including the right to "the enjoyment of the highest attainable standard of physical and mental health," as defined by the Constitution of the World Health Organization.[2] Finally, global mental health is meant to index the practice of researching, developing, and delivering mental health care on a global scale, with a health and health care equity agenda.[3]

Promisingly, the 21st-century scale-up of global health has seen mental health care find inclusion both conceptually and as a core service delivered by state health agencies and nongovernmental organizations on the global stage.[4] The rise of global mental health as a moral concern, and as a body of action to address inequities in the care of human suffering, closely parallels the development of global political commitments to the right to health—and dovetails with the twin health and social equity agendas of social medicine.[5] Increasingly recognized in these movements is evidence that many of the paramount predictors of mental health are social in nature; that mental health care delivery occurs within meaningful social contexts that significantly affect treatment adherence and outcomes; and that broad-scale social arrangements both define the distribution and burden of mental disorders and shape the manner in which care is extended or withheld based on the social legitimization of illness and experience.[6]

Yet the mental health fields (broadly, psychology, counseling, psychiatry, and clinical social work), as they extend their practice onto the equity-focused terrain of global health, have focused primarily on the scale-up of technical interventions and systems of care developed in a small set of Western nations (that is, in comparatively affluent, biomedically oriented social and scientific contexts).[7] Research, policy agendas, and clinical care remain animated by a professional legacy and scientific product that focuses attention on pathological, disease-analogous processes internal to the individual, with social, political, and economic life treated as an appendix to the real work of understanding and care.[8] Culture, within the context of caregiving, often becomes operationalized as a technical skill or competency.[9] By tracking the framing and care of suicide in a remote region of the Alaskan Arctic, this study seeks to foster an action-oriented discussion of the broader meaning and purview of care in global mental health.

Suicide care in Arctic Alaska

Perhaps nowhere is the ambiguous purview of global mental health more apparent than with respect to suicide care across the circumpolar North. In the context of the United States, Alaska Native youth suicide rates have become among the nation's highest in the past 60 years, shaping a disturbing trend situated in public discourse as an "epidemic" that warrants broad-scale health system mobilization in response.[10] This takes shape through systems of surveillance, clinical intervention, and rights restriction, enmeshed in complex state regulatory environments and the bureaucracies of rural Alaska health care.[11] In the study region, the suicidal "patient" is typically held in the emergency room, village holding cell, or clinic until evaluated by a trained clinician for what is construed as essentially a medical event within the purview of clinical mental health care and emergency medicine.[12] Assessments for suicide risk and the delivery of care play out in a regimented, protocol-based system centered on clinical diagnosis, risk mitigation, and the prevention of harm—doubtless noble and worthy goals.

Paradoxically, the rise of youth suicide across the North American Arctic closely parallels the development of colonial infrastructure, including health systems and public services, in indigenous communities.[13] Suicide rates have increased in tandem with the rapid and imposed social change that has characterized the "modernization" of the Global North in various waves of colonial settlement.[14] A common narrative in the study region links the social, economic, and political revisions of Arctic life experienced by indigenous people over the past century to mental health disparities, mediated by increased social inequality and diminished access to community and cultural protective factors.[15] Rapid, imposed social change and the dissolution of shared structures of meaning are implicated frequently in public discourse, as well as some research, as drivers of contemporary youth suicide.[16]

For some, the welfare colonialism embodied in health bureaucracies, public health infrastructure, and "Western" forms of care is linked to the generation and maintenance of indigenous health disparities, including suicide.[17] In response, Alaska Native leaders have called for community-based and decolonizing approaches that emphasize the protective value of culture, traditions, and sovereign systems of care.[18] While we focus here on the narratives attached to suicide among health and social work professionals, elsewhere we have contributed similar efforts from community perspectives.[19]

More broadly, this study is intended to investigate the relationship between defining a problem and invoking its solution in global mental health. Precisely what sort of thing is suicide? What can be done to stop it? And how can this assessment inform the strategies employed in global mental health to achieve the aims of fostering health equity, securing human rights, and alleviating preventable suffering?

Methods

This study examines the meanings that health and mental health workers assign to Alaska Native youth suicide, the broader systems that shape these workers' practices of care, and the communities these systems serve. We conducted 14 structured interviews with health professionals in a remote, predominantly (80%) indigenous region of Alaska. Participants were recruited via convenience sampling to represent the key players in suicide care across the health system, including six social workers, three community health aides, two village-based counselors, two nurses, and a family medicine physician. Informed written consent was obtained from all participants.

Our interviews asked specifically about participants' knowledge and beliefs regarding youth suicide and suicide prevention. We administered a scripted protocol of 14 questions, including five case study questions asking health workers to consider their responses to specific hypothetical suicide events. For example, one case study question asked participants to anticipate their response if a family member of a suicidal person were to contact them and ask for help. Another asked health workers to consider their response to rumors of a suicide pact among a number of village youth after the death of one of their peers. Additional questions covered successes and failures experienced with suicide prevention in professional and personal caregiving roles, perceived causes of youth suicide, training, recommendations to other health professionals for effectively intervening to prevent suicide, and perceived health system successes and failures (as well as recommendations for improvement) broadly across the region.

Each interview was recorded and selectively transcribed (omitting full transcription only of information that we deemed to be unrelated to the topic) to capture recurring themes. Key concepts were documented from every interview; these concepts included (1) specific theories on the nature and causes of suicide, (2) consistent patterns of care and collaboration across case study questions, (3) perceived successes and failures of the health professional's own work, as well as of the health system broadly, and (4) discrepancies between beliefs and actions as a professional and as a community or family member with respect to suicide prevention.

We employed a grounded theory approach to induce recurring themes in health professional narratives about the nature and prevention of Alaska Native youth suicide across the region, allowing for an iterative process of grouping common meanings into the four categories noted previously as the analysis progressed. Grounded theory is a social science methodology that generally begins with a question—in this case, how is Alaska Native youth suicide defined by caregivers, and how does this shape the care offered in response—and progresses to assess common themes and develop theories from coded data. In this study, we annotated interview transcriptions in Word documents with a code set developed progressively from common concepts across the four domains described above. Weekly teleconference meetings allowed us to consult with each other regarding our independent findings, and only themes common to both of our analyses are presented in this paper.

We further drew on 25 combined years of clinical, research, and health policy experience in the region to corroborate our findings. However, this experience may introduce bias into the interpretation of data, as we hold perspectives as health workers and have many personal relationships in the region. Our research was approved by the institutional review board of the University of Massachusetts-Amherst, and was conducted in partnership with the region's tribal health and social services organization. All names have been fictionalized, and specific clinical roles and other personal attributes changed to protect confidentiality.

Results

Results are organized across three conceptual binaries: psychiatric and social explanatory models for mental health, bureaucratic and relational forms of care, and biomedical and biosocial models of care delivery. These act as useful, if wildly simplified, heuristics for understanding how mental health is understood, safeguarded, and supported within this tribal health system and among its Alaska Native and non-Native caregivers.

Psychiatric and social explanatory models for mental health

Efforts at suicide prevention are necessarily animated by a set of beliefs about what the suicidal desire is to begin with.[20] Answers to the question "What do you see as the root cause of Alaska Native youth suicide?" fell into the categories of psychiatric explanatory models (depression, mania, other mental health disorders, disrupted biological rhythms, inability to regulate emotion) and social explanatory models (historical and intergenerational trauma, social inequity, social logic, attachment and relationships). Alcohol use, by far the most frequently referenced associated condition, occupied a middle ground between the social and psychiatric, interwoven with notions of trauma, grief, and forgetting—but also indexing, for many health workers, a diagnosable mental health condition that leads to increased impulsivity, depression, and suicide.

Psychiatric explanatory models for suicide. We found a disjuncture between both Alaska Native and non-Native health workers' personal beliefs about suicide, on the one hand, and the structure of care for suicidal individuals, on the other. No interviewees endorsed the ubiquitous clinical narrative that links suicide to psychopathology, yet psychiatric explanatory models were reflected in the care delivered by every participant in the scenario questions. This course of action is unsurprising in this context, as it is a psychiatric understanding of suicide that roots intervention to health care in the first place.[21] Yet many health workers found this medicalized understanding of suicide to be a poor reflection of their own personal and professional caregiving experiences.

Melissa was asked about her experiences with suicide prevention in her capacity as a community health aide (a frontline provider in rural Alaska's community health worker system). Turning immediately to the Community Health Aide Manual, the book of protocols for village-based health care, she began to read:

> *So page 694 in our manual is the stuff on suicide … "Begin here if the patient seems to be having a new mental health problem such as anxiety, nervousness, feeling sad, thoughts of suicide …" And there's a whole list of questions … If patient is thinking about hurting self or others, say to the*

> *patient, "I'm glad you came to clinic today. I am concerned about your safety or the safety of another person. I'm going to talk to the doctor, who will help you and make a plan for your safety. But first I need to ask you some more questions and do an exam to be sure the feelings … are not being caused by a physical problem."*

Various iterations of this regimented style of intervention defined every answer to the scenario questions posed. Health workers universally turned to diagnostic manuals, clinical protocols, and psychiatric explanatory models to describe their actions in suicide care and intervention. Yet when asked about their personal beliefs, the same health workers tended toward social understandings of suicide that would seem to favor social and structural modes of intervention.

Social explanatory models for suicide. Social explanatory models relate suicidality to lived social conditions on one of two levels. The first focuses on the social contexts of suffering and despair—pointing to poverty, lack of opportunity, relationships, adverse experiences (especially physical and sexual abuse), marginalization, and trauma (including historical and intergenerational trauma) as causes of suicidality. The second social framework identifies the suicidal desire itself as a kind of social logic; that is, an idea to which certain individuals are more or less susceptible based on the incorporation of suicidality as a socially mediated logic of behavior into one's sense of self.[22] The vast majority of health workers' theories of suicide were social, focusing both on social determinants and social logic, yet this did not translate to social models for intervention.

Deborah, a non-Native social worker who has been in the region for close to a decade, explained her view of the social-relation cause of suicide as follows:

> *When I first got here I remember my supervisor telling me to be very careful about the diagnoses I gave to people … She said, "What you see is not what is happening." And I didn't get that … I saw clients and was quick to give them diagnoses in my own mind, like dependent personality disorder. And then I remembered what she said, and tried to remind myself of this. I realized it was more about their relationships and connections with other people, and when those relationships are gone or change there's no outlet … to deal or process what they are experiencing.*

Deborah also addressed Linehan's parasuicidogenic expectancies, or the set of narratives, social constructions, and practices that shape a social logic of suicidal behavior.[23]

> *To me, suicide … can be glorified, because when somebody dies there are gatherings, and people come together to eat, there's food at the cookhouse in the villages, the whole town is busy-busy-busy for one person. And how that plays in the person's mind … A lot of villages are scared that that promotes suicide. They see all of this stuff going on for this one person and they are afraid someone will think, "I want that attention, too."*

A public health nurse, Clarissa, expanded on the social logic of suicide and the legitimization of suicide as a viable outlet for pain:

> *Suicide seems to be acceptable. It seems to be an acceptable alternative when you're kind of down and drinking. In my neighborhood … in the last two years, three young men have committed suicide. In the last 10 years, many, many more. I think people do things when they're drinking that they normally wouldn't do. And I don't know where the idea that that's an acceptable thing to do, or is an alternative … But it does seem to be. As you know, it's very, very common here.*

Alcohol as middle ground. Every health worker referenced the association of suicide with alcohol use, though the relationship was described in varied ways. Non-Native health workers were more likely to think of alcohol in a causal relationship to suicidality, whereas Alaska Native community health aides tended to describe alcohol as an intermediary between historical and personal trauma, social suffering, grief, and suicide. (In the study region, there is a dearth of Alaska Native physicians, advanced practice providers, and mental health counselors, yet most community health aides are Alaska Native.) Social worker Deborah spoke to the confusing role that substance use plays in suicide:

> *I thought at first … that the suicidal thoughts were there and that the alcohol just brought them to light. As I worked more with people, I have learned that is not necessarily the case at all. It doesn't mean that just because you took a bunch of pills, that thought was always there.*

Deborah views the suicidal person's experience as often disjointed from their sober experience, noting that the sober "version" of the person may not feel suicidal at all. It is common for intoxicated, suicidal people, she noted, to become medical patients in the emergency department for a night—only to be released the next morning when they are sober and categorically deny any suicidal ideation. It is important to clarify, however, that many people with experience—either firsthand or through friends or family—know that expressing suicidal ideation can result in rights restriction and displacement for inpatient psychiatric care several hundred miles away. As Katie, a nurse, stated of her patients' attitudes, "What do I really say? I don't want to be Title 47-ed [have my rights taken away]. I don't want to be told what to do."

Bureaucratic and relational forms of care

A second fault line in suicide care relates to the meaning of care itself, as either a fundamentally relationship-driven act or a prescribed and professionalized system. These qualities correspond to the designations of relational and bureaucratic care, respectively.

While there are important cultural dynamics at play in how care is felt and expressed, the disparity between personal and professional caring roles was described as the key point at which bureaucratic and relational care diverge.[24] Especially for Alaska Native health professionals and those who have spent significant amounts of time in the study region, a disjuncture was often noted between personal and professional roles in suicide prevention. That is, the expectations and regulations that shape one's professional approach to suicide prevention sometimes bore little resemblance to the personal attitudes and beliefs held by the same person. The cultural gap between clinical roles at the village level (Alaska Native community health aides) and in the regional hub hospital (generally non-Native providers, nurses, and social workers) compounded and confused these dynamics, as professional roles are often further bifurcated along these lines.

While the discretion "allowed" in these professionalized caregiving relationships is shaped by an unwaveringly bureaucratic interface, community health aides are necessarily caring for friends and family in both formal and informal capacities as the sole health care providers in village communities.[25] Melissa, a community health aide, captured this disjuncture succinctly. When asked what she would do if confronted with a suicidal patient at the clinic, she responded:

> *I would go to the [Community Health Aide Manual] section that, you know, asks those questions … [She finds the section and begins reading:] "CHAP is not expected to make a specific assessment and plan for mental health problems. You will report to your referrals doctor who will make the assessment. The next two to three steps will help you with your report. Use 'Chart A: Signs that a mental health problem may be caused by a physical illness' to decide if patient's problem may have a physical cause. If needed, use index in this manual to find the problem … If you think this patient has a mental health problem, use chart B to help you decide what might be wrong with the patient."*

The interviewer then asked Melissa if she could recall another time that she had intervened in a suicide event. Melissa spoke in a measured voice about how one of her children had died by suicide and that after this, another child had attempted suicide several times. She explained:

> *And then I realized, after his third attempt … I figured I wouldn't just take him to the hospital. I would take him out in the country. So we got in the boat and left. But that was the last time he attempted …*
>
> *After that I decided to move my family to camp. We homeschooled our … little kids for three years*

> *in subsistence camp. And that's where we regained … how we associate with our family, you know? We had to work out a lot of things at camp … But that's what it took.*

Melissa's statements point to a fissure between two culturally mediated forms of care—the bureaucratic and the relational. This fissure is also structured through the tension between professional role-obligations and personal relationships. On the one hand, Melissa cares for her patients at the village clinic through the strictures of medical standing orders and clinical protocols, themselves authored by non-Native policymakers and administrators enmeshed in the ethos of a bureaucratic "care delivery system." Within her professional role, Melissa is responsible for providing a prescribed form of care that does, in fact, prevent suicide events.

At the same time, Melissa recognizes the insufficiency of clinical care for suicidality when it comes to her own family. She takes a seemingly antithetical approach to supporting her own children by removing them from clinical care and embedding them in a specific form of cultural and family life. This care centers on strengthening relatedness among family members, the land, and culture.

It is well argued that the space occupied by family members and health professionals ought to be distinct, along precisely these lines. However, the point we seek to illustrate is that bureaucratic forms of care often come to *supplant* relational ones, as the health care system legitimizes itself as the primary vehicle for addressing suicidality. Moreover, on the small scale of village-based care, friends, family, neighbors, and patients are far from distinct. This same health aide told a story of abandoning her post at the clinic to go to the cemetery when she had a "bad feeling" about a patient. She found him there, unconscious on top of his brother's grave after a prescription drug overdose. Melissa saved his life but violated the rules defining her professional role by leaving the clinic.

Bureaucratic forms of care. Bureaucratic care describes the systematization of care "delivery" and the professionalization of caregiving roles. This form of care deeply informed responses to suicidality throughout the study region. Intense concerns over fault and agency characterized the experiences of mental health counselors especially, who saw their role as one protective both of their patients' lives and of the interests of the health system broadly. In response, clinicians turned to the clinical protocol to describe and rationalize their care. Deborah, a mental health counselor, explained her role thus:

> *Now I am to the point where if they say A, I know we have to do that, and if they say B, C—I know that is what we have to do. And if they say they don't want to do A, then here's what comes next. So I am pretty comfortable with how things work and I know how to get people here, still not violating their rights, and making sure they are safe.*

Such statements, highlighting the role of the clinician as a navigator of a preordained decision tree, were pervasive throughout interviews, where health workers felt their agency to be defined and circumscribed both by explicit protocols and by the expectations and norms of their professions. Even when personal beliefs about effective and moral forms of care diverged from bureaucratic ways of proceeding, it was bureaucratic care that typically defined what was offered.

Relational forms of care. Where in bureaucratic care the object of care comes to matter abstractly, rationally, and as an instance of a broader population, the opposite is true of relational care, where the individual matters specifically, emotively, and contextually. Acts of care emerge in this sense from an active relationship that itself establishes one's capacity to help.

Jane, a social worker, discussed her role in supporting distressed and suicidal students in the school system. She emphasized the importance of coming to understand, from her students' perspectives, the nature and origins of their suffering. Jane also understood the primary vehicle for addressing students' problems to be the relationship itself. When asked about what she finds most meaningful about her job, Jane replied:

> *[Laughs] Actually helping the students. All the other stuff, I'm pretty sure it's not meaningful. But when I have an opportunity to help the students, that's really what I signed up for this job to do. And that goes anywhere between helping them out in family or relationship situations, or helping them through a struggle with drugs or alcohol, or just connecting with them because they've been bullied in class. Or even in situations of suicide, the whole gamut.*
>
> *[Researcher: And what do you feel in those scenarios helps you be helpful?]*
>
> *Especially in this region, one of the first things … I know it seems trivial, but simply just knowing their name, to start out with. Just being able to call them their name.*

Being able to recognize and call a student by name is, for Jane, the beginning of the act of care. To name is to call a specific and definite relationship into being, and Jane characterizes her relationship with youth as the core of her ability to help.[26] In doing so, Jane resists many of the bureaucratic forms of care that define her professional role. Under special circumstances, for example, Jane gives her personal cell phone number to youth when they are having trouble at home. She also describes leaving the school to search the streets for a youth about whom she is concerned. If a student's parents were drinking and fighting the night before, leading to the student's dismissal from class due to inattention or disruptive behavior, Jane habitually provides a quiet place for the student to sleep at the school. If food shortage was the origin of distress, the student is fed. All of these forms of care extend beyond the prescriptions of Jane's professional capacity, yet she describes them as by far the most important elements of her work and care.

Biomedical and biosocial systems of mental health care delivery

We found specific acts of caregiving to both shape and be shaped by broader systems of care delivery. That is, explanatory models for suffering structured the broader context in which mental health challenges were addressed, just as these contexts contoured caregiving at the most local and immediate levels.

Biomedical care systems tend to construe mental health care delivery as primarily a matter of accurate and timely diagnosis of a discreet category of disease, whereas biosocial perspectives strive to organize care around the social forces that affect the distribution and burden of mental distress or disorders, the manner in which these forces become embodied in personal suffering, and the social dynamics that mediate access to, compliance with, and efficacy of treatment.[27] This kind of practice may involve engaging the broader social and structural determinants of health, or simply inform the use of biomedical therapeutics to maximize efficacy. As Kasper and colleagues write, "Even when biomedical interventions are the best option, patients' ability to benefit from them are embedded in social, economic, and political systems that impact the outcomes of medical care."[28]

Biomedical systems of mental health care delivery. The arc of treatment for suicidal youth in remote Alaska often begins and ends in an improvised room in the local village clinic. "High-risk patients" are transported by aircraft to the regional hub city to be admitted the emergency room and then inpatient ward of a small hospital as they await the opening of a psychiatric bed in Anchorage, more than 500 air miles away. Wait times for psychiatric beds run into the weeks, and many rural and remote communities provide little by way of care beyond restricting access to lethal means through physical restraints. Perhaps unsurprisingly, skepticism is widespread regarding many forms of mental health care—from to psychotherapy to psychiatric care.

Once a youth is "stabilized," referrals to a community behavioral health program are generally provided; however, mental health care is widely underutilized in the study region. In the study region, only 8% of people who die by suicide have accessed mental health care over the course of their lives.[29] Carol, a village-based counselor, addressed the delivery gap in mental health care, which she sees as maintained through local frustrations with the bureaucratic process of intake and clinical care—symptomatic of a biomedical system that fails to reflect local values, including the rejection of bureaucratic care:

> *If you look at how many people who are screened for suicidal behavior and how many actually go on to sign up for [behavioral health services] and receive services, there is a huge gap. The system isn't working for people who need help the most due to paperwork requirements and policy and procedure requirements and red tape.*

Melissa, a community health aide, built on Carol's narrative:

> *I know there's way more ideation in these small communities than what's reported. There's a lot of them that go unreported—probably half of them … Because people know, if they call the cops or go to the clinic, they're going to get put in the hospital in that one room where it's all padded.*

As Melissa notes, *avoiding* clinical care can become a priority for people who are suffering. Many health professionals noted that the poor fit of clinical mental health care, relative to Alaska Native traditions and social expectations, creates a significant barrier to care. On the broadest level, framing suicide within the discursive registers of medicine and mental health strikes many in the study region as fundamentally poor logic. Instead, calls for engaging traditional healers and tribal doctors, family members, and broader social networks are widespread throughout rural and remote Alaska.

Biosocial models of health care delivery. Every health worker interviewed made reference to the importance of understanding the social context of Alaska Native communities, be it through knowledge of culture, communication styles, idioms of distress, patterns of service utilization, gaps in services, or the colonial history of the North. Many also noted that health professional training should be adapted to fit local contexts. Katie, a nurse, explained:

> *I think there should [be] a lot more cultural training. You know, you only get 30, 45 minutes … they really should expand on that, especially for people who are not from Alaska, so they're not aware of a lot of the cultural differences … You're coming to a community that is 80% or better Alaska Native. And you're not.*
>
> *If you've never been around an Indian culture or a community where you are the extreme minority … I think there needs to be a lot more training on how to identify … subtle signs and symptoms of people who may be suicidal. And it's different here than it is in the Lower 48, where I come from, because the reasons that people kill themselves here are different. I've been here a year—I'm finally figuring out the "why."*

Perhaps ironically, the reasons Katie cites for Alaska Native suicide relate to daylight exposure and mania, rather than specific social or historical forces; yet she feels strongly that social health and care represent essential aspects of health promotion in Alaska Native communities. Along with every other health worker interviewed, Katie noted that "culture"—used colloquially in the study region to index a constellation of racial and ethnic identity, shared social life, and geographic solidarity—bears heavily on both the causes of illness and the meanings attached to care.

Many Alaska Native health professionals invoked critiques of biomedical care related to history and rights: specifically, the relationship among colonial social violence, tribal sovereignty, and systems of care. While there was a notable lack of consensus regarding what a truly biosocial care system might look like in the context of mental health, key recommendations included addressing the social determinants of health at the root of mental, emotional, and social suffering; attending to cultural safety in existing care systems; and supporting community- and culture-based healing initiatives in addition to formal clinical care.

Discussion

The meaning of care

In this study, "care" is taken to mean both "the way someone comes to matter and the corresponding ethics of attending to the other who matters." [30] As Arthur Kleinman and colleagues note, care spans moral, emotional, and enacted dimensions.[31] However, the turn in contemporary medicine—and, by virtue of their relationship, global mental health—has been toward a near-exclusive focus on technical aspects of care, to the point of disregard for the "coming to matter" part of care.[32]

Arctic anthropologist Lisa Stevenson notes this absence in her description of the failures of caregiving in the neocolonial north.[33] Framed through Michel Foucault's concept of biopolitics, which describes the politicization and governance of citizen health through enacted state power and control, Stevenson describes the role of biopolitics in terms of the "maintenance of life itself".[34]

> *[B]iopolitics as a logic of care informs not only the way policies concerning the population are enacted, but also how individuals engage with other individuals while adhering to the logic of biopolitics that treats individuals as members of a population.*[35]

Stevenson sees biopolitics in individual acts of care, describing such care as "anonymous"—that is, "one cares, but indifferently," without specificity, context, or relation.[36] One cares for the individual, as a representative instance of a population, *because* of one's role as a professional charged with their care. This ethos is justifiably central to global mental health, with its focus on population health, professional care, and universal rights. Yet biopolitics as a logic of care, made manifest in the individual and specific interactions between caregiver and care recipient, can be experienced as uncaring, disingenuous, and violent. Within these tensions, the "health care crisis" of Alaska Native youth suicide plays out.

Redefining suicide care

Suicide care involves navigating within caring relationships through the most practical and exigent of risks, the prescriptive nature and practicalities of care systems, and the complex social conditions that give rise to the level of suffering that suicide inherently marks. In the neocolonial context of many circumpolar indigenous communities, the movements of power throughout history—and within contemporary life—bear further on both the meaning and causes of suicide, and the meaning and purview of care.

Linking suicide prevention and care to an explicit and actionable human rights agenda, realized through social medicine, is a critical step. The 2019 statement on suicide prevention issued by the United Nations Special Rapporteur on the right to health summarizes this frame succinctly:

> *Providing holistic support for individuals and populations as a whole, particularly those who are most vulnerable, enables the attainment of the right to health by addressing the structural and psychosocial determinants of distress, such as childhood trauma and abuse, social inequality and discrimination. A focus on locating problems and solutions within individuals obscures the need to address the structural factors that make lives unliveable.*[37]

Within this context, we propose a reframing of global mental health to include a focus on what makes lives livable through social medicine and the broader human rights that such care must deliver, including political participation, work, and a standard of living adequate for health and well-being.[38] Such an effort further entails reframing suicide care to foreground the social explanatory models, relational care, and biosocial care systems described in this paper. Priorities under this social care agenda include redefining the problem of suicide; centering caring relationships, both between patient and caregiver and between community members; and building care systems around the right to health, with moral clarity and practical understanding that all human rights are health rights.[38]

First, suicide should be described, defined, and addressed within meaningful social, historical, and political contexts—especially by those whose lives are affected by this tragedy. Examples of this include the National Inuit Suicide Prevention Strategy of the Inuit Tapiriit Kanatami, the national representational body of Canadian Inuit, which invokes the social history of the problem and contextualizes care within the broader project of fostering healthy conditions and meaningful livelihoods for indigenous people by realizing a full range of human rights.[39]

Second, we must again create space in the clinical encounter for the "coming to matter" part of care. Global mental health allows for little by way of universalisms—but if there is one that works, it is that healing occurs within meaningful relationships.[40] Community health worker programs, longitudinal academic partnerships, and local training programs all work to promote this agenda.[41] Broadly, it is essential that health resources, from payment models to clinical roles, be brought in line with the expectation that relationships between health workers, care recipients, and community caregivers are the foundation for global mental health.

Third, care systems must incorporate a fuller understanding of the drivers of health and illness—beginning with a rejection of exclusive reliance on neuropsychiatric treatments to accommodate social inequality.[42] If we are to accept the role of state intervention for the maintenance of life itself, parallel demands must be made on the human rights that such a system supports.[43] This process includes supporting locally governed development agendas; facilitating the horizontal integration of government, social, and health services; and decentralizing authority in global mental health to include indigenous knowledge and healing traditions, community and peer supports, and sovereign systems of care.[44]

Promoting social medicine and human rights in global mental health

Broadly, social medicine and human rights can advance several complementary perspectives in global mental health. First, both disciplines, at their best, look beyond the biologic bases of mental disorders and the biopolitics of technical intervention for their remediation.[45] They create vibrant environments for understanding how social, political, and historical forces affect mental health—and for structuring interventions that act across multiple strata of social determinants of health.[46] This in turn raises important questions regarding who provides global mental health care, what that care looks like, and how it is paid for.

Second, human rights and social medicine inevitably engage with issues of political economy, human rights, and health and social equity.[47] General awareness of the social, economic, and political forces affecting the distribution and burden of mental disorders is a poor guarantee that such understandings will be positioned to influence health and social policy, without explicit and intentional negotiations to wed global mental health to an equity plan that seeks to reduce social stratification for its own sake and as an avenue to better health outcomes.

Finally, social medicine and human rights invoke the moral and emotional aspects of care, alongside the technical requirements of care delivery.[48] These fields can advance a human and relational approach to mental health care that takes seriously the first-person perspective, its social location, and the patient-caregiver relationship as essential domains of care.

Conclusion

This study explores the meaning and purview of care in global mental health by contrasting practices of suicide care in a remote region of Alaska. We offer an alternative to notions of cultural competence as a technical skill, instead reconsidering health workers as engaged observers of the social arrangements that both produce and are propagated by poor health. Social medicine and human rights shape approaches to understanding and redressing mental health disparities that advance the intellectual and moral scaffolding of global mental health. By wedding these perspectives to each other and to an advocacy and equity agenda that holds central the claim to health as a human right, a hopeful future for global mental health is in sight.

Acknowledgments

Funding for this research came from the National Institute of Mental Health (awards R34MH096884 and R01MH112458) and was conducted in partnership with Maniilaq Association, which approved the publication of this paper.

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Exploring the Potential of a Rights-Based Approach to Work and Social Inclusion for People with Lived Experience of Mental Illness in Ghana

URSULA M. READ, LIONEL SAKYI, AND WENDY ABBEY

Abstract

Much of the focus on human rights and mental health in low- and middle-income countries (LMICs) has been on protection from coercion and abuse and on expanding access to mental health services, rather than on promoting and protecting social and economic rights. Despite the importance of work for mental health, there has been very limited consideration of the relationship between work and mental health in LMICs. This paper draws on ethnographic and participatory research in urban and rural sites in Ghana to illustrate the meanings and value of work, as well as experiences of support, exclusion, and discrimination, among people with lived experience of mental illness in Ghana. The paper outlines the policy context of mental health and human rights in Ghana and evaluates the challenges of implementing mental health, disability, and labor legislation to protect the rights of persons with mental illness—particularly the poorest and most vulnerable—in both formal and informal employment. The paper closes by discussing the potential of practices of solidarity and social activism to promote the rights of people with mental illness and push for change.

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Competing interests: None declared.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) asserts that persons with disabilities, including psychosocial disabilities and mental health problems, have the right to "full inclusion and participation in all aspects of life" (article 26) and to inclusive, accessible employment.[1] Article 27 commits state parties to "safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment." This involves taking appropriate steps to prohibit discrimination on the basis of disability.[2] Although the CRPD has been ratified by 181 countries, including 46 of 54 states in Africa, there has been a paucity of research on the work experiences of people living with mental illness in low- and middle-income countries (LMICs). In many LMICs, particularly in Africa, rights-based initiatives have tended to focus on civil rights and freedom from coercion and restraint rather than on social and economic rights, such as the right to work.[3]

The economic rationale for scaling up mental health treatment has emphasized the lost productivity of people with mental health problems and implications for growth and development.[4] Efforts to improve access to work thus risk being reduced to arguments for a "return on investment."[5] Furthermore, this approach may leave behind those most affected by severe mental illness (such as psychosis) and overlook the potential harms of poor working conditions on mental health.[5] This includes precarious employment, overwork, and unsafe working environments. Nonetheless, for many people, meaningful work and being able to provide for oneself and one's family is inherent to a sense of well-being and identity. In many societies, working and contributing to household income and the wider community is an important milestone in gaining social status and respect. From a rights-based perspective, the argument is not to simply increase the productivity (and by correlation reduce the welfare dependency) of people with mental illness but to ensure fair pay, safe and flexible working conditions, and equal opportunities as beneficial for all.[6] As articulated by the United Nations Special Rapporteur on the right to health, "the right to health is not the right to be healthy, but a right to both conditions and services that are conducive to a life of dignity and equality, and non-discrimination."[7] Rights are thus interdependent, with labor rights to health and safety at work and fair remuneration, for example, as crucial to mental health as specific disability or mental health rights, such as the rights to inclusive workplaces and suitable accommodations.

Much of the research in this field has been conducted in high-income countries, with very little known about the relationship between work and mental health in LMICs. A recent review found only eight studies on mental health and employment from Africa.[8] A study of experiences of persons with a diagnosis of mental illness in Kenya found that barriers to employment included mental illness factors, social exclusion and stigma, a non-accommodative environment, and socioeconomic status. Factors that facilitated employment included self-awareness and acceptance, self-employment, provision of reasonable accommodation, improved health services, removal of discriminatory laws and practices, and social development programs.[9] Scaling up mental health care in LMICs has focused largely on improving access to psychiatric treatment, with few services that support reintegration into work and other opportunities for social inclusion.[10] Psychosocial interventions in LMICs are predominantly concerned with psychoeducation and therapy, rather than vocational support.[11] A few nongovernmental organization (NGO) projects support sustainable livelihoods for people with mental illness by providing capital, loans, and training.[12] However, these tend to be small scale, unevenly distributed, and short lived. While legislation is advocated to protect the rights of people with mental illness, including access to work and protection from discrimination, there are challenges to implementation. Legal protections may be least accessible to the most disadvantaged, such as those without formal education, who may be unaware of avenues for redress and struggle to access legal representation.[13] This reinforces gender inequities, as women generally receive less education. A further concern is how such protections can be enforced in informal employment and across both private and public sectors.

Questions also remain as to the social and cultural meaning of work in LMICs and the impact of changing economies. With the global transition to neoliberal economies, the labor market is changing in low- and high-income contexts alike, with increased precarity, public sector retrenchment, and reduced worker protections. Following the international epidemiological studies on schizophrenia by the World Health Organization (WHO) in the 1960s, researchers speculated that better outcomes in "developing" countries might be a consequence of greater opportunities for integration into informal work.[14] This was hypothesized to be due to greater flexibility, with less rigid workplace demands than in industrialized economies.[15] This argument overlooks precarity within the informal economy and changing aspirations for young educated Africans.[16] Over 85% of Africans are estimated to work in informal employment, with few social protections in the event of sickness, disability, or pregnancy.[17] Women perform the majority of unpaid labor, such as child care and household chores, which are often labor intensive, reducing their potential to generate income outside the home. As more people complete secondary education, many aspire to professional, service, and sales jobs, rather than farming and manual labor. Public sector positions that offer greater workplace protections, such as nursing and teaching, can be increasingly attractive compared to precarious lower-level private sector employment. In sub-Saharan Africa, economic growth has not been accompanied by a rise in jobs, and youth unemployment and underemployment remain high.[18] Access to "decent work for all," as articulated in the Sustainable Development Goals, is a struggle for many Africans, not only those with mental illness.[19]

In this paper, we explore the aspirations and work experiences of people with diagnoses of mental illness in Ghana, including their experiences of support, discrimination, and exclusion. We consider the potential of legislation, social protection programs, civil society, and community support to promote the right to work as an important component of mental health and social inclusion. This focus arose out of ethnographic and participatory research on the meaning of article 19 of the CRPD (the right to live independently in the community) in rural and urban settings in Ghana. Ghana has been the focus of considerable concern regarding the human rights of persons with mental illness following the exposure of abuses in prayer camps, shrines, and psychiatric services.[20] There have been substantial efforts to improve mental health care, with support from international agencies such as WHO and the UK Department for International Development. In 2012, Ghana ratified the CRPD and passed a new Mental Health Act that draws on many of the principles of the convention, including the right to equal participation in employment. However, with international attention on human rights violations by traditional and faith healers and on scaling up treatment, there has been a policy focus on expanding community mental health care and collaboration with healers.[21] Less attention has been paid to social and economic rights, including the right to work and participate in society in meaningful ways. Although the mental health workforce has expanded, it is made up primarily of mental health nurses, with very few social workers, psychologists, and occupational therapists. As in other low-resource settings, treatment is generally restricted to the provision of psychotropic medication and crisis management, with very limited psychosocial interventions. Sustainable livelihood initiatives are provided through NGOs as short-term projects that are unevenly distributed throughout the country.

Our research in Ghana included observation, conversations, and interviews with people with lived experience of mental illness and their family members, as well as with stakeholders such as mental health workers, human rights organizations, and other NGOs. We considered the following questions: What is the meaning of work for people living with mental illness in Ghana? What role does it play in perceptions of recovery and social inclusion? What is the experience of accessing and remaining in work? What is the potential of legislation, social protection programs, civil society, and peer support to promote the rights of people with lived experience of mental illness in this context, and how can they be made accessible to the least advantaged? What could be the role of communities in supporting the right to social inclusion for people living with mental illness?

Methods

This research forms part of a larger collaborative research project on mental health and justice. Ethnographic research was conducted in the capital, Accra, and in Kintampo South in the Bono East region. Research questions focused on the meanings of article 19 of the CRPD and barriers and resources that affect the social inclusion of people with lived experience of mental illness. The study employed various methods, including participatory research, naturalistic observations, and in-depth interviews with people with lived experience of mental illness, family caregivers, mental health workers, healers, social workers, civil society organizations, and policy makers.

Fieldwork took place over 22 weeks spread over five field visits between 2018 and 2020. We visited participants at their homes and in community spaces, such as churches, social venues, and workplaces, where we engaged in observation and informal conversation. We recorded our observations in fieldnotes and photographs. Interview participants were purposively sampled. Participants with lived experience of mental illness had been diagnosed with schizophrenia, schizoaffective disorder, and bipolar affective disorder (BPAD).

Interviews were conducted in English or Twi and audio recorded with participants' consent. One participant chose not to be recorded. Recordings were transcribed verbatim and translated into English.

Two participatory groups of people with lived experience of mental illness were formed in Accra and Kintampo in 2018. To date, six meetings have been held in Accra and four in Kintampo, with a total of 27 participants (13 men and 14 women), 15 of whom participated in the interviews. Participants were recruited through NGOs, people receiving treatment from mental health services, and participants from previous research.[22] Participants ranged from university graduates to those with no formal education. Through activities such as the Tree of Life narrative approach, our meetings involved discussions on the meanings of, opportunities for, and barriers to social inclusion.[23] The participatory groups were facilitated by the researchers alongside two occupational therapists in Accra and a community mental health worker in Kintampo.

Initial analysis was conducted manually through listening to interview recordings and by close reading of fieldnotes and interview transcripts. Conceptual and theoretical development was developed through triangulation of audio, visual, and written data. Themes were developed inductively through an iterative process and summarized as codes. Fieldnotes and transcripts were then coded using NVivo, and codes were further refined. Three members of the Accra participatory group also read a draft of our paper and provided feedback. Our analysis took an interpretive case study approach, drawn from anthropological theories of illness narratives and situation analysis.[24] This explores how lived experience of crisis or social change is situated within the historical, political, social, and cultural context. It includes a consideration of how socioeconomic status, education level, rural/urban location, age, and gender intersect to affect lived experience.

Ethics

Ethical approval for the study was granted by King's College London (approval no. HR-17/18-5393) and Ghana Health Service (approval no. GHSERC008/11/17). Participants were provided with information on the study in English or Twi and were asked to sign a consent form. If the person was unable to read or write, they were asked to provide a thumbprint in the presence of a witness. Several participants with lived experience of mental illness have become public advocates for mental health and spoken openly about their experiences. Participants were therefore asked to choose whether they wished to disclose their identity in research outputs. Pseudonyms are used for those participants who chose to remain anonymous. All participants whose first names are used have read the paper and given consent for their real names to be used.

Findings

The meaning of work for social inclusion

The desire to work and earn sufficient money to support oneself featured prominently in concepts of recovery and social inclusion articulated by people with lived experience of mental illness and family caregivers across urban and rural settings. During group meetings, participants spoke about aspirations to work as central to "living independently and being included in the community." For example, during discussions on "What does being independent mean to you?," participants generated statements such as "having the strength to work and take care of myself," "support in all areas, especially with work for example, support to begin a business," and "being able to go back to work." Participants also engaged in spontaneous discussions regarding experiences of discrimination in the workplace, pressures from family and peers, and the challenges of finding employment. These themes recurred in interviews and informal conversations. Alex, a 31-year-old graduate from Accra, explained how he wanted to achieve financial independence and no longer rely on family support: "I just trust God that what happens the sickness will not come back any more, so I'm just looking forward to get a job now." Work would enable him to get together enough money to rent his own place and meet social expectations of independence and maturity: "as a man growing up, you need to stay on your own."

For young men, being able to work is also important to attract a marriage partner. Henry, who lives in Kintampo and has a diagnosis of BPAD, complained that his relationship with a nurse had ended because of his difficulty holding down a job:

> *She planned to marry me, but she saw that I'm not working … She told me if I had worked, I'd had a work, a menial job. She understands my problem and everything. She said if I have had a menial work to do, for her to respect me as a husband, she would marry me.*

Earning a livelihood and being able to provide for others (importantly, a spouse, children, siblings, and older parents) is central to achieving adulthood and respectable social status in Ghana, particularly for young men, and thus crucial to individuals' sense of identity and self-worth. Persons who are unable to work may be perceived as lacking moral and social value. Indeed, it is common to hear people with mental illness fear being labeled "useless" because they are seen as not contributing to society or to the household. The impact of mental illness on work status can lead to prolonged dependence on a parent, spouse, or sibling to meet everyday needs. Kwame developed mental health problems when he was at university and had to return to live with his mother in Kintampo. Despite several attempts to resume his education, he continued to experience poor mental health, which prevented him from getting his degree and moving on to the professional employment he hoped for. Whereas normative expectations are that a son should support his mother as he moves into adulthood, in this case the mother continued to support her adult son even though she was in her seventies. She explained:

> *You know as a young man in his thirties he should be doing his own work. When he wakes up in the morning I have to give him money, if he's going to barber his hair I have to give him money, if he wants to wash his clothes, I have to buy soap. The phone that he's using I had to buy it for him. I am not supposed to be the one to provide for him at this moment but I'm the one doing everything.*

Like Alex, Kwame was acutely aware of the stigma attached to his status as a person with a diagnosis of mental illness and no independent income. He explained that socially he's "considered as a kid" because he isn't earning any money and remains dependent on his mother's support: "I'm under her care and I don't have any business, I don't have any employment, and, I'm also considered as a patient at the psychiatry." He continued, "I'm not a fully equipped adult because I lack a lot of things that make up an adult."

Experiences of work and mental illness

Nearly all participants reported challenges in both finding and remaining in employment. At one level, the illness itself created difficulties in the workplace. Several participants described how they had argued with members of the public or work colleagues when unwell. Some had caused concern by expressing unusual beliefs or engaging in behavior that transgressed social norms. John grew up in Accra and has a diagnosis of BPAD. His symptoms began just as he started his career after graduating from university. He had accepted a prestigious position working for a large pension company. Shortly after commencing, he experienced a serious manic episode and was hospitalized. He described how he had gone from being "really, really depressed" and not talking to anyone to being "all over the place" and confronting his colleagues:

> *So one time I barged into work, running and started shouting and started talking: "The boss is sleeping with this girl" and they are thieves. So they realized something was wrong and they called my dad … and I had a big notebook of all … a lot of ambitions, I wanted to be president and I was writing my manifesto, crazy stuff man!*

For John, this led him to worry about the impact on his long-term work prospects: "I don't think I would be able to hold onto a job for a long time … when my mood disorder comes, I mean, no one wants someone like that."

The majority of Ghanaians, even those living in urban settings, work in the informal sector. This includes running small shops, street trading, and food preparation, and trades such as tailoring, hairdressing, and soap making. In Kintampo, farming is the most common occupation for men. Informal enterprises offer a degree of flexibility and independence, which can make them attractive to people who experience fluctuations in their mental health. Like Kwame, Henry had been unable to complete his studies and establish a professional career. He had been fired from his first job in a bank following a "misunderstanding": "They were potential customers, they were students. I had an exchange of words and they reported it to the manager. 2016 January, the manager fired me. He won't let me work with the bank again." Later, he got into an altercation at the college where he worked as a security guard: "Because of my problem, I had a loggerhead. I had an exchange of words with the students and some of the lecturers." Again, he was fired. Henry was also trained as a tailor and said that he preferred such work because it allowed him to be his "own master": "If I work, they would fire me because they don't understand me. They don't know my condition. But for the tailoring work I'm a master of my own." Similarly, Alex stated his preference to set up his own business to avoid the stress of formal employment and commuting, a major concern in Accra, where rush-hour commutes typically last well over an hour:

> *The kind of work or job I need now is something that I should be controlling, go and visit it at my own time, you get it? Not something I have to go to maybe like a bank job, do from morning to evening and close. By the time you get home, traffic, you can be stressed and all that … the body may break down at a time because you need rest.*

However, many individuals, particularly those from poor families, found it difficult to obtain capital to establish a business. Henry described the struggle he faced obtaining the resources to set up a business as a tailor: "You need money. Maybe you want to open a shop like this my work, I have to get a container, get my set of machines … buying my own threads." As Alex complained, bank loans require collateral and are thus unavailable to many. A few received gifts or loans from relatives, friends, or church members, as described below. Success in business also lies in establishing a customer base, which is not easy when fluctuations in mental health could result in prolonged absence from a competitive market. Such enterprises offer few protections (such as paid sick leave), and a small business can easily fold if the person becomes unwell. This was the case with Justice, whom we met in a healing shrine near Kintampo. Justice had set up a successful barbering shop in town and had invested significant capital in the tools of his trade, such as sterilizing equipment and a barbering chair.

However, during the months he spent at the shrine, his customers "scattered." On his return, he was faced with the challenge of rebuilding his customer base from scratch.

Experiences of discrimination in the workplace

Aside from Henry, other participants described being dismissed from work after experiencing a deterioration in their mental health. Cecilia was a teacher in a private school in Accra and has a diagnosis of BPAD. Although she had been receiving treatment for her condition, she had been unable to afford the costs of medication and experienced a relapse. She described what happened:

> *Things were getting very difficult for us. Even what to eat was difficult, so we couldn't buy the medication. So one time I was going to work without taking the medication for some time. And then I had a crisis there. I don't really remember everything. They said I broke the glass, the louvre pane. So when like I came to normal the school governors were like if it should happen again they would sack me. So it didn't happen again, I was working alright. But sometime then I felt a sharp pain in my head, a very sharp pain. So they took me to the hospital. So when we came back then they told my husband that I should stay home and take care of myself. But I didn't know they've sacked me. So when I became ok after about two weeks I was at home, then the following, the third week I went back to work. And that very day they told me that they have taken someone else, and that they have told my husband I should stay home and take care of myself, they have taken someone in place of me.*

Cecilia's story illustrates the intersection of structural factors affecting mental health and social inclusion. Due to shortages of psychotropic medication in public hospitals, Cecilia and her husband were forced to purchase them out of pocket. But since they worked in low-wage jobs, they were unable to afford such treatment in the long term, and the precarity and struggle to survive negatively affected Cecilia's mental health. After not taking her medication for some time, Cecilia relapsed, setting in motion events that led to her dismissal.

Cecilia's experience also highlights the weak employee protections within the private sector and the potential consequences of disclosing a diagnosis of mental illness to employers. Yaa, a young graduate, also has a diagnosis of BPAD and was dismissed from her job as a teacher in a private school in the capital. She had confided her condition to a colleague, who then told her employers. To her distress, her employers told her she was unfit to work with children and that she should have disclosed her condition upon being hired. However, Esenam knew that had she done so she would not have been offered the job in the first place. Esenam also described difficult working conditions that she feared would affect her mental health—she was expected to work long hours from early in the morning until late in the evening. Her long commute home in heavy traffic was exhausting. She would then become sleepy during the working day, worsened by the effects of her medication. Like many other employees in the private sector in Ghana, Esenam's ability to seek justice was further compromised by the fact that she did not have an official contract setting out the terms and conditions of her employment.

Alex's story reveals the ways in which negative stereotypes about mental illness, such as a popular association with drug use, could exclude people from the workplace and in turn exacerbate mental distress. After passing a rigorous recruitment process, Alex had been offered a job in a bank. However, just before starting, he was asked to meet with the managing director (MD). His sister explained what happened:

> *We heard that the MD just wanted to meet him one on one, even though he's gone through all the interviews, just to have an interaction with him. In the course of the interaction the MD needed to know the reason for the gap in his schooling, like why he deferred his course and all that. So that was where the issue was … Alex is someone who likes honesty, he doesn't believe in lying, just like me, he wants to be plain, because he doesn't believe in twisting things, he wants to say things the way they are, so in trying to be honest about it he told the MD he took ill, he needed to seek some medical help. Then the MD was curious to know what sickness could*

> *take you out of school for a whole year so he probed further and he explained that it was more like a mental-related thing and of course no MD would want to … he would not want to probe to know what resulted to that, were you were doing drugs? But the general overview would be that, mental issue, ok, that means maybe you were smoking weed or you were in a bad peer group or something … you were a bad boy or coming from a bad home, it could be any of those … So that was the blast for him, he lost that job and he went right down into serious depression.*

For those who were self-employed and in informal work, stigma and discrimination in the community could also affect social inclusion and opportunities to earn a livelihood. This was particularly evident in Kintampo, where people were more likely to be engaged in informal work and known to people in their neighborhood. When Justice returned from the shrine and reopened his barbering salon, he was careful not to disclose where he had been to people in his community, telling them only that he had "traveled." Akua, a middle-aged woman from a poor background in Kintampo, has a longstanding mental illness and has experienced several serious breakdowns. Akua was desperate to work to support herself, given that she is unmarried and does not have the financial support of a husband. Over the years, she has engaged in various kinds of small-scale trading, disrupted by periods when she is unwell and unable to work. Most recently, a church friend offered her work helping sell fish. However, people avoided buying from her—she suspects due to her "madness" and the belief that she is being followed by *mmotia*, forest-dwelling spirits—and she had to stop. Mental illness is perceived by many to be transmissible via such malign spiritual forces, and people may fear that eating her fish might in turn infect them with madness.

Experiences of workplace protection

Those working in the public sector as part of a unionized workforce generally have access to greater legal protection in the event of illness. Upon hearing Esenam's story during a meeting of the Accra participatory group, Ruth, a former teacher with the government-run Ghana Education Service, expressed her outrage. Her own experience had been very different, even though she suffers from a longstanding psychotic illness, with disturbing visual and auditory hallucinations. Ruth's employers had given her regular paid leave from work when she experienced a crisis, and when she was unable to work in the classroom, she was placed on "light duties," working in office administration. As she explained, at the Education Service she was protected from dismissal:

> *They have a law … that if a person is sick, or something has happened to that person, you don't terminate his or her appointment, unless it is a grievous offence, the person has committed a grievous offence … they will transfer you and give you a light duty.*

Ruth remained in full-time employment until her retirement and now lives on her teacher's pension.

In contrast to small businesses, larger private companies may also offer a higher level of worker protection, although it is unclear how widely this is the case. Although John was unable to return to work following his breakdown, his employer continued to pay his salary for well over a year. Janet, another participant in the group, works at a professional level for a large international company. She told the group that she had informed her employer of her condition and was able to negotiate time off when she was unwell.

The potential of human rights legislation

These examples illustrate inequities in workplace protection and how those with the lowest socioeconomic status are most likely to suffer the consequences of discrimination and exclusion. How, then, might human rights legislation work to protect the most disadvantaged? Could it protect people such as Akua from the stigma and fears surrounding mental illness, as well as enable people such as Cecilia to seek redress? Ghana's Disability Rights Act and the CRPD set out a state duty to prohibit discrimination and ensure "reasonable accommodation" in the workplace. Ghana's Labour Law also provides safeguards against employment-related discrimination under broader provisions for persons with disabilities. According to these provisions, mental illness cannot be used as the sole basis for denial or termination of employment. In addition, Ghana's Mental Health Act, which was praised by WHO and researchers in global mental health for its rights-based credentials, reiterates the illegality of terminating employment due to mental illness.[25] Consistent with Ruth's experience (which predated the Mental Health Act), if a person's mental health condition occasions "dysfunctions in performance of duties," the law directs employers to assess whether the person's residual capacity would allow for a reassignment of duties in the same employment or a corresponding position. Where necessary, adjustments may include training at the employer's expense or assistance in receiving medical attention. Should it become necessary to terminate employment, the employer should provide appropriate remuneration.

Most of this legislation, including the CRPD and the Mental Health Act, has been only partially implemented. Ghana's first report to the Committee on the Rights of Persons with Disabilities, submitted four years behind schedule, notes that discrimination in access to employment for persons with disabilities is "very high" and that people are denied "facilities and conditions that would enable them to work effectively," but it does not identify concrete steps to address this.[26] The Mental Health Review Tribunal mandated to provide redress specifically for contraventions of the Mental Health Act, including employment-related cases, has yet to be established, apparently due to insufficient funds. The Commission on Human Rights and Administrative Justice (CHRAJ) and the Legal Aid Commission, which were set up under the Ghanaian Constitution, provide legal support and representation, ostensibly free of charge. However, as with many government services, both entities face significant financial and human resource constraints. As a CHRAJ director complained, "We have as one of our mandates, CHRAJ, to conduct public education, you know, either through the media, or visits to communities, organize people, talk to them and then ... but again the resource constraints, resources are not provided."

An NGO worker further noted that people with mental illness are often unaware of their rights, which prevents them seeking legal redress:

> *People with mental disorders themselves do not know that they have a certain right. So once they don't know, or even if it's trampled upon it, they don't even know that such a thing has happened, because they don't know what it means, or they don't know what constitutes it. So if there's a violation and a breach, he doesn't have an idea! It is somebody who can draw his attention or your attention, that look this thing that was done to you, you could go to the court and get judgement or something.*

Access to social protection programs

Aside from legislation, Ghana has two social protection programs that should in principle be available to people with mental illness who are unable to work. The Livelihood Empowerment Against Poverty (LEAP), a cash transfer program adopted in 2008, provides small monthly payments to people with "severe" disabilities. Secondly, a proportion of the "Common Fund" is allocated to local government to be made available to those with disabilities. In practice, these funds are difficult to access and inconsistently distributed.[27] Some mental health workers and NGOs work with Social Welfare officers to help people with mental health problems apply to their local district assembly for these funds, but most of those we interviewed had not received them. Mental health and social workers complained of long delays in accessing the funds: "The [district] assembly too is not fast enough. Sometimes we go and they say they don't have funds. All the funds are finished." This was corroborated by an NGO worker who claimed that some district assemblies might deliberately withhold the money to use for other activities:

> *Unfortunately some of the district assemblies don't disperse the money to persons with disabilities. They wait, when their budgetary allocation for them is almost exhausted then they fall on the Common Fund for persons with disabilities and use for their activities in the district, do you understand? So sometimes it's deliberate.*

A further problem was the lack of recognition of people with mental illness under the category of "persons with disabilities," as described by this human rights worker:

> *Most of the district assemblies they don't consider people living with mental diseases as beneficiaries of the District Assembly Common Fund, because when they talk about disabilities, they end up having separate sides of disabilities. But they end up talking about physical disabilities without specifically talking about mental health.*

The Mental Health Authority, the government body overseeing mental health in Ghana, has brought much-needed attention to mental health, pushing for implementation of the Mental Health Act and leading the reform of services. However, the establishment of a separate body for mental health has arguably created silos, which may hinder the shared policy action needed to address the social and economic rights of persons with mental illness.[28] There are concerns that people with mental illness are not considered by agencies such as the National Council on Persons with Disability (NCPD) under the category of "disability," partly as a consequence of this organizational distinction. As argued by a human rights worker, the creation of the Mental Health Authority and the NCPD under the Mental Health and Disability Acts, respectively, as "two completely different agencies" presents a "divided front" in the struggle for social and economic rights:

> *NCPD can push for benefits for persons with disabilities but the category of disabilities they are concerned with looking at does not include persons with mental illnesses. So NCPD talks a lot about, for example, the disability Common Fund, social and economic opportunities for persons with disability and they can push through the government to get things if they want them but then their categories of disabilities ... They said, "Yeah we know what mental illness is," but in terms of policy and receiving budget allocation or specific interventions, they don't consider mental illnesses because the Mental Health Authority has been set up. I see it as more of a divided front which is not helping particularly when it comes to social and economic opportunities.*

Civil society and advocacy

NGOs and civil society organizations in Ghana are increasingly active in campaigns to improve public awareness of the rights of persons with mental illness, counter stigma and social exclusion, and implement the Mental Health Act and the CRPD. Some receive training and funding from international groups such as the WHO Quality Rights initiative and the "Time to Change" global anti-stigma campaign.[29] NGOs have established peer support groups and provided capacity building on skills such as public speaking and assertiveness. These efforts aim to empower people with mental illness "to do their own advocacy, as rights holders demand their rights from duty bearers directly," as an NGO worker put it. Several people with lived experience of mental illness, such as Cecilia, have become active mental health advocates and shared their stories on social media, TV, and radio. They have also engaged in "awareness raising" in markets and shopping malls. WhatsApp groups and meet-ups provide fora in which people with lived experience of mental illness are beginning to offer mutual support, as emerged in the participatory group meetings.

However, the recovery narratives produced through international campaigns are often depoliticized, focusing on individual behaviors to challenge stereotypes and emphasizing the productive contributions of people with lived experience of mental illness.[30] Wider structural issues and political and judicial pathways to justice are seldom discussed. The NGO worker also expressed disappointment that in his experience, despite training, the poorest and those with the least education often lack the confidence to advocate for themselves, for example in petitioning their district assembly for funds. This suggests that training in empowerment may have the unintended effect of reinforcing inequalities, particularly in a context of entrenched hierarchies. It is notable that, as in a recent article highlighting the emergence of "middle-class, young and educated" Ghanaian men discussing their mental health, such advocacy is concentrated in the capital and reaches primarily younger, educated groups.[31]

Social media is accessible to only a small section of society, and the poorest, who do not speak English or have reliable access to the internet, are most likely to be excluded from such conversations. No participants in Kintampo were regularly engaged on social media, even those who spoke English. In addition, despite substantial provisions for workplace protections for people with mental illness in the Mental Health Act and the CRPD, these have received less attention than education on mental illness as a medical condition, improving access to psychiatric treatment, and regulating traditional and faith healers.

A few NGOs are involved in livelihood support for people with mental illness and their families in rural areas, providing capital and training to set up small businesses such as mushroom farming and goat rearing. However, these initiatives are often driven by external priorities and unevenly distributed. The only mental health-focused NGO in Bono East is now targeting maternal mental health and is not operating in Kintampo North. In Accra and Kintampo, informal networks made up of family, friends, work colleagues, and church members rather than formalized social or legal interventions were the most common resource for those seeking to reintegrate into work. Frank, for example, after recovering from addiction and psychosis, had been given funds by his sister to set up a chicken farm on the outskirts of Accra. This provided him with a livelihood selling eggs to local storekeepers. Henry was supported by his sister and mother, who bought him an overlocking machine that he operates in his sister's tailoring shop.

Such small-scale enterprises could offer informal workplace accommodations grounded in familiarity with the day-to-day needs and preferences of the person. Kwame has continued working in a modified role at his mother's wholesale food business. Although his mother had to contract her business due to the failure of creditors to pay their debts, Kwame attends the store every weekday, awaiting those who come to pay and recording their accounts. He is not paid by his mother for the work, but, as she describes above, she supports all his daily needs. Aside from the family, there are other community-based networks that can provide access to employment opportunities, such as religious groups and local businesspeople who engage in philanthropic activities. After Akua lost her job selling fish, another member of her church engaged her to help bake bread. Such forms of mutual aid and support are an essential aspect of getting by or "managing" everyday life in Ghana, making things possible in the context of under-resourced state infrastructure and scant welfare systems.[32] From paying a sibling's school fees, to contributing to health care costs, to supporting elderly relatives, to give but three examples, these practices are embedded in everyday social relations and moral economies. Despite the danger of entrenching patronage and hierarchies, their social embeddedness gives them a pragmatic scope and local accountability seldom matched by NGO projects, government programs, and state legislation.[33]

Discussion

As we have shown, social inclusion through work is a common aspiration for people with lived experience of mental illness in Ghana as elsewhere. Having the means to support oneself is valued not only for its economic but also for its social value and is thus central to a rights-based approach to social inclusion. Nonetheless, work itself can produce stress, and social expectations can present challenges for those who experience ongoing struggles with their mental health and face enduring discrimination. The fluctuations in mental health experienced by participants in this research show the importance of workplace accommodations, such as paid sick leave and flexible working hours, to enable those with serious and enduring mental health difficulties to exercise their right to work. However, experiences of exclusion and discrimination, particularly in the private sector, reveal the extent to which the right to work and to workplace accommodations as described in the CRPD and Ghana's mental health, disability, and labor laws are routinely flouted. In addition, these protections might be least available to the most disadvantaged. Aside from the challenges and costs in accessing legal representation, legislation is more difficult to implement within the informal sector, where most Ghanaians work, particularly women and those with little education. Legislation may also be less efficacious in addressing the kind of community stigma that Akua and others experienced. An adversarial approach may conflict with the ethics of civility within Ghanaian society and disrupt the vital social networks on which people depend.[34] As we found in this research, such networks are often the most important facilitators of employment.[35]

Analyses of social protection programs such as LEAP have shown that even small cash transfers may not only reduce absolute poverty but enhance social inclusion by providing some measure of financial independence and funds to engage in social networks.[36] However, they have been criticized from a social justice perspective as failing to empower recipients and address the root causes of poverty and inequality.[37] There are justifiable critiques of the charity model, which can increase dependence and reinforce hierarchies. Indeed, the CRPD explicitly states that support services must be considered a right rather than a form of charity. In the case of persons living with mental illness in Ghana, confusion over the definition of mental illness as a "disability" and inefficiencies in administration have reinforced dependence on intermediaries to access such benefits and deprived many of entitlement to basic social protection.

The emergence of peer support and advocacy in LMICs suggests the potential for building solidarity through which to build collective action to claim rights.[38] However, to date, these have had a limited influence on mental health policy, and activities are hampered by lack of resources.[39] There might also be potential to nurture solidarity within communities, building on the social commitments evidenced by those who provided support for people living with mental illness to establish a livelihood. While NGO projects tend to be short-lived, unevenly distributed, and driven by external funding and agendas, community networks and resources such as church groups, youth clubs, trade unions, and professional societies are rooted in organic social values and relationships.[40] These might be mobilized to support social inclusion through enabling opportunities for participation in work and other socially valued activities, as well as organizing to address injustice and claim rights.[41] Building these forms of practice-based solidarity could contribute to overcoming discrimination at the community level, such as by encouraging owners of small businesses to employ people with lived experience of mental illness. However, community participation should not be confined to the "lowest rung" but reach upstream to challenge those in power and hold them to account.[42]

Conclusion: Community mental health as social activism

In a recent editorial to mark the anniversary of the Centre for Global Mental Health, Richard Horton argued that "mental health professionals and civil society need not only to rediscover their solidarity but also their raging soul." The "mental health community," he claimed, "has failed to devise any credible means to hold political leaders accountable for their promises and commitments."[43] Since publication of the *Lancet's* seminal series on global mental health, Ghana has become a significant focus of activities that aim to promote the rights of people with mental illness, including ratification of the CRPD.[44] However, while the human rights community has focused on abuses by traditional and faith healers, as we have shown, rights to social inclusion and participation in the workplace are routinely contravened. Political leaders in Ghana have not been held to account for their failure to implement the CRPD and protect the rights of some of their most vulnerable citizens. The emphasis is often on individual stigmatizing behavior and "harmful cultural practices" rather than on challenging the ways in which discrimination is embedded into social and political structures.[45]

In the face of such injustice, we would argue that national and global efforts should move from a narrow focus on service development and individualized interventions to considering how best to work across different sectors to challenge social, structural, and political barriers to social inclusion.[46] Building on recent work on "community competencies" and social activism for mental health, we suggest that bringing together people with lived experience of mental illness alongside allies within families, communities, and civil society could hold local and national government and employers in the private and public sectors to account and ensure full and equitable participation in all aspects of life, including work.[47] In this way, it may not be the Mental Health Act that becomes Ghana's pioneering legacy for mental health and human rights, but the ways in which Ghanaian citizens and their allies built a social movement to fight for social justice and inclusion.

Acknowledgments

We gratefully acknowledge the contribution of all the participants in this research, in particular the members of the participatory research groups and Nana Abena Korkor, Esenam Drah and Cecilia Ashaley for their feedback on the paper. We also extend thanks to Dr Annabella Osei-Tutu and the University of Ghana for their support for this research, Osei Isaac Kwame and Adwoa Agyeman for assistance with research, transcription and translation and Sarah Gyau, Ann Fordie, Fauzia Ibrahim and Osei Isaac Kwame for their work with the participatory groups. This research was funded by the Wellcome Trust as part of the Mental Health and Justice project (203376/Z/16/Z).

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HHR Health and Human Rights Journal

Crisis Response as a Human Rights Flashpoint: Critical Elements of Community Support for Individuals Experiencing Significant Emotional Distress

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Abstract

This paper proposes a set of nine critical elements underpinned by human rights principles to support individuals experiencing a serious crisis related to mental health problems or psychosocial disabilities. These elements are distilled from a range of viable alternatives to traditional community mental health approaches and are linked to a normative human rights framework. We argue that crisis response is one of the areas of mental health care where there is a heightened risk that the rights of service recipients may be infringed. We further make the case that the nine critical elements found in advanced mental health care models should be used as building blocks for designing services and systems that promote effective rights-based care and supports.

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Competing interests: None declared.

Introduction

Over the last two decades, the United Nations and other organizations have released a number of groundbreaking reports documenting widespread, systemic human rights abuses within mental health systems worldwide.[1] Overall, these documents emphasize the need to seek better health and social outcomes through sustainable means, using a human rights-based approach in keeping with the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the right to health framework. These normative standards, along with persistent calls by service users and advocates, have brought attention to the rights of persons with psychosocial disabilities, particularly the right to freedom from coercion in mental health services. They provide the impetus to find suitable practices to transform and modernize mental health care in communities everywhere.

However, the form and substance of rights-based interventions through which mental health service providers, family members, and other engaged citizens might offer support, without resorting to coercive and dehumanizing interventions, remain unclear. While promising non-coercive interventions for persons experiencing serious emotional crises have been piloted in several countries, usually as alternatives to involuntary hospitalization, better evaluation and research is needed to increase their potential for widespread implementation.[2] And although recent publications argue for such rights-based approaches, how to operationalize this evolving framework has yet to be described.[3]

The present paper fills this important gap by identifying a set of elements that are likely critical to rights-based support for individuals experiencing serious emotional crises, whether or not they use mental health services. The aim of this paper is to help ensure that a rights-based approach to crisis response becomes a distinct and crucial operational component of mental health care. Crisis response is a human rights flashpoint where coercive structures and practices dominate and the human rights threat to individuals is consistently manifest.

The critical elements presented in this paper are grounded in the rights-based approach and the right to health. Specifically, they correspond to principles underlying the key normative frameworks enshrined in the CRPD and to the principle of the right to the enjoyment of the highest attainable standard of mental and physical health, which are incorporated into article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR).[4] We follow the 1946 Constitution of the World Health Organization in defining health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[5]

A quest for rights-based mental health systems

Practices with the potential to transform or replace community-based mental health care have been in existence, and many shown to be effective, since the advent of modern community psychiatry in the mid-1960s. Some, such as the Italian and Brazilian experiences, involve large-scale mental health reforms driven by deinstitutionalization and the development of sectorized community mental health services.[6] However, they also include highly innovative, small-scale efforts that have eluded larger systems.[7] These have been spearheaded by former patients or by visionary psychiatrists; many focus on people experiencing psychosis.[8] Most began as alternatives to coercive treatment and enhance personal liberties. Although these initiatives preceded the contemporary human and disability rights discourse by years, they contain critical elements which align with these rights.

A first type of innovation, beginning in the 1970s, involves small, community-based support structures. For example, the Soteria model provides a safe community home, largely non-professional staffing, and minimal medication use as a substantive, non-coercive alternative to acute hospitalization for people experiencing early psychosis.[9] Consumer/survivor/ex-patient groups have established other alternatives to mainstream mental health services for people in crisis.[10] The strongest outgrowth—peer-run respite facilities—provides peer support and non-coercive safe spaces where individuals in crisis can stay for varying periods of time.[11] Some such solidly established initiatives include the Berlin Runaway House (Germany), the Bapu Trust (India), and Western Massachusetts Recovery Learning Community (United States).

A later crisis response paradigm is embodied in the now widespread Open Dialogue model, created in Finland in the 1980s. Instead of an alternative residential setting, Open Dialogue uses systemic network approaches to support individuals in crisis in their homes and communities.[12] Structured conversations between a treatment team, the person in crisis, and members of her social network give equal weight to all viewpoints on the crisis, even those that would elsewhere be dismissed as "psychotic." By engaging persons in crisis with their network members, Open Dialogue attempts to transform the experience of "psychosis" and to destigmatize and empower the person in crisis.[13]

Alternative and "radical" models often show better social and clinical outcomes than "standard care"; others, according to Piers Gooding et al., may contribute to lowering coercive hospitalization.[14] Yet they have failed to spur rights-based, voluntary mental health systems. Instead, involuntary hospitalization, mandatory community treatment, and other coercive measures have risen significantly in Europe and North America, despite consistently poor outcomes.[15] Meanwhile, in the Global South, where mental health care is either lacking or depends almost exclusively on hospitalization, powerful global health actors working to close the "treatment gap" promote interventions focused primarily on medication use, rather than strategies to reduce coercion and safeguard human rights.[16] While advocates critique these neoliberal development strategies, global health proponents argue that only evidence-based practices merit replication.[17] This criterion excludes many rights-based alternatives which are difficult to test through traditional experimental designs. Yet usual crisis responses (such as police intervention and involuntary hospitalization) are taken for granted without being submitted to the same research standard.

This contradictory situation calls for a wide range of localized innovations that adhere to human rights law while offering workable alternatives to the dominant mental health system.

This paper contributes critical elements as guideposts for such efforts. Rather than proposing one paradigm, a competing technology, or total system reform at once, it offers rights-based building blocks that, when endorsed by local stakeholders, can contribute to system reconfiguration of responses to serious mental health crises.

Methodology: Linking abstract principles and practical responses

To identify critical elements of a rights-based approach to crisis response, we modified Paul Hunt's three-step process for developing a normative framework of human rights principles and values and translating them into practical elements.[18] Whereas Hunt's model moves from the abstract to the practical, we chose to identify already existing practices and confirm their human rights underpinnings.

First, we located the human rights laws and standards that should underpin elements of a rights-based approach (normative framework). Second, we specified a core set of human rights principles and values expressed in this framework. Third, we identified elements of crisis response practices that research shows or that our clinical and advocacy practice suggests are anchored in human rights. Most research to date focuses on whether entire programs, but not specific components, contribute to avoiding hospitalization, and its results are mostly inconclusive. Most studies focus on avoidance of coercion as the outcome, but some studies examine the association of these practices with a subjective sense of empowerment.[19]

The critical elements identified through clinical and advocacy experience are described in the second part of the paper. Our practice employs experience-based phenomenological processes to discern what persons in crisis might experience as coercive—a dimension that conventional, positivist evidence-based research may not pick up.[20] Rather than relying on normative criteria based on objective behavioral response, we focus on understanding the singular subjective processes involved in a situation of crisis. This approach better suits the perspective of human rights, especially if social, cultural, and individual differences are to be taken seriously. We selected those elements that seemed aligned with specific human rights principles in the normative framework. The result is a set of nine critical elements that can be operationalized, subjected to research, and embraced as components of rights-based approaches to mental health crises.

Normative framework

There is no universal definition of a "rights-based approach to health" in general or specific to the mental health context.[21] This paper takes a rights-based approach to crisis response to include the full spectrum of civil, political, social, economic, and cultural rights: the rights of the child; the rights to privacy, life, participation, association, non-discrimination, equality, and family; and the prohibition of torture and cruel, inhuman, or degrading treatment or punishment. Health policies, strategies, and programs are to be guided by all these human rights standards and principles and should aim at empowering rights holders and strengthening the capacity of duty bearers. The proposed critical elements emanate from these core normative standards, but they importantly and explicitly foreground the right to the enjoyment of the highest attainable standard of physical and mental health (the right to health) and the specific rights enshrined by the ICESCR, adopted in 1966.

The right to health is recognized in various international and regional human rights treaties and enshrined in the Constitution of the World Health Organization. All states have ratified one or more of these instruments. While the right to health includes both freedoms and entitlements and has been interpreted to encompass both health care and the underlying social and psychosocial determinants of mental and physical health, operationally it has been understood to possess unique elements essential for the effective implementation of a rights-based approach to crisis response.[22]

According to Sofia Gruskin, Dina Bogecho, and Laura Ferguson, a minimal set of operational elements of the right to health includes availability, accessibility, acceptability, and quality (the AAAQ framework), as well as participation, transparency, and accountability.[23] The AAAQ framework finds its legal basis in General Comment 14 of the Committee on Economic, Social and Cultural Rights and is a unique and essential feature of the right to health. How these operational elements of the right to health have been articulated over time both through the CRPD and through the work of authoritative sources, such as the Committee on the Rights of Persons with Disabilities and reports of the United Nations Special Rapporteurs on the right to health and on the rights of persons with disabilities, informs our proposed framework.

The CRPD represents the highest standard of protection for the rights of persons with disabilities. It calls for the full realization of all human rights and fundamental freedoms for all persons with disabilities (actual or perceived), and it outlines specific steps to be taken by state parties to ensure the full and equal enjoyment of these rights.

Emphasizing the universality, indivisibility, and interdependence of human rights, the CRPD effectively contributes to a rights-based approach to crisis response by stressing the principle of non-discrimination and the notion of support in the exercise of rights. Article 12 of the CRPD affirms the legal capacity of all persons with disabilities in all areas of life and acknowledges the role of supported decision-making in exercising legal capacity. Article 14 of the CRPD clarifies that "the existence of a disability shall in no case justify a deprivation of liberty," which the Committee on the Rights of Persons with Disabilities and other bodies and experts have interpreted as an "absolute ban" to involuntary commitment to a mental health facility, including in crisis situations.[24] Furthermore, as underscored by Catalina Devandas, article 25 of the convention reaffirms the right of all persons with disabilities to the enjoyment of the highest attainable standard of health without discrimination, including the right to free and informed consent.[25]

In sum, under the CRPD framework, impairments—whether actual or perceived, or temporary or long standing—cannot be a legitimate ground for the denial or restriction of human rights, particularly in the context of crisis response, which often has been considered as exempted from those very safeguards. The support paradigm of the CRPD calls for non-coercive support responses within and outside the health sector.[26] In doing so, the CRPD questions previous international and regional standards that allow for exceptional circumstances in which the rights of persons with psychosocial disabilities could be restricted in the context of mental health provision.[27] While some CRPD detractors claim that a ban on coercive practices may endanger the right to health of persons with psychosocial disabilities, there is an increasing consensus that the CRPD represents an opportunity to realize a rights-based approach to mental health care.[28]

Key underlying principles

The core set of human rights principles and values that underpin the critical elements spring from the need to mitigate the losses of rights described in the ICESCR and CRPD that can occur when individuals experiencing a mental health crisis interact with emergency services and other systems of care. To be diagnosed with a mental illness can be stigmatizing and can result in a loss of social capital for individuals within their communities. In many legal contexts around the world, a diagnosis amounts to being labeled *non compos mentis* and means a loss of the enjoyment of a range of rights under international law. Once this occurs, substitute decision-making takes the place of self-determination. Emergency responders—police, medics, and others—are often empowered to apply force, to medicate without consent, to restrain, and to detain an individual for observation. In the worst such circumstances, individuals experiencing what appears to be a mental health crisis lose not only their rights but also their lives. Most survive the ordeal but, in many countries, they may be detained indefinitely, ostensibly for the safety of the larger community and without the provision of adequate care. In more progressive countries, where deinstitutionalization has advanced, substitute decision-making can remain in force for years, and legally mandated treatment with psychiatric medications as a condition for release from institutional detention or regaining other rights and freedoms is widespread and growing.[29]

The key principles that guide the identification of the critical elements for rights-based mental health care are selected here because they can eliminate substitute decision-making and promote self-determination for individuals within crisis response and systems of mental health support. Without these assurances, crisis situations, whether gradually or rapidly evolving, are likely to result in the immediate and sustained infringement of human rights. Crisis is defined but not limited to a broad range of experiences: sudden or frightening levels of agitation or turmoil; long-term withdrawal and isolation without attention to basic needs, physical health, or safety; suicidal intent; intense interpersonal animosity; expression of extreme fear or beliefs at odds with those of others; elevated mood or behavior; loss of awareness of surroundings; and struggling to plan and use foresight in their actions.

Participation and empowerment. Empowered participation has proved critical in improving care through preserving and bolstering the rights of persons with psychosocial disabilities in countries that have undergone deinstitutionalization, such as the United States, Italy, Portugal, and Brazil, to name some of the best-documented instances. In the United States, empowerment became the central organizing principle among the consumer/survivor/ex-patient movement that emerged from the era of deinstitutionalization and that has improved care for those with the most severe diagnoses, reducing inhumane practices and excessive use of seclusion and restraint. Empowerment and inclusion are proposed by consumer/survivor groups as measures of mental well-being. In our view, empowerment establishes a virtuous cycle of increased freedoms and well-being for those who are diagnosed with mental illnesses. Ideally, all critical elements should either promote or not restrict participation and empowerment.

Equality and non-discrimination. Article 5 of the CRPD upholds a complex substantive model of equality that addresses structural and indirect discrimination, values different layers of identity, and acknowledges intersectional discrimination.[30] Consistent with this strong definition of non-discrimination, the critical elements of mental health programs and systems should "recognize that all persons are equal …, prohibit all discrimination on the basis of disability …, and take all appropriate steps to ensure that reasonable accommodation is provided." Persons with psychosocial disabilities must be supported in exercising rights and should not be restricted in their exercise.

Quality and diversity of care. If the quality of mental health care is deficient, then the right to mental health care is effectively curtailed. Consistent with the principles of non-discrimination and equality, the critical elements should require that programs and systems of mental health care and psychosocial support be of high quality, be at least on par with quality standards for general health care, and demonstrate a record of, or hold reasonable promise of, promoting improved well-being and recovery. The effectiveness of supports should be measurable in ways that are meaningful to the individuals receiving care, and supports should be provided within an organized and accountable network. Because there is no singular recognized cure for any mental health problem, and because both personal and cultural diversity have strong and largely unpredictable effects on mental well-being, a multiplicity of options for care and models of care is essential.

Social inclusion. Social exclusion often lies at the heart of mental health problems and crises and limits the achievability of empowerment while interfering with the basic human need for social connectedness. Therefore, the critical elements must not inhibit and, when applicable, should actively promote social inclusion for and destigmatization of individuals with psychosocial disabilities.

Autonomy and dignity. The principle of autonomy means that individuals can make their own decisions about their lives, with adequate support if required, avoiding substitute decision-making. Respect for autonomy bolsters individuals' rights to choose the types and elements of the care and support they receive and to make decisions about their lives as independently as possible. It must be accounted for within the critical elements of crisis response. Each person should be respected as an individual with the right to autonomy and with the inherent dignity of a free person with equal rights to all others. People with psychosocial disabilities have the right to make decisions that others feel are unwise or with which they disagree.

Critical rights-based elements for crisis response

The critical elements of rights-based services for individuals in psychiatric crisis should be underpinned by the five key principles described above. Each of the following nine rights-based critical elements for response to mental health crisis incorporates up to five of these principles (Table 1). While no single critical element encompasses all five principles, a human rights-based crisis response integrating more than one element would likely translate all five into concrete practices.

1. *Communication and dialogue*

The reality or the belief that it is impossible to be heard and understood is often central to an individual's mental health crisis. Connection to a trusted professional, friend, or "person with experience" can help resolve the immediate situation and avoid coercive consequences. Supportive communication underlies programs ranging from the widely disseminated Friendship Bench, developed in Zimbabwe, to free-standing peer-support techniques.[31] Dialogical encounters, the communication paradigm underlying Open Dialogue and other programs, foster unexpected viewpoints, contradictions, and change. Both paradigms may broaden social capital by reinforcing already available relationships or building new networks around the crisis. The range of dialogical communication can extend from simple one-on-one exchanges to complex engagements in group-formats ("network meetings").

Communication and structured dialogue correspond to three key rights principles. Both facilitate *empowerment*, *autonomy*, and *social inclusion* through listening, gauging the distressed person's tolerance for others present, and involving him or her in deconstructing the situation of crisis. *Social inclusion* is preserved through acceptance of coexisting differences and conflicts, which in turn avoids a collapse of interpersonal relationships. Interventions based on immediate, frequent, and sustained dialogue with people experiencing psychosis have been shown to have better clinical outcomes than usual treatment and to circumvent coercion and overmedication.[32]

2. *Presence ("being with")*

Alongside communication, presence—the idea of simply "being with"—responds to the basic human need for authentic human companionship, especially in crisis situations. As a result, it reinforces three rights principles: *participation*, *social inclusion*, and the *autonomy and dignity* of the person in crisis. The art of spending time with a person, without a predetermined objective, has been a key element in pioneering programs for persons experiencing acute psychosis ("altered states"), such as Windhorse, Soteria, Diabasis, and Emanon.[33] Time spent together may occur in a scheduled manner, such as during three-hour "basic attendance" sessions (Windhorse, a crisis support program based on contemplative principles) or 24–78 hour shifts (Soteria) or more spontaneously. Autonomy is preserved through continual renegotiation of the degree of physical closeness and active engagement in a space that protects the safety of the person in crisis. The mere fact of sharing space with someone in extreme distress communicates trust and has been shown to have a sustained calming effect.[34]

3. *Flexible location*

Ideally, mental health workers should encounter someone in extreme distress in flexible locations, especially wherever that person happens to be or to feel most comfortable. *Equality, non-discrimination*, and *social inclusion* are preserved through flexibility as opposed to transporting the person to a "special" or stigmatizing place (such as a psychiatric service or institution). *Autonomy and dignity* are assured if the person in crisis invites the worker into his or her home or "personal territory" on the street, or if his or her personal space is safeguarded in shared living spaces.[35]

Mobility, outreach and home visits recognizing flexible location are key components of many community mental health services, including crisis intervention.[36] Ethnographic research has shown that respecting or being welcomed into the spaces occupied by homeless persons in crisis can be conducive to a better understanding and resolution of the situation.[37]

4. *Safe spaces of respite*

Persons in distress may seek safe spaces of "respite"

TABLE 1. Correlation of critical elements with key underlying principles

	Participation and empowerment	Equality and non-discrimination	Quality and diversity of care	Social inclusion	Autonomy and dignity
Communication and dialogue	◆			◆	◆
Presence ("being with")	◆			◆	◆
Flexible location		◆		◆	◆
Safe spaces of respite	◆	◆		◆	◆
Continuity			◆		
Peer involvement	◆	◆	◆	◆	◆
Harm reduction				◆	◆
Judicious use of medications			◆	◆	◆
Response to basic needs	◆		◆		

from harmful or traumatizing environments, which may have provoked or could sustain the mental health crisis.[38] Respite spaces can provide around-the-clock support for individuals in crisis, through several-day to two-week stays.[39] Such spaces meet key rights principles of *empowerment*, *equality and non-discrimination*, *social inclusion*, and *autonomy and dignity*, as long as decisions to use them are made by the person in crisis or collaboratively.

Respite services involve peer workers, make pantry and cooking facilities continuously accessible, organize group meetings, and allow residents to come and go and pursue outside activities. Overtly illegal acts are not tolerated and can lead to being asked to leave.[40] Trained lay families or friends can also provide relief outside the home. Both types of respite have been shown to have better outcomes than hospitalization and to safeguard human rights.[41] Such rights-based respite approaches must be differentiated from those affiliated with locked or otherwise coercive mental health services.[42]

5. *Continuity*

Continuity of care remains an elusive goal of mental health services, in spite of widespread consensus regarding its essential role.[43] Continuity of personnel beyond the moment of crisis is almost nonexistent in current systems of care.[44] Critical Time Intervention, peer-bridgers, and Open Dialogue provide continuity by at least one person from the initial encounter through crisis resolution, but they are exceptions to this rule.[45] Such ongoing connection empowers the person and assures *quality and diversity*. In contrast, such typical practices during crisis assessments as "assessment and referral," triage, and other means of handing the person over to another service emphasize technical and managerial solutions rather than the development of emotional bonds. While some respond well to a one-time intervention, the offer of an ongoing relationship provides a powerful tool for persons in crisis to reconstitute their lives, even in the face of fractured connections. Continuity may be especially crucial when the person in crisis is suicidal.

6. *Meaningful peer involvement*

"Experts by experience," also known as peer workers or peer specialists, are trained to use their personal mental health and psychosocial disability experiences to help persons in crisis. While the personal life experiences of anyone who seeks to help others can be used in powerful ways, interventions based on the unique personal experience of extreme mental states and with various treatment responses have been widely embraced. Meaningful peer involvement in crisis situations, alone or with other mental health providers, ideally meets all five key rights principles in our framework.

When peer workers engage and judiciously disclose their personal experiences as they apply to the crisis situation at hand, they support and *empower* the person in crisis in a *non-discriminating* manner that preserves *dignity* and promotes *social inclusion*.[46] To ensure the standard for *quality* that the right to health assumes, peers should be well trained in the subtle and often tacitly acquired skill (for example, Intentional Peer Support). Peer collaboration has been used by some non peer respites and Open Dialogue teams to generate innovative types of support.[47]

Peer-led services appear to contribute to reducing coercive interventions and the cost of services.[48] In this regard, the extent to which crisis responses require professionalization or can be directly provided by lay or peer practitioners outside medicalized frameworks is an essential question that requires greater attention.[49] To be successful, peer involvement must be meaningful and not be implemented in a tokenistic fashion. In too many instances, peer involvement is encumbered by power imbalances, where peer workers are involved in a superficial manner and have little or no control over crisis responses.[50]

7. *Harm reduction*

Harm reduction approaches prioritize access to care by reducing or eliminating behavioral thresholds linked to disturbing, taboo, or even illegal behaviors. This model was pioneered in the domain of substance use services but can be applied to mental health, including for those without substance-related problems. Within the harm reduction paradigm, people are supported in their efforts to eliminate, avoid, or lessen risks associated with mental health problems, such as cutting or other forms of self-harm, unsafe sex, radical isolation, and illicit drug use. In this way, harm reduction assures the principle of *diversity in health care*, through *social inclusion* that respects the *dignity and autonomy* of the person. One can assume that reconceptualizing risk assessment into harm reduction will increase the *quality* of care and its outcomes.

Harm reduction focuses on providing care in a non-stigmatizing manner while tolerating the engagement in risky behavior. Such care is achieved by maintaining a collaborative stance with the person, who may be ashamed and fearful of losing rights due to such behavior, when seeking help. Importantly, harm reduction considerations are different from risk-benefit calculations, since no external assessment of risks or benefits concerning the situation or behavior is involved.[51] In other words, engaging with a broad range of risks in mental health supports is taken as a given, rather than a separate "administrative" layer of concern, which inherently interferes with a host of human rights principles.[52]

Responses to mental health crises that incorporate harm reduction principles may be more acceptable to distressed persons because they destigmatize harmful acts and reduce shame. For example, a person who engages in physical self-harm can be supported by considering less harmful ways instead of provoking categorical interdiction. Still, some situations will require the ongoing presence of another alert human being who may step in to engage the person in a conversation, or even, with permission, to gently prevent them from self-harm by physical contact (for example, through touch, not wrestling).[53]

However, violence against another person should be considered not a psychiatric problem but a likely violation of criminal law. A person in crisis who engages in interpersonal violence may be warned; in addition, the threatened individuals may be protected, and non-discriminatory police intervention may be called on to avert potential harm. Judicial guarantees and safeguards protecting the rights of those accused of a crime should apply in such cases, including the presumption of innocence, the right to a fair trial, and the provision of procedural accommodations.[54]

8. *Judicious use or avoidance of psychotropic medications*

Because the distinctions among prescribed psychiatric drugs, over-the-counter remedies, and licit (for example, alcohol) and illicit substances is relatively arbitrary, a harm-reduction approach is applicable to all of them. Meta-analyses suggest that less psychotropic medication is superior to more and that cautious gradual introduction is preferable to an immediate and high-dose prescription. Intermittent use under the person's control is likely less harmful over the short and long term than ongoing "maintenance" administration.[55] However, intermittent use may also increase the risk of harm due to inconsistent effects on receptor sites, an issue beyond the scope of this paper.[56]

Judicious psychotropic use enhances the *quality and diversity of health care* and ensures the *autonomy and dignity* of the person in crisis. How the person in distress views medication can help determine the most beneficial alternative.[57] Providing medication at the request of the person in crisis—for example, for quick relief of insomnia or intense anxiety—can be an important step in crisis resolution that also protects the person's rights.[58] On the contrary, the forced administration of psychotropic drugs is considered by many to be equivalent to torture and physical abuse.[59] Indiscriminate use of medication can undermine trust; it interferes with optimal, dignified care and frequently ignores the person's preference.

9. *Response to basic needs*

Many, if not most, crises manifested in emotional distress originate in interpersonal problems or environmental stressors (such as poor nutrition; lack of clothing, funds, or access to transportation; housing conditions; and legal problems). Such adversities can push someone from a state of adequate functioning to severe distress.[60] *Empowerment* of the person in distress and *quality and diversity of health care* are promoted when basic needs are addressed immediately. This may involve mobilizing a person's natural support system, collaborating with him or her on problem-solving, and even providing material resources, such as food, clothing, or money, which will yield desired results quickly. Bureaucratic obstacles also often trigger crises, and a competent guide through such mazes (for example, concerning health coverage, financial benefits, or access to essential services) can go a long way. The worldwide Housing First movement advocates for housing without requiring that the person in crisis be in a stable condition.[61]

Practical application of critical rights-based elements

Peer-run organizations such as the Western Massachusetts Learning and Recovery Center and Bapu Trust in India incorporate all nine critical elements.[62] Although current mental health systems would be unlikely to accomplish this, it is possible to demonstrate how crisis response can engage the nine critical elements as safeguards of the five key rights principles.

The following example from our work illustrates this possibility in real life. It involves a woman in her forties who was first encountered in the streets when she appeared to be wandering into traffic without paying much attention. When an outreach team pair (peer specialist and social worker) approached her, she seemed intoxicated from alcohol and spoke about scary people who were following her. By listening, without encroaching on her space, the team was able to conclude that the women's fears were outside consensual reality but that she recognized the need to be more careful with street traffic *(communication and dialogue, presence, flexible location, and meaningful peer involvement)*.

The same team re-contacted the woman several times on the street and brought her food and warm bedding, which she had requested. She eventually accepted going to a respite space instead of being taken to a psychiatric emergency room (*continuity*, *respite*, and *basic needs*).

At the respite center, her drinking bothered residents who were trying to stay sober. The respite workers successfully sought a "wet house," which allowed her to drink and supported her in limiting the amount and frequency (*harm reduction*). The outreach team pair continued to spend time with her and support her with nutrition, personal hygiene, and forward planning (*presence* and *continuity*). When the woman complained about medications she had taken in the past, a consultant psychiatrist involved her in a collaborative plan to use medication only as needed which was the least adversely interactive with alcohol (*judicious use of medication*). The team pair helped her apply for long-term supported housing and reconnect with her children.

Accountability

Accountability, one of the most powerful aspects of a rights-based approach, should tie all nine critical elements to a rights-based culture. Accountability is necessary for ensuring that the rights of individuals within a system of care are upheld and that quality of care is preserved.

It is also an essential aspect of how rights-based critical elements can be "rightly" implemented. As such, it requires a system or organization that can embed what is to be accounted for, to assure not only that rights are respected but also that a full range of critical elements, perhaps even beyond those mentioned above, are validly and reliably put into practice as proposed.[63]

In order to succeed in creating a rights-based alternative to coercive standard care, a robust accountability framework should take into account the above critical elements and local law. It should provide means of pressuring existing mental health systems and programs to operationalize alternatives through a plurality of appropriate choices. The adoption of such measures, as well as an effective but not overly onerous approach to ensuring quality of care, must be acceptable to relevant stakeholders, particularly users of mental health services and supports. One example of a tool that can monitor such a process is the World Health Organization's Quality Rights Initiative.[64] Evaluation of crisis response is a crucial component of this accountability framework, and the promotion and upholding of the CRPD standards should be incorporated as outcome measures. Finally, the meaningful and routine inclusion of service users within teams that evaluate, monitor, and report on service implementation and outcomes is an important part of ensuring accountability.

Risks and limitations

The greatest limitations to establishing supports that uphold human rights for individuals in mental health crisis lie with the vested interests that hold most power within existing mental health systems.[65] The two most prominent are the pharmaceutical industry and the mainstream medical establishment, which is still largely centered around hospital-based services.[66] Half a century ago, antipsychotic medications were heralded by policy makers as miracle cures that would enable those deemed in need of being separated from society to leave psychiatric institutions. The ensuing deinstitutionalization failed largely from lack of adequate community-based alternatives. In the meantime, the efficacy of psychotropic medications has been shown to be equivocal, adverse, even lethal, outcomes (such as dependency, metabolic disease, and suicidality) are not uncommon. Despite this, the pharmaceutical industry and its lobbyists have shaped public policy for decades.[67] Psychiatrists and other mental health professionals are key players in this status quo, and their incentives are skewed toward a focus on short-term evidence of medication effectiveness and away from long-term well-being, recovery, and human rights.[68]

Mainstream critics largely dismiss psychosocial interventions on the grounds that they lack an adequate evidence base. They also argue that implementing such alternatives would put people in crisis and the community around them at risk. Psychosocial interventions, which we argue can preserve rights and improve well-being, are much more complex and difficult to study. Yet their study receives vastly less funding than medication-related research. Researchers should advocate for more funding and develop the evidence base for such alternatives, and civil rights advocates should join forces with them in this effort.

As we have noted, several international developments and reports uniformly decry present conditions and call for a complete revamping of the current mental health system. However, countries, guilds, and mental health systems have yet to take these challenges seriously. Exceptional local efforts to redesign mental health services remain insular and rely on limited funding and practical experience, while broadcasting excellent values and beliefs.

Another important tool that has not been addressed in this paper is the availability and promotion of psychiatric advance directives that can be used by persons with psychosocial disabilities in an attempt to influence crisis response in the future.[69] While important to the advocacy movement and to many persons with psychosocial disabilities, of advance directives' the widespread impact on system transformation is still doubtful.[70]

Where do we go from here?

The trajectory within international law clearly bends toward greater freedom and autonomy for people with psychosocial disabilities, although significant barriers to upholding those freedoms and autonomy remain, particularly at a point of crisis when state authorities may intervene. However, since the 1960s, when the era of deinstitutionalization began, a range of alternatives to coercive treatment, especially for those in crisis, have been developed that can show the way toward the realization of rights-based crisis mental health care.

In countries where health systems are less funded and medical professions less powerful than in the Global North, the status quo may resemble the pre-deinstitutionalization era and may be replicating some of the least promising practices in post-colonial settings.[71] Global South nations must rely on cheaper and hence older generic medications, which have high-risk profiles, especially in the short term. As a result, seclusion and restraint, including the chaining of individuals, are frequently used.[72] Implementing the nine critical elements that preserve human rights, for example as part of a comprehensive Open Dialogue approach, requires considerable human interaction by paid staff, and certainly costs more than medication-centered practices.[73] In resource-poor environments, providing training to non-professional lay providers from the community and mental health peers that allows them to assist in preventing coercion and restraint and in implementing basic interventions may help overcome cost barriers.

Based on the characteristics of some of the more promising and prominent alternative models in the literature, we have distilled nine critical elements that incorporate key principles of the right to health. These can provide valuable guideposts for those who are either reforming or developing community mental health supports in an effort to adopt international humanitarian standards of care.

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HHR Health and Human Rights Journal

A Human Rights-Based Approach to Psychiatry: Is It Possible?

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Abstract

While it is becoming more common to hear calls for a human rights-based approach (HRBA) to health, documented efforts to apply the approach in practice remain scant. This paper presents a review of a pilot study applying an HRBA to psychiatric care in Gothenburg, Sweden. Based on the reflections of some involved in the pilot, and on the evaluation carried out, it presents the context, process, effects, and lessons learned. In the paper, we structure our experiences of an HRBA around the United Nations' guiding principles of dignity and empowerment, equality and non-discrimination, participation and inclusion, accountability, and transparency. We discuss challenges encountered during the project, such as realizing meaningful participation and challenging the hierarchies of different professions within care. We also discuss successes, such as contributing to an overall strategic goal to eliminate all coercive measures in psychiatric care. We then offer our reflections, as the core team involved in the pilot, on how to make an HRBA sustainable in a large organization and provide practical recommendations based on our experiences.

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Competing interests: None declared.

Introduction

Translating international human rights law into practical work in Sweden is a relatively new process. Until the early 2000s, work on human rights was perceived above all as something related to foreign policy and development assistance in developing countries. Speaking about the promotion of human rights within Sweden has often been perceived as quite foreign.[1]

The purpose of this paper is to describe the lessons we learned through the adoption of a human rights-based approach (HRBA) to psychiatric care, as part of a regional governmental initiative. The authors are two rights holders from the relevant psychiatric care units, and two duty bearers from the regional authority. We adopt a narrative approach to discuss some of the challenges that were encountered during the project, such as realizing meaningful participation and challenging the hierarchies of different professions within care. We also discuss some of the successes, such as contributing to an overall strategic goal of a zero vision against coercive measures for the whole region. When an organization tests and develops new ways of working, this often takes place in the form of a pilot project in a smaller part of the organization. The organization has existing systems in place for optimization and measurement to ensure that we stay the course. The logic for the pilot project is different when the focus is on learning and exploration. Thus, a pilot project cannot be evaluated with the same tools or metrics that the organization uses. In an exploratory mode, it is not about how much you are doing but what you learned along the way. Even mistakes can be of great importance in a pilot project if you learn and offer feedback to the organization. The connection between the pilot project and the wider organization is therefore central, so that the exploration feeds into the wider goals.[2]

We begin the paper with a short description of how regional authorities and psychiatric care are organized in Sweden. We then discuss the organization of the human rights project before turning to lessons learned based on the core principles of an HRBA.

Region Västra Götaland and HRBA pilot projects

Västra Götaland is a large region in southwest Sweden, with 1.7 million inhabitants and 49 municipalities, the largest being the city of Gothenburg. Västra Götalandsregionen (VGR) is the politically led regional government. VGR employs 55,000 people, 85% of whom work in health care. The remaining focus areas are public transport, regional development, and culture.

In 2011, a political committee for human rights was formed in VGR, tasked with initiating an HRBA and promoting and advising on human rights issues within the organization. The committee was transformed in 2019 into an advisory committee for human rights that is part of the regional executive board and has the mission to prepare and advise on policies and strategies concerning human rights.

An office of civil servants is attached to the advisory committee, and its main assignments are combating discrimination and promoting equality in VGR. As the committee for human rights was the only one in Sweden, politicians were keen to find out what a systematic HRBA could mean in practice at the regional level in a Swedish context, in terms of the added value it could bring to both the organization's work and, most importantly, to the region's residents.

A pilot project was formulated with three areas that would reflect the region's overall responsibilities concerning health care, culture, regional development, and public transport. Experiences from the pilot project would be continuously transferred to and exchanged with the region, with the goal of scaling up and mainstreaming the HRBA throughout the entire region. For the period of 2012–2015, the Angered Hospital, the Bohusläns Museum, and parts of the psychiatric clinic at Sahlgrenska University Hospital were selected to incorporate human rights into their regular work. Angered Hospital is a local hospital whose mission is to "serve the community with accessible, welcoming, quality health care based on the needs of the local residents." Bohusläns Museum is a regional museum based in Uddevalla. The reason for including the museum is that culture is a regional responsibility. Sahlgrenska University

Hospital houses psychiatric clinics, which the committee for human rights noted should be part of the pilot project. At Sahlgrenska, therefore, the pilot site was Psychosis Care Chain Northeast, which consists of Psychosis Care Northeast (an outpatient clinic with voluntary care) and Ward 242 (an inpatient clinic with both voluntary and compulsory care).[3] Psychosis Care Northeast is an open community clinic belonging to Sahlgrenska University Hospital, and it serves about 500 patients from northeast Gothenburg. This part of the city has more than 100,000 residents from more than 100 countries. It has a slightly younger population, with lower income, education, and employment levels than the rest of Gothenburg.[4]

The organization of psychiatry and the situation of mental health in Sweden

The Swedish health care system is based on decentralization and on the principle that health care must be accessible to all without discrimination. While Parliament and the government provide the framework for mental health policy through laws and budgets, the regions and municipalities carry out organizational and administrative health work.[5] VGR is thus responsible for providing care and treatment to Västra Götaland, as well as creating the conditions for good quality and equal care. Consequently, the right to the highest attainable standard of health for every human being is central to VGR's work.[6]

In recent decades, mental health has been a priority in Swedish policy development. This was part of the de-institutionalization process in the 1960s, and the development of the 1995 suicide prevention program, updated in 2006, through which comprehensive reforms were carried out to increase the quality of life for people with mental health conditions, and where local care was at the center. Mental health policy has been further strengthened in recent years, such as through a comprehensive national plan for 2012–2016.[7]

Current developments in mental health in Sweden indicate improvements in some areas and deterioration in others. De-institutionalization and increased access to health care have increased the quality of life for many people suffering from serious mental health conditions. At the same time, mental health conditions, especially mild and moderate, are increasing in certain groups, especially among young people and in the workplace.[8] The proportion of people affected by severe conditions, however, has remained relatively unchanged. Each year, some 1,500–2,000 people in Sweden are affected by some form of psychosis. The lifetime risk of developing schizophrenia is about 0.8%. About 30,000 people with schizophrenia in Sweden need community support and care.[9]

The importance of human rights in psychiatry

Psychiatry tests and challenges human rights in Sweden through, for example, the law on psychiatric compulsory care.[10] This legislation states that under certain circumstances, a person may be treated against their will—for example, if the responsible doctor considers that the person needs continuous psychiatric care, or if the doctor considers the person a risk to themselves or others. The law strictly regulates permissible coercive measures, such as forced medication, straps, and belts, yet situations arise in practice that present ethical dilemmas. This includes instances where the law permits and there is a need for coercive measures in order to protect a person's life and dignity, even though the measures go against the person's rights to self-determination, participation, and integrity. These coercive measures challenge human rights.

In their reviews of Sweden's compliance with human rights, the United Nations (UN) Committee on the Rights of Persons with Disabilities and Committee on the Rights of the Child have criticized Sweden for using too many coercive measures in psychiatry and for having insufficient documentation in this area. These treaty bodies have therefore called on Sweden to develop work and attitudes that reduce the number of coercive measures and increase transparency in psychiatry. As the two committees note, the regulations in relation to psychiatric care are in accordance with human rights standards, but the application violates these standards.[11] Therefore, it is of great importance to incorporate an HRBA into the daily work of psychiatry.

What does it mean to work according to a human rights-based approach?

In 2003, the United Nations Development Group (now the United Nations Sustainable Development Group) adopted a "Statement of Common Understanding on Human Rights-Based Approaches to Development Cooperation and Programming."[12] In it, UN agencies agreed on the principles that characterize an HRBA.

The starting point for the work in VGR was to test whether this model of an HRBA would work in a regional, decentralized context. The short answer to that question: yes, it works. The longer answer: yes, it works, but it is not necessarily easy to understand, and it needs a lot of guidance in order to be applicable in day-to-day Swedish health care. An initial challenge was simply about language. While the statement of common understanding is brief, it is jargon heavy, which brings translation challenges, not only into Swedish but also into simpler and clearer language that relates more directly to everyday health care. Thus, we developed two sets of guidelines based on the common understanding but adapted to Swedish and regional conditions. The two documents follow the same steps and principles, but one is targeted at rights holders and the other at duty bearers.[13] In each guideline, we have adopted four principles that should permeate the HRBA in our region: dignity and empowerment, equality and non-discrimination, participation and inclusion, and accountability and transparency. In addition, we follow five steps for an HRBA that is more adapted to the conditions of VGR and where all steps except the first are consistent with the steps commonly used in quality development work.[14] The four principles mentioned above permeate all five steps, which are as follows:

1. Obtain knowledge about human rights related to mission and duties. This knowledge includes human rights in general and with a specific focus on the organization's core mission (such as human rights within psychiatry, at a museum, or at a school).
2. Analyze. Which human rights are the organization's main responsibilities? Who are the rights holders? Do different groups of rights holders have different access to their rights?
3. Set goals and plan. Link goals clearly to human rights. Use the language of human rights and try to reach those persons who are most in need first.
4. Carry out. Ensure that decisions are made as close to those affected as possible. Develop cooperation placing the rights holder at the center.
5. Follow up. Evaluate goals, results, and process.

Human rights-based approach at Psychosis Care Chain Northeast

The HRBA pilot at Psychosis Care Chain Northeast began in the spring of 2013. Early in the process, three service users (that is, rights holders), as well as representatives of civil society, were invited to join the project. The working group of the pilot at the psychosis care chain consisted of users, health care professionals, managers, representatives from two user organizations, and civil servants from the department for human rights. The project was also followed by two independent researchers. The makeup of this group proved very important.

In line with the first step of the guidelines mentioned above, the working group began by acquiring basic knowledge of human rights, specifically in relation to the right to the highest attainable standard of physical and mental health and in relation to psychiatry. The group studied relevant UN conventions, general comments of UN treaty bodies, and treaty bodies' concluding observations on Sweden. Continuous human rights training has, in fact, been one of the main themes throughout the work. This open-ended learning process was our foundation and one of the key factors for the success of the pilot and the work that followed.

The group also analyzed who was a rights holder and a duty bearer in relation to psychiatric care, and what those concepts mean. We agreed that service users and their relatives were rights holders. This means that they have the right to the highest possible attainable standard of health and that this right is protected by the UN covenants relating to health. It also means that care providers were duty bearers, and therefore the provision of care is an obligation stemming from the UN covenants relating to health. We also concluded that staff are rights holders in relation to their employer. It is an employer's duty to make sure that staff are safe and properly trained to perform their own duties. These duties include awareness of the human rights they are set to protect and safeguard for service users, as well as the human rights of their colleagues.

Another analysis focused on the perceptions of rights holders and duty bearers relating to dilemmas and challenges around human rights, what is already being done well, and how good practices can be further strengthened. Several ethical themes emerged through our working group discussions, including the difficult balance between the perceived need for coercion versus the right to self-determination and autonomy.

Based on these discussions, the working group planned and prioritized the remainder of its work, including linking existing governance to human rights objectives.

At the end of the pilot project in 2015, a new working group continued this work in a project titled "To Come to One's Own Right: Empowerment-Based Psychiatry." This group consisted of three people with personal experiences of psychosis and psychiatry, and two people employed in psychiatry (a nurse and a physiotherapist). In this project, which operated from 2016 to 2019, the working group used different methods and further developed the HRBA within psychiatry, using experiences from the pilot project.

Relating the work to HRBA principles

Below we share some of our experiences in applying an HRBA to psychiatry. We structured our rights-based approach around the following principles:

- dignity and empowerment
- equality and non-discrimination
- participation and inclusion
- accountability and transparency

The principles are intertwined, and some of our examples fit easily into other principles as well. We also elaborate on what it takes for an HRBA to be sustainable in a large organization such as ours.

Dignity and empowerment

Reduced coercive measures. Ward 242 worked actively to reduce the use of coercive measures, particularly belting. The employees made a direct link between the UN's criticism to Sweden about the use of coercion and their daily work. For instance, they suggested using low-impact treatment to reduce coercive measures and suggested removing unnecessary rules and procedures that existed in the ward that did not fill any direct care-related function but instead were mostly intended to control patients. One such rule dictated that patients were not allowed to drink coffee after 5 p.m. and were not allowed more than one pillow in bed. These seemingly small interventions in a person's life had great effects on their autonomy and sense of dignity. These kinds of rules and procedures created frustration that easily escalated and led to actions perceived by staff as destructive to self or others, which in many cases ended up in different coercive measures. Staff also observed that coercion can violate the dignity of the patient and create new traumas.

The staff noted that the reduced use of coercion was important not only for patients but also for the promotion of a better working environment and health for staff. Reduced coercion resulted in the decreased use of sick leave and in decreased patient deviations that needed reporting. Staff also stated that the new way of working increased their desire to remain in their jobs. The HRBA was an important part of this achievement, which was also supported by previous and present efforts and initiatives, such as person-centered care and "better care, less coercion." Human rights became the framework for ideas and initiatives that had previously existed at the ward and became the compass for further developing these initiatives. During the pilot project, staff reduced the use of belts from about four times per month to four times per year. Ward staff described this reduction thus:

> *The use of coercion, and above all belts, has decreased throughout the house. It's very rare that the alarms become a belting. The mindset may have spread. (employee, Ward 242)*[15]

> *The pain threshold for me has increased. When I started here, if the patients screamed then we sent them into the room. Now they may yell at me, it doesn't matter. I would also have been pretty upset if I had been here against my will. I think that we also are humbler in general about coercion measures in the group. Even the doctors who make decisions. We will do it if we have to—but preferably not—and we try to work with the participation of the patients more. (employee, Ward 242)*[16]

Moreover, the rights holders felt that the decrease in coercion was important for their improved dignity and health. As one service user stated, "That's what human rights is about—to change things … it is important to realize that it is possible to work in this way and to achieve real effects or changes."[17]

The working group continuously discussed the need to find a balance between empowerment and self-determination, on the one hand, and coercion, on the other; they raised the dilemma that allowing some patients too much self-determination could be neglectful, which would also violate patients' human rights and the staff's duty to protect them.

Ward 242 employees also described how an HRBA empowered them to question coercive measures prescribed by doctors. In this case, the employees found that the coercion was not necessary and risked the dignity of the patient.

> *We are now better equipped to question coercion. We have more strength in us against the doctors. [The staff] have internalised the information [from the human rights education] … that it risks the dignity of the patient. We've had good discussions even before, but now the working group is getting tighter … We have it in the back of our minds, how to do [coercion] in a better and more dignified way. (employee, Ward 242)*[18]

Visibility and legitimacy. Another experience in the project was that the very link to human rights itself increased the status of work within the health care sector and thus improved duty bearers' responses to different situations or dilemmas that may arise during their day-to-day work. Connecting one's daily work to UN covenants made their work more valuable and increased the importance of executing it as well as possible. This improved care providers' relationship with right holders. It also created a sense of pride for duty bearers in tasks that would previously have been viewed as trivial or mundane. Speaking of psychiatry and health in relation to human rights promoted empowerment among both rights holders and duty bearers. They expressed the feeling that everyday dilemmas and areas discussed were not trivialities but important and real. Human rights thus conferred greater legitimacy to thoughts and ideas that had existed for a long time, thereby offering a concrete tool for development.

Rights holders' hopes centered around making sure that everyone's voice was heard, that full participation was achieved, and that all forms of demeaning treatment were avoided.

> *That one, even if one is psychotic, is allowed to participate in all meetings, even during an active psychosis. That one is fully informed about what is happening is important for one's dignity and health. (service user, Ward 242)*[19]

Language. Human rights also highlighted the importance of language and of the words we choose. With the aim of improving their self-esteem and empowerment, right holders identified terms that they would prefer to be called, such as a "self-specialist" and "experience expert," rather than "patient." These names terms helped show that rights holders' personal experiences of mental illness and treatment are a valuable source of knowledge—just as important as health care professionals' knowledge and experiences. When an HRBA is employed, it becomes clear that a meeting between a health professional and a patient is a meeting between two experts whose knowledge is equally valued.

Another important aspect that emerged was the fact that rights holders and duty bearers, including interpreters who were used on a regular basis, often had different cultural and linguistic backgrounds. The working group discovered that speakers of different languages sometimes had different words for and views on mental health and illness. In some languages, the words for mental health issues all have a negative or even offensive meaning, which might severely affect the dialogue if not properly considered. And sometimes the needed words simply do not exist. Intercultural dialogue was therefore central to overcoming obstacles and achieving more inclusive health care provision.

Equality and non-discrimination

Power dynamics. In the joint learning of human rights in the working group, the discussions touched on power norms and hierarchies between patients and staff, among patients, and among different professions. We discussed the importance of reviewing one's own position of power, including the privileges and power that come with different positions. Techniques of ruling, counterstrategies, and affirming techniques became important tools. Both rights holders and duty bearers testified that these tools and the connection to human rights empowered them and thus also their own health.

Acquiring knowledge on human rights and learning that such rights are acknowledged by the UN gave the rights holders the strength to question certain decisions that had been made and to be more motivated to influence their own situation. For example, after participating in "to come to one's own right picnics" (see below) and lectures on human rights, one rights holder felt so empowered that she decided to demand a psychologist whom she had been previously denied and had not felt powerful enough to claim. The same could be seen for duty bearers, who stated that human rights gave them strength to be more active at staff meetings and challenge existing hierarchies at the workplace.

"Our lives are the story of ourselves." A narrative approach is an important part of approaching human rights-based work and a powerful tool in spreading human rights. It puts the rights holder and their story at the center, and it acknowledges and highlights the value of one's own experience. "To come to one's own right" conversation groups created safe rooms where participants felt free to share their stories. When a person's story is told and listened to in a safe room, a seed is planted that can grow stronger on the path to recovery. By allowing a person to tell and transform their story, the image can also become more cohesive for the person herself, allowing a better opportunity for healing.

The rights holders who were part of the working group used their personal experiences, histories, and stories in meetings with staff, as well as in meetings with other rights holders (such as in the conversation groups).[20] These stories created a great impact on duty bearers, for seeing and understanding another human being's perspective is a strong experience. This increased the legitimacy of the work within psychiatric care and the staff's sense of belonging. At Ward 242, initiatives were taken to capture rights holders' personal stories; for example, rights holders who had previously been hospitalized were offered the opportunity to come back and talk about how they experienced care and any coercive measures. Individuals who had the opportunity to make such a return visit were very pleased and stated that it had helped them in their recovery. This also provided a valuable learning opportunity for duty bearers.

Compensating for obstacles to human rights enjoyment. The pilot project understood that access to activities for rights holders was severely reduced in the summer due to the holidays. In order to fill this gap, the project started arranging human rights picnics. To reach as many people as possible, the group worked to identify obstacles and help people overcome them. For example, one of the ideas was to make the city's green areas accessible to rights holders. Here, the working group identified and compensated for the following barriers:

- Financial barriers: Many rights holders lack financial resources due to their ill health. Parks are usually free to visit, but public transportation is not. Therefore, the project offered to pay for rights holders' public transportation. Participation in the picnic and refreshments were free of charge.
- Cognitive and social barriers: Many rights holders felt insecure about finding their way or taking public transportation by themselves. Therefore, participants were invited to meet up and travel together to the places they usually visited.
- Various physical obstacles: Some rights holders found it difficult to walk long distances, others had a hard time sitting on blankets on the ground, and some needed to know that there was a toilet nearby. The locations were chosen with great consideration so that participants would not have to walk too far, so that there would be access to folding chairs and toilets, and so on.

Participation and inclusion

A focus on preparation. All decision-making in the work group was taken with the rights holder at the center and with the ambition to achieve as equal conditions as possible between rights holders and duty bearers. To do this, we used a checklist called "The aim of the meeting" that was based on the human rights principles mentioned above. In preparation for each meeting, we considered how the meeting would fulfill the principles of an HRBA, wrote it down on the meeting agenda, and distributed it prior to the meeting. Each meeting ended with a joint evaluation to see whether and how the principles were met, what worked well, and what needed to be adjusted before the next meeting.

Continuous improvement. During the project period, the working group grew as more participants were included. After a while, it became clear that this growth had become an obstacle to participation for some of the rights holders. It was difficult for them to be heard and to raise questions in such a large group. Therefore, a small working group was formed in which questions were processed before meetings with the larger group. The small working group consisted of the three rights holders and two employees. This is an example of recognizing that nothing is perfect but that it is possible to constantly thrive to compensate shortcomings as they arise.

Accountability and transparency

Administrative aspects of the interdependence of rights. The project used the AAAQ framework (availability, accessibility, acceptability, and quality) to assess whether duty bearers were living up to their obligations under the right to health.[21] In the discussions, the right to housing arose beside the right to health. It is a problem that some patients remain in the inpatient ward even after finishing their treatment, simply because they do not have a home that meets their needs. The working group therefore conducted an analysis on the right to health and housing. It became clear that these two rights are strongly linked to each other. One conclusion drawn was that cooperation between VGR (responsible for health) and the municipalities (responsible for housing) is needed to fulfil both of these rights.[22] This was raised in the health care cooperation body, where the regional and municipality levels meet, so that the fulfillment of these human rights could be effectively addressed.

Sustainability: Creation of user council. Another result of the HRBA was that regular meetings were initiated for rights holders in Psychosis Care Chain Northeast. These meetings were later transformed into a user council. The user council now has its own office connected to the waiting room. The office is usually staffed with someone from the user council so that right holders can ask questions, make comments, or perhaps become involved in the user council.

Policy impact. In 2017, VGR systematized some of the experiences from our pilot project into its strategic action plan for human rights, entitled *For Every Human Being*. The plan describes and substantiates the work of realizing human rights within VGR during 2017–2020. The action plan, which contains 12 goals with their respective measures and indicators, was developed in collaboration with businesses and civil society in Västra Götaland.[23] The 10th goal of the action plan contains a "zero vision" for the use of coercive measures, meaning that it seeks their complete abolishment. This goal was a direct result of the project, and the working group was involved in its formulation and content. The goal also specifically states that patients subject to coercive measures should be offered a structured follow-up talk after the application of the measure in order to prevent new trauma.

Striving for transparency. A direct effect of talking about duty bearers' obligation to monitor rights holders' human rights from a broad perspective could be seen during the time of elections to the European Parliament in 2014. The employees at the inpatient ward involved in the project secured the right to vote in general elections for the patients at the ward, a human right that in practice is often limited when a person entitled to vote is subjected to compulsory care. The patients at the ward were given the opportunity to vote inside the ward, which ensured their right to participation in democratic elections.

Working toward transparency as far as possible and opening up a fairly closed business as psychiatry was also considered a success factor. The unusual interaction and equal participation of both rights holders and civil servants, and allowing them to pose their sometimes naïve questions, also improved transparency and demonstrated a willingness to embrace shifts in perspectives.

Conclusion: Lessons learned from the project

At the end of the project, we carried out interviews with participants from the pilot, which allowed us to extract a number of key lessons:

1. **The importance of broad representation.** Broad representation from representatives of rights holders and duty bearers is needed to achieve legitimacy. Otherwise, there is a risk that only one unit, group of staff, or organization will become involved in the work, which will not be integrated throughout the different strategic interests and levels of organization needed to ensure sustainability. It is also difficult for one single rights holder to represent the entire group and gain an empowered voice.
2. **Meaningful involvement of rights holders.** It is important for rights holders to become involved at the start of the process and all the way forward. This allows the stories and experiences of rights holders to be placed at the heart of the work, and it helps ensure that all participants work together on equal terms. We met several challenges related to, for example, the real participation of rights holders and the reactions they received when trying to change hierarchies in health care. These prompted us to find new ways of looking at things, which allowed us to improve our approach.
3. **Time for reflection.** One lesson learned is that it is possible to work with human rights in practice if there is mutual learning. There is great value in learning during the journey, and it is important to understand that changes take time and must be *allowed* to take time in order to be sustainable. Time for reflection and education was the single most important investment in this project. In each meeting, time should be taken to agree on the next step and who is responsible for it.
4. **Active use of human rights principles.** Using the principles actively helps ensure that everyone is allowed to speak and take part in meetings on equal terms, and it supports the right of everyone to express themselves on their own terms. The document "The aim of the meeting" became, as stated above, an important tool for us to keep the principles in mind during meetings. Since we made it clear that the principles of human rights would permeate our work, each one of us felt supported in raising issues regarding equality, participation, and influence.
5. **Linking human rights to what is already being done.** Human rights can sometimes feel abstract and large. It is thus helpful to start with something specific within an organization or sector as

a clear, relatable example and as an inspiration for change. An HRBA is an ongoing endeavor.

6. **Committed senior management, enthusiasts, and strategic partnerships.** The success of this pilot was in many ways made possible by the commitment and engagement of enthusiasts and strategic individuals within the hospital's hierarchy. The commitment of senior management was a decisive factor for success. To take one example, one of the unit managers from Psychosis Care Chain Northeast recently moved to head another psychiatric ward, where she introduced the HRBA. As a result, the use of coercion has been reduced by 70%, and staff sick leave by 30%, in this new ward. This shows that an HRBA promotes empowerment and health among both rights holders and duty bearers and that the experience is transferable to departments that were not part of the pilot.[24] We also learned that it is important to develop strong collaborations with strategic partners who can help bring about change based on an HRBA. In this regard, the project collaborated with NSPHiG (a non-governmental users' organization), the Social Insurance Agency, the Employment Service, and the City of Gothenburg.
7. **Starting small and taking small steps.** Expecting too much too soon can paralyze the working process. Human rights can become overwhelming, with the result that nothing ends up being done. We realized that even if hierarchies cannot be—and perhaps should not be—eradicated within the health field, an inclusive attitude that avoids focusing on professional or disciplinary prestige, and a willingness to not always be right, is important in order to succeed with an HRBA. By striving to achieve trust among members of the group, we dared to try new ways of working, even if they were not always successful. It is also important to focus on the human rights that our organization is responsible for and thus narrow the workload down a bit.
8. **Human rights as a guide for prioritization.** The staff at Ward 242 had started an initiative prior to the pilot project to reduce coercive measures. They found additional support and guidance in human rights from the pilot project to continue processing these changes. Human rights helped provide an important answer to the question of why, for example, coercive measures should be reduced. Many of the processes the project started and scaled up might have been possible without the project. But we have good reason to believe that the pilot helped roll out these processes more quickly and more sustainably. With the help of human rights, we were able to see new areas that needed to be changed or improved. The fact that we focused on the human being as rights holder meant that we were able to confront dilemmas and challenges that we might otherwise have missed.
9. **Continuous evaluation and learning.** Our constant evaluation of the extent to which activities and processes were fulfilling HRBA principles meant that we got a good idea of what worked and what did not. It also allowed us to adjust fast. Central to this ability was the fact that everyone who participated in the work was also included in follow-up efforts. Mistakes were seen as opportunities to learn rather than something to be ashamed of.

As we have described, this project showed that it is fully possible to apply an HRBA to psychiatric care and that such an approach has great benefits for individuals and organizations alike. It can often be a challenge to create change on a large scale and to disseminate the effects across an entire organization. Many times, it is the small changes that effect change through a butterfly effect. Therefore, it is imperative to achieve a constructive and empowering process of mutual learning that occurs continuously and not only at the end of a project.

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HHR
Health and Human Rights Journal

Reconceptualizing Psychosis: The Hearing Voices Movement and Social Approaches to Health

RORY NEIRIN HIGGS

Abstract

The Hearing Voices Movement is an international grassroots movement that aims to shift public and professional attitudes toward experiences—such as hearing voices and seeing visions—that are generally associated with psychosis. The Hearing Voices Movement identifies these experiences as having personal, relational, and cultural significance. Incorporating this perspective into mental health practice and policy has the potential to foster greater understanding and respect for consumers/survivors diagnosed with psychosis while opening up valuable avenues for future research. However, it is important that a focus on individual experiences of adversity not supersede attention to larger issues of social and economic injustice. Access to appropriate mental health care is a human right; this article will argue that the right to health additionally extends beyond individual-level interventions.

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Competing interests: None declared.

Introduction

The diverse phenomena gathered under the diagnostic umbrella of "psychosis" are often perceived as uniquely biological. In the public imagination, depression and anxiety are intuitive responses to adversity; indeed, it is commonplace to describe a situation as "depressing" or "anxiety provoking." Schizophrenia, on the other hand, connotes a kind of alien intrusion, wherein a person's humanity is first colonized and then inevitably eroded.[1] In this sense, understanding experiences like hearing voices as part of a spectrum of human reactions to our environment remains a frontier within the mental health field. Pioneering this understanding is the Hearing Voices Movement (HVM), an international grassroots project that challenges the traditional wisdom that these experiences are best treated as a biogenetic disease state.[2]

In contrast to the ravenous but impersonal pathology implied by a diagnosis of psychotic disorder, the HVM searches for the underlying *meaning* of experiences such as hearing voices or seeing visions.[3] This deliberately open-ended directive encompasses a range of beliefs; however, most scholarly work to emerge from the HVM invokes an ecological framework that situates voices in the context of a person's culture, life history, past and current relationships, socioeconomic status, and so on.[4] Stressors such as poverty, loss, and abuse are cited as potential loci around which voices might take root, and voices are assumed to be personally (and perhaps socially) significant experiences that are richly informed by and embedded in the external world, and can thus provide a valuable window of insight.[5] The HVM centers the knowledge of "experts by experience," those with lived experience of hearing voices, both as an emancipatory project and in recognition of the scientific value of qualitative and narrative explorations of voice hearing.[6]

In this article, I will draw on the principles of the HVM to argue for a rights-based, trauma-informed, and socially grounded approach to the diverse experiences constituting psychosis and, more generally, for a reexamination of psychosis as a diagnostic construct. This approach has practical implications for mental health service provision. Access to safe, respectful, and effective care is a human right; unfortunately, the care available to people diagnosed with psychotic disorder may, at times, be none of the above.[7] At present, commonplace psychiatric interventions may be experienced as dehumanizing and (re)traumatizing.[8] The use of force and coercion in treatment settings appears to be especially harmful.[9] Additionally, questions remain about whether current "best practice" guidelines for the use of antipsychotics are beneficial or actively detrimental in the long term.[10] Outcomes for people diagnosed with schizophrenia have not improved in the last 50 years, despite medical advances, while the longevity gap between those diagnosed and the general population continues to widen.[11] Clearly, more appropriate and humane models of care for this population are warranted; research emergent from the HVM provides a roadmap.

The right to health, however, extends beyond the individual right to care. Social factors are closely intertwined with experiences of health and illness, and reducing inequality and exposure to violence on a larger scale is a critical aspect of the right to health.[12] The role of power and disempowerment in the lives of those diagnosed with psychotic disorder, I will argue, must remain a focus in building on the work of the HVM. Policies and therapies that fail to address ongoing structural and economic violence will inevitably replicate the same harmful logic: that mental distress is a matter of individual dysfunction, to be dealt with through (sometimes unwanted) individual-level interventions, rather than an understandable reaction to frightening, oppressive, and demoralizing circumstances. A non-pathologizing approach that remains attentive to larger issues of injustice is called for.

A note on terminology

In this article, I follow the terminological conventions of the literature I cite, while remaining agnostic toward the preconceptions underlying their usage. I approach diagnoses as *constructs*, with the understanding that, for example, research concerning "schizophrenia" may in fact capture information about a wide range of phenomena cohered by cultural rather than intrinsic factors. It is worth emphasizing that while individual perspectives vary, many voice hearers reject a medical framing of their experiences. Thus, where referencing literature concerning self-identified voice hearers, I avoid clinical terminology.

I also employ the terms "psychiatrized," "Mad," "consumer/survivor," and "diagnosed with" to refer to, respectively, people whose experiences are labeled as psychiatrically disordered; people who self-identify as Mad and scholarship emerging from Mad Studies; people who have direct experience with the psychiatric system; and people who have received a particular psychiatric diagnosis. I consider these terms overlapping, but not interchangeable, while recognizing their complex history.[13]

Background

The origin of the HVM is attributed to conversations between Dutch voice hearer Patsy Hague and her psychiatrist, Marius Romme, which led to Romme and Hague appearing on television together to discuss Hague's voices and her theories about their significance; viewers who heard voices themselves were encouraged to call a telephone line.[14] The response was tremendous, with 700 individuals calling in response to the program, 450 of whom heard voices.[15] An open-ended questionnaire was distributed to gather firsthand accounts of how voice hearers coped with their voices, and, subsequently, a congress was organized in Utrecht, where 360 voice hearers gathered to share their experiences.[16] Following this initial flurry of interest, Romme and his partner Sandra Escher went on to spearhead further research gathering voice hearer perspectives, particularly on the origins of voices, relationships of voice hearers to their voices, and strategies for managing distressing voices. Notably, it became apparent that many people who heard voices had never been in contact with psychiatric services, nor did they feel the need to be.[17] Many voice hearers were also able to link their experiences to a larger social or traumatic context.[18]

Romme and Escher argued for the importance of an "emancipatory" approach to hearing voices, arguing for the establishment of groups where voice hearers could exchange ideas and experiences.[19] Thus, the HVN was born, first as a loose, grassroots collection of self-help groups, and later in the form of national chapters, gathered under the umbrella of the international organization Intervoice.[20] Simon McCarthy-Jones identifies the HVM as emerging from postmodern and postcolonial thought, wherein individuals are moved to take ownership of their own narratives and identities, and the present-day HVM remains explicitly concerned with the right of voice hearers to self-determination.[21] Blackman interprets the HVM as promoting the recognition and integration of parts of self, in contrast to the denial that characterizes biomedical approaches.[22] For its part, Intervoice describes the movement's core values as follows:

> *[H]earing voices, seeing visions and related phenomena are meaningful experiences that can be understood in many ways; hearing voices is not, in itself, an indication of illness—but difficulties coping with voices can cause great distress; when people are overwhelmed by their experiences, support offered should be based on respect, empathy, informed choice and an understanding of the personal meaning voices have in someone's life.*[23]

A number of methods of working with voices have emerged from the HVM.[24] It remains an essentially pluralistic movement, stepping outside of the bounds of pathology and meandering across disciplinary lines, exposing the entanglement and co-construction of social and biological realities in the process.[25] Consequently, I will employ an interdisciplinary approach in considering how the HVM can inform a reconceptualization of psychosis, by situating it in richly enmeshed biological, social, cultural, and political contexts.

Support for a social etiology of psychosis

Given that the HVM engages heavily with the social context of voices for the individuals who hear them, its proliferation has sparked clinical interest in cultural and relational models of psychosis. The peer-reviewed journal *Psychosis: Psychological, Social and Integrative Approaches* was founded in 2009; in 2014, the British Psychological Society published *Understanding Psychosis and Schizophrenia*, a report outlining psychosis as shaped by and responsive to social factors.[26] The HVM is beginning to be cited as an influence in disciplines as ostensibly incompatible as computational psychiatry.[27] Meanwhile, a growing body of research has highlighted the need for clinicians, researchers, and policy makers alike to attend to the role of environment in the origin of psychosis.[28]

The cardinal significance of heredity in schizophrenia is now disputed.[29] However, psychiatric genomics research continues to be communicated in a misleading way to the public, contributing to the negative impact of genetic determinism on public health policy, resource allocation, and experiences of stigma.[30] It is therefore critical that what John Read et al. refer to as "a genuinely integrated bio-psycho-social model" of psychosis be foregrounded.[31] For instance, the link between poverty and schizophrenia is long established and continues to emerge as a risk factor in recent large-scale population studies.[32] Countering the argument that schizophrenia merely predisposes individuals to experience hardship later in life, parental socioeconomic status and socioeconomic status at birth both independently predict later diagnosis.[33] Others note that low socioeconomic status predicts a diagnosis of any mental illness much more than a diagnosis of mental illness predicts downward class mobility.[34] Unsurprisingly, low socioeconomic status of origin also appears to negatively affect prognosis.[35]

Poverty is just one facet of the panoply of social stressors now recognized as central to psychosis; other culprits include isolation, inequality, racial discrimination, food insecurity, and migrant status.[36] Recent reviews and meta-analyses likewise find a robust connection between childhood trauma, particularly abuse, and later psychosis.[37] A systematic review and meta-analysis by Thomas Bailey et al. further determined that childhood trauma is associated with the severity of psychotic symptoms, while a meta-analysis by Antonella Trotta et al. found an impact on their persistence.[38] Addressing concerns about confounding variables, a recent birth cohort study confirmed that substantiated reports of child maltreatment predicted a later outcome of psychosis, including when substance use and childhood behavioral problems were controlled for.[39] The only psychiatric outcome more strongly associated with traumatic life events, in fact, appears to be post-traumatic stress disorder (PTSD).[40] Interestingly, a diagnosis of PTSD itself predicts the later development of psychosis.[41]

Mechanisms implicated in the relationship between adversity and psychosis are varied and include heightened stress reactivity, negative belief systems about the self and the world, a tendency to perceive events as externally controlled, and the learned anticipation of threat.[42] The deleterious neurobiological consequences of childhood trauma are long established and may likewise play an important role in later psychosis.[43] Other authors suggest that psychotic symptoms may represent traumatic intrusions, akin to flashbacks and other "re-experiencing" symptoms in PTSD, or result from the misattribution of trauma-related affects and memories.[44] In light of the latter, alongside the observation that the so-called Schneiderian symptoms characteristic of schizophrenia are also—and perhaps *more*—prevalent in highly dissociative individuals, dissociation has also been proposed to mediate the relationship between trauma and later psychosis.[45]

This latter approach has found popularity within the HVM. Eleanor Longden and Simon McCarthy-Jones, both prominently associated with the movement, argue that the distinction between auditory verbal hallucinations occurring in PTSD (attributed to dissociative mechanisms) and those occurring in schizophrenia is flimsy at best.[46] This perspective is bolstered by subsequent reviews finding evidence of a connection between dissociation and voice hearing across a range of diagnoses.[47] Further, there is some evidence that dissociation could mediate the relationship not only between trauma and later hallucinations but also between trauma and later delusions.[48] Integrative theories that draw together dissociation and psychosis as post-traumatic attempts to manage overwhelming or confusing memories, sensations, and affects have therefore achieved some prominence, as I have elaborated on elsewhere.[49]

Participants in "hearing voices groups" are encouraged to engage their voices (among other techniques—there is, by definition, no singular prescribed method) as disowned parts of the self that contain difficult emotions, embody core beliefs about the self and the world, or represent the phantoms of past survival strategies.[50] Drawing in part on this legacy, psychotherapy for psychosis has gained some traction in the clinical world.[51] Trauma-focused interventions specifically have shown tentative but promising evidence of their effectiveness.[52] Indeed, the shift toward trauma-informed care is now recognized as a salient issue within the mental health profession generally, summarized as a "move from thinking 'What is wrong with you?' to considering 'What happened to you?'"[53]

Complicating the medical model

In light of the abundance of research linking adversity and psychosis, the difficulty in differentiating between psychotic and post-traumatic or dissociative diagnoses has become a concern.[54] Several authors have proposed a model of overlapping, and perhaps interrelated, continua of experiences.[55] Read et al. call for a "traumagenic neurodevelopmental model" of schizophrenia, while Błażej Misiak et al. advocate for what they call a "unified theory of childhood trauma and psychosis."[56] Others go further, underscoring the notorious unreliability and heterogeneity of psychiatric diagnoses generally.[57] Dimensional models, which avoid rigid diagnostic categories and make blurrier distinctions between "sickness" and "health," have resulted in the concept of an "extended psychosis phenotype" or "psychosis continuum."[58] For its part, the HVM takes a depathologizing approach to those experiences gathered under the term "psychosis," arguing that phenomena such as voices and visions fall on the spectrum of human diversity and need not be understood through a disease lens.[59] To many of the movement's proponents, applying the label of psychiatric disorder is seen as disempowering and instilling a sense of fear and hopelessness.[60]

Cultural psychiatry offers a helpful lens for understanding the complexity of drawing these lines. Psychiatric diagnoses are necessarily culturally bound, based on socially constructed ideas of what is "pathological" or otherwise aberrant.[61] For example, Ethan Watters documents the exportation of Western conceptions of mental (ill) health over the past century, while Suman Fernando criticizes the idea that a "global" approach to mental health is possible, given the vast range of valuable *local* perspectives on what mental distress looks like, how best to respond to it, and whether it can be understood through a framework of sickness versus health.[62] Cultural neuroscience, meanwhile, holds that culture is embedded in and enacted by our cognitive processes at every level, emphasizing that how we conceive of distress is shaped by the metaphors and idioms we are given to communicate it.[63] In the West, psychiatry has equipped us with an arsenal of "idioms of distress" that relies on the language of neurological disease states; however, it is hardly the only cultural vocabulary that exists to convey distress.[64]

Medical anthropologists are equally careful to point out that modern biomedicine's conceptions of a "normal" body (and by extension, a "normal" mind) are historically and culturally specific, and, as such, deeply political.[65] Others note the risk of imposing "medical imperialism."[66] This is particularly relevant in the field of mental health, which by its nature concerns highly subjective experiences.[67] Indeed, critics suggest that globalization has presented the two-pronged problem of a simultaneous exacerbation of factors underlying mental distress and subjugation of indigenous systems of knowledge for interpreting and managing it.[68] While a biopsychosocial approach to psychosis informed by the HVM's attention to trauma and adversity as root causes is undoubtedly a step toward a more nuanced understanding of mental distress, it remains critical to resist a new dogma that retains its inflexible, disease-based structure.

Medicalization as obscuring social realities

A grisly tradition of "biologizing social facts" exists within psychiatry.[69] Concepts such as degeneration and drapetomania have historically justified racist and eugenicist political projects; the pathologization of responses by black Americans to oppression in civil rights-era America is theorized to have shaped the modern diagnosis of schizophrenia.[70] This attribution of social problems to genetic defects has a clear utility for ideologies that attempt to demonstrate the biological inferiority of particular demographics. However, the advancement of neoliberal values and policies likewise favors naturalizing inequality through the lens of biology, locating the suffering caused by *social* problems within *individual* bodies, which are perceived as self-contained and (ideally) fully independent.[71]

An environmental etiology of psychosis may dispel the specter of biological determinism, but the issue of *medicalizing* problems which may be better understood as social remains. Even a post-traumatic medical model risks eclipsing structural inequality and violence by focusing on how they manifest at the individual level, a process of contextual stripping-away that Howard Davis calls the "depoliticization of trauma."[72] This narrow view of trauma banishes public concerns to the private domain, tidily dislocating them from shared reality and ascribing the suffering of traumatized people to their own internal inability to cope.[73] As cautioned by the survivor-led activist collective Recovery in the Bin, as long as the onus lies on the individual to "recover" from the harms inflicted by systems of power far beyond their control, the workings of the latter remain obscured, and the material needs of the former go unaddressed.[74] Heidi Rimke refers to this sleight of hand as "psychocentricity," explaining that

> *[p]sychocentricity dovetails seamlessly with the values of neoliberalism by giving the appearance that "normalcy" is desirable, concrete and attainable. From this perspective, personal success is marketed as readily accessible to everyone and anyone.*[75]

It remains contentious, too, whether it is appropriate to treat post-traumatic reactions as dysfunctional. Bonnie Burstow argues that the symptoms of PTSD are often protective responses to genuine threat.[76] Indeed, some of the aforementioned neurocognitive changes in maltreated children may be adaptations to living in a dangerous environment—adaptations that, in the short term, are beneficial.[77] For China Mills, despair and pain are "normal" reactions to unbearable circumstances, and reconfiguring these expected and necessary feelings as symptomatic of illness contributes to the perception of impoverished people and communities as "deficient."[78] This sense of deficiency pervades research that attempts to link PTSD to an individual lack of resilience or personal failure to use effective coping strategies.[79]

Lastly, it is important to bear in mind that attempts to divest individuals of trauma responses, including those that take on a psychotic guise, are not always welcome, warranted, or politically neutral. Kathryn Becker-Blease cautions clinicians to "reject those trauma-informed practices that leave individuals well-adjusted but inactive in the face of oppression and trauma" and warns that even the most ostensibly progressive of interventions can become "just a different way of labeling and managing" individuals.[80] Some disability scholars further emphasize the role of "madness as testimony": as Clementine Morrigan explains, so-called symptoms occurring in the wake of trauma may in fact be "acts of resistance to violence," "a means of sounding an alarm that something is very wrong."[81] In my own words writing for the BC Hearing Voices Network:

> *the personal mythology of delusion offers a sanctuary: a domain in which we are free to speak about our injuries without the intrusion of outside perspectives. Society cannot or will not follow us into this magical-metaphoric thicket. Here, we are free to imagine and reimagine our experiences in ways that would otherwise be forbidden to us.*[82]

Broadening the focus from "what happened" to "what is still happening"

Consumer/survivor initiatives have historically been subsumed and repurposed in less radical ways by the psychiatric institution.[83] In recent years, for example, attention has been drawn to the appropriation of the "recovery narrative," which has divorced it from its activist origins.[84] Jasna Russo and Peter Beresford describe the balancing act that Mad scholars must perform "between exclusion and colonization," wherein all too often our voices are wrested away from us in service of institutions from which we are barred.[85] In light of this, it is important that insights derived from the HVM do not inadvertently reify exactly the structures and policies they are meant to critique. That is, a social understanding of psychosis must foreground society, and not sick or damaged individuals. Asking "what happened to you?" is an excellent start—but asking "what is still happening to you?" may be even more crucial.

After all, adversity has a cascading effect. Research consistently identifies a subpopulation of people who experience very high levels of trauma throughout the course of their lives; usually, these people are born into and live in poverty.[86] It stands to reason that often, at the point of engagement with mental health services, these same adversities will be ongoing. Indeed, Scott Stumbo et al. found that while a higher number of adverse childhood experiences predicted worse outcomes for people diagnosed with serious mental illness, it did so via the likelihood of having faced *recent* traumatic events.[87] Similarly, a systemic review and meta-analysis found extremely high rates of recent sexual and domestic violence among people diagnosed with serious mental illness—a sixfold increase from rates in the general population.[88] This kind of active victimization is routinely under-detected and overlooked in mental health settings.[89]

It is critical that discussions about the causes and significance of psychosis borrowing from the HVM not overlook the role of *present-day* economic injustice, gendered and racialized violence, and so on. As the concept of "continuous traumatic stress" put forward by Gillian Eagle and Debra Kaminer reminds us, "for many citizens of the world today, trauma exposure is both current and to be realistically anticipated in the future, rather than being past or post."[90] In these cases, conventional trauma therapies may not be appropriate, nor can ongoing distress justly be considered pathological.[91] Regardless of geographical location or political climate, it is fair to say that many traumatized people who go on to be diagnosed as psychotic are, in fact, in real danger, and not merely troubled by a shadow of the past; research investigating pathways to and through homelessness, for example, commonly reveals histories of compounding adversity precipitated by poverty and abuse early in life and later culminating in a cycle of psychiatric hospitalizations, housing insecurity, and continued victimization.[92] While a trauma-informed approach to mental distress in this population is needed, it must ultimately also be a *political* approach that concerns itself with changing the present in addition to charting the past.[93]

Toward a social approach to mental health

The HVM has fueled a move toward new ways for voice hearers to reflect on and engage with their experiences, with promising implications for the provision of services for this demographic. However, the right to health is not limited to clinical settings, nor are services traditionally perceived as medical or psychotherapeutic the only means of ensuring mental well-being. Material safety and practical support with present day concerns, such as housing and food security, must remain a core focus for mental health professionals and policy makers. Asking that disenfranchised people and communities reinterpret their distress as the fallout of traumatic events is insufficient when the traumatic conditions are ongoing. Additionally, it is important to consider the appropriateness of medical approaches to a problem that relates not only to health care but to human rights issues and abuses in a variety of domains.

Recent insights in the fields of psychology, neuroscience, sociology, and anthropology (among others) have the exciting potential to coalesce with the HVM to establish a novel paradigm for understanding voice hearing, and perhaps mental health generally. Nevertheless, it is important to attend to the political scaffolding that undergirds how these developments are interpreted, communicated, and actualized in policy and future research, as the nascent projects of "critical neuroscience" and "postpsychiatry" have attempted to foreground.[94] Further, a focus on the autonomy and self-definition of those accessing mental health services will be essential to avoid replicating existing patterns of disempowerment, which appear to be compounded for survivors of previous violence.[95] Efforts to integrate this respect for individual meaning-making and self-directed treatment with awareness of social context have already resulted in ambitious new models of mental distress, such as the British Psychological Society's Power Threat Meaning Framework.[96] Alongside the 2014 *Understanding Psychosis and Schizophrenia* report, the Power Threat Meaning Framework calls for a socially informed, rights-based approach, outlining necessary changes to clinical practices and mental health legislation, as well as to policies concerning economic, racial, and gender injustice. Centering consumer/survivor-led activism and organizing will be key to sustaining this transformation within and outside academia.[97] Moving forward, collaboration between a broad range of experts by experience and education can ensure that insights emergent from the HVM continue to guide understandings of health as a fundamentally social, cultural, and political process.

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HHR Health and Human Rights Journal

PERSPECTIVE

Traditional Healing Practices Involving Psychoactive Plants and the Global Mental Health Agenda: Opportunities, Pitfalls, and Challenges in the "Right to Science" Framework

JOSÉ CARLOS BOUSO AND CONSTANZA SÁNCHEZ-AVILÉS

Introduction: Global mental health and traditional medicines

The global mental health (GMH) movement aims to establish a world in which every human can access mental health services based on two fundamental principles: respect for human rights and evidence-based treatments. Despite being criticized, especially for its neocolonial tendency to impose psychiatric systems that defy local epistemologies, this movement is garnering increasing attention.[1]

The anti-psychiatry movement led to the first mental health reforms based on human rights, which notably influenced World Health Organization (WHO) policies and the development of ethnopsychiatry. However, despite the vast anthropological literature supporting the importance of traditional health systems for the well-being of local communities, the recognition of traditional medicines and healers is highly marginalized within the GMH agenda.

For example, WHO's Mental Health Action Plan 2013–2020 acknowledges the value of traditional medical systems only subsidiarily, qualifying them as "informal": "Greater collaboration with 'informal' mental health care providers, including families, as well as religious leaders, faith healers, traditional healers, school teachers, police officers and local nongovernmental organizations, is also needed."[2] Similarly, the Lancet Commission on Global Mental Health and Sustainable Development's report mentions traditional healing systems only when stating that "[g]lobal mental health practitioners have shown that integrating understanding of local explanatory models of illness experiences is possible while respecting the complementary role of Western biomedical and local traditional approaches to treatment."[3]

Paradoxically, in most parts of the Global South, traditional healers are more numerous than mental health workers, and they constitute the main health resource that local populations use and believe in. For

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Competing interests: None declared.

example, in Ghana, with a population of 27 million, there are only 18 psychiatrists, 19 psychologists, 72 community mental health officers, and 1,068 mental health nurses. In contrast, around 45,000 traditional healers are reportedly operating in this country.[4] However, there is a scarcity of institutional documents and international GMH proposals that consider investing in traditional medical practices and research.

In today's globalized world, a large diversity of people from a broad range of genetic and cultural backgrounds coexists and travels throughout various territories and countries. Traditional healers conduct ceremonies in Western countries, and Westerners travel into indigenous territories in search of traditional treatments. Thus, different medical systems, backed by their respective epistemologies, coexist. If traditional practices and epistemologies are not properly addressed within the GMH movement and WHO's Mental Health Action Plans, this may pose a challenge to health-related human rights. Among these rights, it is worth noting that everyone has the right to enjoy the highest attainable standard of physical and mental health and the right to enjoy the benefits of scientific progress and its applications.[5] In specific cases where psychoactive plants containing internationally scheduled substances are used for mental health purposes, as is the case with certain South American plants (containing what Western pharmacology considers hallucinogenic compounds), people are vulnerable to possible criminal prosecution. In the case of indigenous peoples for whom those plants are part of their traditional medical systems, the right to access their traditional medicines and to maintain their health practices may also be violated.[6] Thus, this complex scenario produced by contemporary globalization offers some challenges to reflect upon.

Traditional healing practices involving psychoactive plants: Human rights challenges

Worldwide interest in ayahuasca and related traditional Amazonian medical systems is typical of contemporary globalization.[7] Ayahuasca is a highly widespread tool within traditional Amazonian health systems. In 1986, pioneering work that brought together all available ethnographic information on ayahuasca found over 400 bibliographical references, referring to over 70 different Amazonian ethnic groups in which it was traditionally used and over 40 different vernacular names given to the decoction.[8] Today, those figures may represent only a small part of the bigger picture. Ayahuasca is a decoction containing the leaves of the vine *Banisteriopsis caapi*, which is rich in harmaline alkaloids, and of the shrub *Psychotria viridis*, which contains DMT (N,N-dimethyltriptamine), which is a Schedule I substance controlled by the 1971 Convention on Psychotropic Substances. Although ayahuasca itself is not scheduled in the international drug control treaties, its use is prosecuted in many countries, even in the case of indigenous peoples who travel outside their original territories. Ayahuasca became so popular among Westerners as a self-care practice that even psychiatrists and pastoral counselors have called for their colleagues to be ready to discuss spiritual, healing ayahuasca experiences with their clients, despite their epistemological divergence from psychiatry and their ontological divergence from monotheistic religions.[9] Also, ayahuasca's adverse effects are frequently reported in the scientific literature.[10]

An initial epistemological challenge becomes evident here. Both scientific and traditional mental health treatments often involve psychoactive compounds. However, biomedicine views mental disorders as biochemical imbalances that psychoactive drugs might restore; meanwhile, Amazonian medicine views spiritual forces as being at work and psychoactive plants as a means to harmonize the individual with the surrounding spiritual world. This harmonization tries to achieve an alignment between the individual, the community, the ecosystem, and even the geographical territory. The case of ayahuasca is also paradigmatic, as it shares its neurochemical mechanism of action with antidepressants. Whereas in biomedical systems clinical trials are used to demonstrate the safety and efficacy of psychoactive drugs, regarding traditional ethnobotanicals, safety and efficacy are demonstrated by the long history of use. Although Western countries accept traditional plants as medicines, their safety and efficacy must be proven according to biomedical criteria. This can get really challenging when applied to non-biomedical medical systems with conceptions of safety and efficacy that may not be equivalent.

An important consideration arises here: article 15 of the International Covenant on Economic, Social and Cultural Rights recognizes everyone's right to enjoy the benefits of scientific progress and its applications, and the states parties that signed this covenant agreed to respect the freedom indispensable for scientific research. In practice, these rights are conceived of and applied in the context of Western epistemologies, leaving aside traditional approaches to mental health and related research.

These issues are addressed (although not exclusively within the context of mental health) in the recently adopted General Comment 25 by the United Nations Committee on Economic, Social and Cultural Rights. The general comment states that "[l]ocal, traditional and indigenous knowledge, especially regarding nature, species (flora, fauna, seeds) and their properties, are precious and have an important role to play in the global scientific dialogue" and that "[i]ndigenous peoples and local communities all over the globe should participate in a global intercultural dialogue for scientific progress, as their inputs are precious and science should not be used as an instrument of cultural imposition." Nevertheless, traditional treatments should not be the only option available, and "States parties must guarantee everyone the right to choose or refuse the treatment they want with the full knowledge of the risks and benefits."[11]

The right to science is essential in order to adopt a perspective based on human rights and evidence, since various health-related human rights rely on the right to science, such as everyone's right to enjoy the highest attainable standard of physical and mental health. This is especially relevant, as mentioned above, in the case of indigenous peoples, and even more so in terms of their use of plants with psychoactive properties that are under international control. The *International Guidelines on Human Rights and Drug Policy*, developed by several United Nations agencies, academics, and civil society representatives, echo this problematic, specifying that states should "refrain from depriving indigenous peoples of the right to cultivate and use psychoactive plants that are essential to the overall health and well-being of their communities."[12] Furthermore, General Comment 25 explicitly states that "the prohibition of research on those substances is in principle a limitation of this right."[13] Considering that the general comment defines "science" as encompassing both natural and social sciences, this makes ethnographical research an option, which could be more reliable and feasible than biomedicine as a source of evidence for evaluating traditional medicines involving psychoactive plants.[14] However, the application of non-biomedical methodologies can be challenging since, as the same general comment affirms,

> *knowledge should be considered as science only if it is based on critical inquiry and is open to falsifiability and testability. Knowledge which is based solely on tradition, revelation or authority, without the possible contrast with reason and experience, or which is immune to any falsifiability or intersubjective verification, cannot be considered science.*[15]

The post-colonial and biomedical-oriented aspects of the right to science

Several Western epistemologies—such as psychoanalysis, certain approaches in psychology, and other social sciences (including certain ethnographies within anthropology)—cannot always meet these falsifiability and testability criteria. Although those disciplines and epistemologies are also based on reason, cumulative knowledge, and experience, their ontological assumptions may not fit within the exigencies of scientific methodologies. Even research in biological psychiatry might not always meet the criteria of falsifiability and testability, since it has various flaws. The etiopathogenesis of mental disorders is completely unknown; there is not a single psychopharmacological treatment that offers a cure, and, at best, psychiatric drugs serve to treat acute symptoms (such as panic attacks and psychotic breakdowns) but over the long term can be ineffective and potentially dangerous. Radical critics of psychiatric drugs consider them to actually be part of the problem regarding the chronicity of mental illnesses, rather than part of the solution.[16] This inefficacy could be partly due to the poor heuristic models of mental illnesses. In sum, science applied to mental health demands that other disciplines and epistemologies meet methodological criteria that psychiatry itself does not always fulfill. A broader framework regarding the assessment of mental health systems should be developed in which different epistemological approaches, including indigenous ones, are considered.

Global mental health, globalization, and plants containing scheduled compounds

Contemporary globalization involves not only the intentional export of scientific mental health systems from the Global North to the Global South. Rather, a new and interesting phenomenon is also occurring whereby traditional medicines are traveling from the Global South to the Global North. Some traditional medicines involving plants that contain psychoactive constituents—such as ayahuasca (containing DMT), San Pedro and peyote (two cacti originally from the Andean region and Mexican deserts, respectively, that contain mescaline), and iboga (a plant from Equatorial Africa containing ibogaine)—are gaining increasing popularity all over the world. Among them, ayahuasca is probably the most popular and widespread.

Ayahuasca has diverse uses among Amazonian cultures, such as in rites of passage from childhood to adulthood, to strengthen community bonds in interethnic festivals, as a sacrament (for example, in Brazilian ayahuasca religions), and even as a spiritual tool to resist neocolonial extractivism.[17] However, ayahuasca is used in Amazonian cultures mainly as a tool for healing, which has been widely documented in the ethnographic literature.[18] Biomedical scientists have also widely studied its neuropharmacology, neuropsychiatric long-term effects, and therapeutic potentials, finding promising results for mental health disorders such as major depression, drug dependence, grief, eating disorders, borderline personality disorders, and post-traumatic stress disorder.[19]

Contrary to what happened with the importation of other psychoactive plants traditionally used in the Americas, such as coca and tobacco, the globalization of ayahuasca has seen its incorporation into ritualistic settings where it is used similarly to how it is used in its original context. These rituals have been conceived of as novel self-care practices.[20] Meanwhile, thousands of Westerners travel to Amazonian regions each year seeking spiritual enlightenment and healing from their physical and psychological conditions. Biomedical researchers are also starting to report the psychological outcomes of traditional ayahuasca practices among Western participants.[21]

This phenomenon suggests that the GMH paradigm could lead to a turning point where, contrary to the assumption that the Western mental health model should and will expand, we are instead witnessing the expansion of traditional forms of healing beyond their native contexts. This is evident in the case of traditionally and ritually used psychoactive plants, especially ayahuasca. The manner in which international drug control conventions have been drafted assumes that traditional cultures will never be capable of expanding their influence to other territories and societies. This has not been the case. Ways of healing previously considered outdated and unscientific are being recognized as highly useful and less costly in terms of adverse effects. Furthermore, Amazonian health systems, based on a world view that appreciates alignment between the individual, the community, the ecosystem, and the geographical territory, may serve as a model for dealing with our mental health crisis that, with the climate emergency and the COVID-19 pandemic, will dramatically increase. Thus, the GMH agenda should start to recognize the immense value of traditional medicines based on psychoactive plants, the ethnographic literature should be used as a legitimate source of evidence regarding safety and efficacy, and research budgets should be allocated for multidisciplinary approaches to study non-institutionalized traditional medicines, such as ayahuasca healing systems.[22] Furthermore, indigenous epistemologies should be carefully respected because traditional healers are the true experts on the medical use of these sophisticated technologies, and appropriate frameworks should be created in which they are considered legitimate knowledge systems that should be protected not only under the umbrella of cultural rights and the protection of cultural heritage, but also within the frameworks of the right to science and the right to health, in compliance with multiple international treaties and United Nations declarations.

Final remarks

The Western popularization of non-institutionalized, traditional healing systems implies multiple challenges that deserves in-depth reflection. In fact, this is already happening in many parts of Amazonia with ayahuasca, in Mexico with peyote, and in Gabon and Equatorial Guinea with iboga. Biomedical and cultural misappropriation, the over-exploitation of natural resources for commercial purposes, medicinal plant tourism that threatens the viability of local community rituals, and disruptions of egalitarian traditional social systems perverted by economic inequalities are among the challenges faced. These challenges can be overcome only if they are dealt with from a perspective of reciprocity that extends beyond the GMH agenda's narrow recognition of traditional medical systems involving psychoactive plants. It is therefore necessary to invest in indigenous epistemological research and practices in order to truly protect indigenous peoples' right to science, since this right, beyond its concern with science, involves much more complex economic and sociopolitical dimensions.

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HHR Health and Human Rights Journal

The Implementation of the Convention on the Rights of Persons with Disabilities: More Than Just Another Reform of Psychiatry

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Abstract

The social model of disability—which is grounded in the lived realities of disabled people, as well as their activism, research, and theoretical work—has enabled a historic turn in the understanding of disability. This model also facilitates the transition to the rights-based approach that is at the core of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). However, the social model of disability does not straightforwardly translate to the lives of people who end up being detained and forcibly treated in psychiatric facilities. This paper examines the implications of the lack of an equivalent theoretical framework to counteract the hegemony of the biomedical model of "mental illness" and to underpin and guide the implementation of the CRPD for people with psychiatric diagnoses. Critically engaging with some recent attempts to make the CRPD provisions integral to psychiatry, we expose fundamental contradictions inherent in such projects. Our discussion seeks to extend the task of implementation of the CRPD beyond reforming psychiatry, suggesting a much broader agenda for change. We argue for the indispensability of first-person knowledge in developing and owning this agenda and point to the dangers of merely remaking former treatment objects into objects of human rights.

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Competing interests: None declared.

Introduction

The implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) for "persons with psychosocial disabilities" or people currently undergoing psychiatric treatment appears to be the most controversially discussed aspect of this international treaty. While the debates regarding the rights of people with physical and sensory impairments progress toward improving laws, policies, and practices, the decision-making processes regarding persons with psychiatric diagnoses continue to regress and still remain very much in the pre-CRPD era: the very possibility of equal rights being achieved in the case of this particular group is being called into question. We are well aware that the implementation process of the CRPD is generally slow and partially also retrograde, and it is certainly not our aim to compete with any other marginalized or oppressed group. But we would like to point out the levels of resistance and also sabotage of the recognition of fundamental rights and freedoms of people with psychosocial disabilities, including the explicit calls to revise the CRPD and exclude us from its provisions.[1] This is the climate in which the efforts to implement the CRPD for people with psychiatric diagnoses is taking place.

Even though significant progress has been achieved in some countries' legislation (such as Peru's abolition of guardianship on the basis of disability in 2018), and despite a few available alternatives to psychiatric treatment, so far no country in the world has effective measures in place that fully protect people deemed mad, mentally distressed, or psychiatrically disordered from detention and forced medical treatment.[2] Moreover, the legitimacy and sense of such potential laws and policies is being questioned and often simply declared utopian. The argumentation employed to justify such views commonly mistakes detention and forced interventions for care and the right to health. In our "Open Letter to WPA [World Psychiatric Association]"—signed by several international organizations of mental health service users, psychiatric survivors, and people with psychosocial disabilities—we extensively engaged with those views.[3] In this special section, we see the opportunity to leave that kind of debate behind and take the analysis forward, beyond the question of whether psychiatrically diagnosed people should have equal human rights just like anybody else. The adoption of the CRPD gives a clear and legally binding answer to that question. However, it opens up another, more urgent and rather complex question of how this can be achieved. In this contribution, we critically examine some of the current clinician-led initiatives to adopt a human rights framework in psychiatry and more generally explore why the biomedical model of mental illness is incompatible with the human rights-based approach. Our analysis is informed by our respective experiences of being subjected to coercion and forced psychiatric treatment, by many years of activism in the Western European and international user/survivor movement, and by our research and theoretical work. Based on this background and spirited by the way in which the social model of disability arose, we advocate for the place of our distinctive, collective knowledge in the long-term project of making the CRPD provisions a reality for our people.

First, we analyze certain contradictions and structural obstacles to integrating CRPD provisions into current psychiatric systems. Second, we discuss some less explored avenues of research, theory, and practice as a means to secure and advance the rights and knowledge of people deemed mad or mentally disordered.

A note on language

Writing a note on language without elucidating the concepts behind the terms we use, their origins, and their implications is almost impossible. An additional difficulty here relates to the very subject of this paper because the power to name (and consequently treat) is central to psychiatrization. Taking that power back in a collective and liberating act of re-naming and self-identification has always been at the heart of the political organizing of (former) mental patients. But our movements are diverse, and the terms we choose need to be seen in their historical, political, and other contexts. Common in the Global North are the notions of "survivors of psychiatry," "mental health service users," "clients," and "consumers," and we agree with Mary O'Hagan's observation that "[t]here isn't even a word for patients that doesn't put us in relationship to the system that dominates us."[4] This is not the case with the concept of psychosocial disability, which emerged later and which is strongly connected to the CRPD. While there is no unity about this concept in the West and Global North, the notion of psychosocial disability is being embraced by movements in the Global South that seek to move away from "mental health" toward social inclusion in much broader terms.[5] This development in less psychiatrized parts of the world opens up new avenues for both theory and action and is highly relevant for the implementation of the CRPD. However, in this paper we focus on the recent psychiatric co-optation of the human rights discourse that we are encountering in our region, Western Europe.

Given the variety of ways in which people choose (or refuse) to identify themselves, we know that the terms we are familiar with will not resonate with everybody. Aspiring to a world in which madness and distress will be understood as part of humanity rather than attributed to certain groups of people only, we deliberately try to move away from defining and labeling. In our struggle to find the right words, we opt for descriptions, such as "people with psychiatric diagnoses," "people with psychiatric experience," and "people deemed mad or mentally disordered." But with the term "our people," we wish to express connection and solidarity with anyone who has undergone or is undergoing forced psychiatric treatment. We use these words while fully aware of our many differences and multiple layers of discrimination that psychiatric experience intersects with due to racist, capitalist, and other hegemonic structures in our lives. The expression is not intended to assimilate or neutralize our unequal exposure to these structures and this oppression.

Can there be such a thing as "human" psychiatry?

The CRPD embodies no less than a demand for a fundamental reconsideration of psychiatric treatment as a conventional societal response to human crisis. At the heart of that demand is the recognition of the legal capacity of people whose right to make their own decisions has been traditionally denied on the grounds of psychiatric diagnoses. It is clear that such a fundamental revision cannot occur via legislation only and that changes envisioned by the CRPD require decisive and synchronized action on many levels. The implementation of the CRPD touches on the history of psychiatry as a discipline and challenges its designated social role. Part of the psychiatric establishment across the globe lobbies for the maintenance of that role and acts as a gatekeeper and opponent to the changes that the CRPD demands. At the same time, there is a growing number of calls and initiatives from less prominent professional representatives to revise psychiatric practice and bring it into harmony with the provisions of the CRPD. Leaving aside the presumably good will of this new edition of "progressive" psychiatry and various services providing housing, sheltered work, or even guardianship for the "mentally ill," we maintain that the task of implementing the CRPD cannot be carried out solely by these professions. The CRPD does not demand a different psychiatry but rather an entirely different approach to madness and distress. The attempts we see being made by psychiatry to take a lead and appropriate the agenda for change run the risk of turning the whole long-term objective into just another psychiatric reform. We have already witnessed the mainstreaming of recovery and "upscaling" of mutual support practiced in our communities via peer specialist workforces within psychiatric services.[6] These developments demonstrate what can happen to progressive and emancipatory concepts once they enter the psychiatric terrain—which is based on very different premises. Detached from their origins, depoliticized, and employed as mere techniques, these novelties have ultimately renewed and strengthened existing mental health systems rather than bringing any substantial changes to their coercive or potentially coercive nature. We therefore wish to highlight the dangers involved in psychiatry adopting a human rights agenda and becoming the lead "implementer" of the CRPD. Such a scenario would fortify the role of psychiatry that the CRPD seeks to challenge. The belief that CRPD provisions can simply be "adopted" in clinical practice lays the pathway to another déjà vu, as described by long-term survivor activist Matthias Seibt: "Everything has to improve. But nothing is allowed to change."[7]

As an example, by taking a closer look at the "Berlin Manifesto for a Human Psychiatry," recently initiated by a critical psychiatrist, we can see how psychiatry cannot just be remade into a human rights-based enterprise.[8] The first principle laid down in this document, signed by many organizations and individuals, including a number of service users, states:

> *A humane psychiatry in accordance with the UN-CRPD guarantees the right of users/consumers/survivors to decide for themselves which type of psychiatric and psychosocial support services they want to use and how to do so. In crisis situations, if and when it is more difficult to determine the person's own preferences, intensive individual support must be offered. Supported decision-making also helps to avoid coercive measures.*

Leaving aside the expectation that persons experiencing a psychosocial crisis would know about and be able to avail of "types of support," we first need to point out the extremely limited and clearly defined spectrum of available "choices" out there. These "choices" are almost all biomedically framed. The right to *choose to refuse* any or all of them is not mentioned. Moreover, the call for coercive measures to be "avoided" rather than abolished obviously takes coercion for granted. The manifesto further outlines principles of transparency, participation, economic security, and inclusion in individual social networks as if psychiatry were not operating as part of the system of social control with a clear assignment and role to fulfill within that system. These kinds of contradictions are inherent in any attempt to change psychiatry within its own realm.

From the establishment of psychiatric treatment in the form of institutions in the 18th century to the present day, which is characterized by the introduction of community treatment orders, what remains unchanged is this discipline's mandate to maintain social order. In distinction to other forms of incarceration such as prison, the target of psychiatric forced treatment is people who have not committed crimes but are seen as potentially dangerous to themselves and to others. So far, all initiatives to bring psychiatric practice into harmony with the CRPD operate on that same unchanged ground. So the obvious question is how psychiatry can safeguard the human rights of its targeted subjects while its task remains precisely to control and preventively deprive them from exercising those rights.

Two other German psychiatrists engage specifically with these questions; they envision a future in which psychiatry no longer has the function of social control and offer a revised concept of mental health services that would then provide "support only."[9] We appreciate the efforts of these authors to explore the concrete implications of such a fundamental revision of psychiatry's social contract for the day-to-day practice of services, and, most of all, we value their determination to work in non-coercive ways.[10] However, we need to problematize the rather naive view that the abilities and skills to provide pure "support" can spontaneously emerge in psychiatric services by virtue of abolishing forced treatment, as the authors suggest:

> *The task for health care professionals is to change to support only, based at the same time on the extent of the disability and on the will and the preferences of the person concerned.*[11]

There is no doubt that the elimination of coercion opens up new prospects for interpersonal interaction of every kind, but "respect for will and preferences" is much more a necessary precondition for any such interaction rather than its sole content. This principle marks the beginning and provides ground to any helping relationship but cannot by itself sufficiently define support. Furthermore, we have serious reservations that mental health services based on a biomedical approach can simply switch to providing comprehensive and ample responses to the range of human crises. Despite their struggle to use a different language, these authors remain faithful to psychiatric diagnoses as a framework to understand psychosocial crises, which they basically approach as impairment:

> *Depending on the extent of the disability, this may be informal support and counselling in minor impairments or wide-ranging and intensive support in severe impairments.*[12]

As previously mentioned, our analysis is not meant to underestimate or devalue the attempts of psychiatrists to rethink their practice and work according to human rights standards. What we want to point out are the contradictions built into the aim of implementing the CRPD via its translation into clinical practice. In our view, the CRPD came about not as a demand to change psychiatry but rather as a clear call to change policies, practices, and mind sets that create psychiatry. As Theresia Degener, former chair of the CRPD Committee puts it, "Like any other human rights treaty, the CRPD is a visionary law designed to transform society into a more just society."[13] However, contrary to the social model of disability, there is no equivalent theoretical framework to underpin and guide such transformation of responses to madness and distress. When we say equivalent, we do not necessarily mean the content of the social model; above all, we refer to its knowledge base grounded in experiences of disabled people themselves. This does not mean that the social model of disability operates as a magic bullet able to make people with physical and sensory impairments be heard and taken seriously, let alone instantly secure their full human rights. But at least it exists as a powerful tool, as a commonly known, easy-to-understand reference point to be employed in that struggle. In her comprehensive analysis of multilayered effects of ableism, the UN Special Rapporteur on the rights of persons with disabilities observes how

> *[t]he claims of persons with disabilities to have their rights recognized are often dismissed and the underlying power imbalance invalidates their lived experiences. Their narratives are considered to be subjective and ill-suited to informing objective decision-making and thus are not given the space to be genuinely weighed or to challenge ableism.*[14]

In the case of psychiatrized people, the situation is somewhat different, and that is not only because we are traditionally feared as irrational and dangerous. The fact that our collective first-person knowledge has not yet amounted to our own model or theory but remains subject to expert interpretations makes us continue to seek better explanations of our own lives and leaves us without a self-articulated framework to understand and communicate our social realities beyond our individual stories. We will come back later to the far-reaching implications of this kind of blank space.

Before going further, we need to raise one more issue. At the time of writing this paper, the "Berlin Manifesto for a Human Psychiatry" tallied over 7,500 signatures.[15] What concerns us is the popularity that such initiatives quickly gain and their ability to obscure the issues at stake and mobilize people toward investing in another, improved version of the same. The distrust in a human version of psychiatry, shared by many survivors of forced treatment, is not just a matter of gaining back trust in services, as some psychiatrists suggest.[16] The oxymoron that the very project of humanizing psychiatry constitutes is well articulated in Frank Blankenship's comment on this manifesto:

> *If it weren't for inhumane psychiatry there would be no need for humane psychiatry. Problem. When inhumane psychiatry has marginalized and disenfranchized, one might say, subhumanized and decitizenized, a segment of the population, humane psychiatry is going to bring it back into the fold again? Let me say that I have serious doubts about the matter. Once inhumane psychiatry targeted a population, humane psychiatry is still targeting them but in a different way.*[17]

This paper gives us the opportunity to explain why survivor advocates like ourselves cannot join alliances with critical psychiatrists, nor subscribe to this type of shared agenda for change. Our further concern is the nature of such alliances and their impact on our movement, as described by UK survivor-activist Peter Campbell:

> *One aspect of the problem is that we have lost control of agendas through working with other groups who are more powerful than us, are more organised and have more urgent agendas than ours. There are underlying difficulties in being involved in work that is wrapped up in the seductive notions of common concerns or partnerships when we are the conspicuously less powerful partner, when others are always issuing the invitations and we are always the new arrivals at the party.*[18]

Campbell's analysis from almost 20 years ago regarding user/survivor action on biomedical psychiatry is still very current:

> *There are dangers in gathering around a flag that someone else has planted, just because it flies quite proudly and has colours similar to ours. But if we have doubts, the answer is not to stand colour-less but to raise our own flag with our own true colours and fight on alongside. The current initiative on biomedical psychiatry deserves a survivor-response and in the course of it, perhaps a second flag.*[19]

In the remainder of this paper, we explore what stands in the way of raising this second flag and also suggest some colors for it.

Who creates and owns the agenda for change?

There are no easily implementable answers to the CRPD's demand for a radically different way of treating madness and distress in our societies. At the same time, many small-scale answers can be found in the variety of ways people treat one another and one another's crises outside of organized "mental health care" systems. Sustainable and self-organized, community-based practices are especially present in places where colonial Western psychiatry has not (yet) achieved its profitable mission of filling "treatment gaps."[20] Many of us who have been through madness and extreme states of mind have found ways to understand and integrate these experiences and live free of psychiatry and pharmacological interventions to our full potentials. The problem with collective knowledge gained through those first-hand experiences is that it is not recognized and explored in its own terms, as a distinctive rather than just an auxiliary epistemic source. Australian scholar Fleur Beaupert terms this phenomenon a "medico-legal incapacitation of expressions, opinions and epistemologies of users and survivors" and highlights the connections between mental health legislation and the suppression of knowledge of people deemed mad or psychiatrically disordered.[21] So when addressing our general absence from places where decisions about our lives are being made, it is important not to just focus on the symbolic violence of our epistemic exclusion but to also consider how its roots lie in the *material* violence legalized by mental health acts around the world. Those acts not only constrain our thinking abilities by virtue of forced drugging but also physically limit our freedom of movement and communication through forced detention. This means that we are continuously and systematically being denied the very possibilities of joining forces and constituting ourselves as a stakeholder capable of developing positions and having a say in policies that directly affect us. Beaupert argues that

> *[t]he medico-legal discourse of mental health laws, by consecrating this symbolic violence, operates to manipulate and nullify individual ways of knowing and being, and to radically diminish opportunities for the epistemologies of users and survivors to exert influence on societal systems and structures. Constructions of people with psychosocial disability as lacking capacity and "insight" are central to these processes of dehumanisation.*[22]

This situation creates a chronically vacant space, leads to token representation, and makes it easy for other stakeholders to speak for us and often also to make our cause their own. Our capacity to think and act for ourselves is being recognized at the most on an individual level, but it always proves extremely hard to constitute and especially to preserve our autonomous grassroots organizations and pursue our own priorities for action. Paradoxically, with the CRPD now legally corroborating the longstanding claims of our movement and making the human rights of psychiatrically treated people part of official agendas, it seems to have become even more difficult to justify the need for us to organize ourselves separately to defend our rights and articulate our own interests. It almost seems as if our goals were apparently achieved with the adoption of the CRPD and the task of implementation is now back in the hands of more "competent" and more powerful players. In their analysis of how structures of "social responsibility" are being created, survivor-authors Anne Wilson and Peter Beresford point to the mechanisms of exclusion inherent in the making of those structures:

> *By speaking for or acting on behalf of those deemed mentally ill, they ("the socially responsible") also contribute to, and perpetuate notions of the "dependency," "passivity" and "incompetence" of people with a mental illness diagnosis; irrespective of whether or not this is their intention.*[23]

Even when distant and apparently opposed to each other, what both psychiatric and human rights discourse have in common is the clear dominance of expert knowledge. However different from each other, both approaches rest on an assumption of "an active 'we' who are the solution and a passive 'them' who are the problem."[24] Beresford describes this deep-rooted, unquestioned division as common to lay approaches as well:

> *People still frequently talk and write about "the mentally ill" as though they were a distant separate group of people very different from the rest of "us." Discussion is still often framed in terms of what can "we" do about "them."*[25]

The substantial involvement of people with disabilities themselves, including people with psychosocial disabilities and survivor-activists, in the making and monitoring of the CRPD has clearly disrupted the traditional making of policy and legislation and demonstrated how things can be done differently. Implementing the CRPD cannot be owned narrowly and requires doing away with these deeply seated divisions. We understand the implementation process as a widely shared undertaking that is about what we can all do for us all. The task of turning the CRPD into reality for people deemed mad brings us to no less than a profound a question as how to approach madness in a radically different way. Central to that different way is the shift from treating madness and distress toward treating circumstances and conditions that create madness and distress. In the next section, we share some thoughts on what is needed in order to enable this shift.

From treating madness toward intervening in a mad world

As mentioned earlier, one crucial distinction between the implementation of the CRPD for people with physical and sensory impairments, on one side, and people with psychiatric diagnoses, on the other, is the fact that the latter lacks an equivalent to the social model of disability. This model, grounded in political activism, research, and theory work by disabled people themselves marked a historic turn in understanding disability.[26] The CRPD exemplifies one of its far-reaching impacts. We do agree with Degener's view that unlike the social model, the human rights model is "a tool to implement the CRPD."[27] But when she states that "most states parties to the CRPD are far from comprehending this new model of disability and are still stuck with the medical model of disability," it should be added that in the case of understanding madness and distress, there is no established model at all to counter the biomedical model of "mental illness" and facilitate a move toward a human rights model.[28] This is where the divergence from the situation of people with physical and sensory impairments becomes the most visible: while the social model of disability has enabled a shift from the medical focus toward an understanding of societal conditions that create disablement, there is no comparable model or theory to overpower the individualizing and pathologizing biomedical concept of "mental illness."

Despite its indisputable achievements, the social model of disability is subject to ongoing criticism, including from the Mad movement in the Global North.[29] We do agree that this model is not easily applicable to experiences of psychiatrization because of the contested nature of the underlying "impairment" in "mental illness" and, even more importantly, because people deemed mad experience not only discrimination but also "criminalization by civil commitment."[30] However, we do not perceive the lack of attention to these issues as weaknesses of the social model of disability. That model never claimed to be an "all-encompassing framework" to capture all our diverse experiences.[31] Rather than engaging in criticism that treats this model as a field for academic battle and intellectual exercise, we approach it as unique example of theory building that is grounded in collective first-person knowledge and also developed from "within." The lack of such a model of madness has tangible implications and cannot go unnoticed. In our view, this absence is one of the main obstacles to realizing the provisions of the CRPD for our people. Even though the overall approach, the language of the CRPD, and the related documents issued by the Committee on the Rights of Persons with Disabilities pose significant challenges and disrupt the biomedical model, this legal treaty itself cannot substitute for the obvious lack of an alternative model to guide the implementation process and replace current practices. The biomedical model that depoliticizes, silences, and ultimately controls rather than listens and helpfully responds to the madness and distress of our lives cannot straightforwardly transform itself into an approach based on human rights. Nothing less than the whole new paradigm to understanding psychosocial crisis would be missing this way.

There are surely many different paths to safeguard the human rights of people deemed mad, and it is not our intention to discourage any of them. However, we need to make it clear that the biomedical model overshadows and powerfully inhibits these much-needed changes. Even though this framework has not been able to offer any sound explanation for the "impairment" that it purports to treat, it remains the ruling explanatory model that is allowed to continue despite an entire body of evidence that contests not only its effectiveness but also its very premises. With the rise of global initiatives in psychiatry and the conquering of new markets for psychiatric drug treatment, the medical model is even being coated in a human rights-based approach: in places where people deemed mad or possessed by evil spirits are being exposed to high degrees of physical violence both in their communities and in traditional healing centers, psychiatric treatment presents itself as a more humane alternative.[32] What effectively upholds this model is neither its scientific nor ethical value, but the whole machinery behind it, made up of the pharmaceutical industry and other interests involved. These are forces that stand in the way of implementing the CRPD for people with psychiatric diagnoses. We have as yet no answer as to how we could confront those forces beyond the act of at least naming them. Exposing the powerful corporate interests behind the medical model is something that still happens too rarely in the debates on the implementation of the CRPD. Such an unequal division of power makes any reasoned argument with the proponents of the biomedical model an endless endeavor ending with the same outcome and forces us to seek alternative modes of action, as wisely suggested by Buckminster Fuller: "You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete."[33]

In our view, the creation of such a model of madness and distress, grounded in our own experiences and knowledge gained through those experiences, is a central task for user/survivor communities and movements of people with psychosocial disabilities in the post-CRPD era. This does not mean that we are unaware of alternative approaches and theories developed by different authors and schools. Many of those come close to our lives and offer viable explanations of human crises. But in all these third-person approaches, we remain the objects of interest, the ones to be explained and ultimately othered through the very process of knowledge production, with its clearly assigned roles. People going through madness and distress have been extensively studied. What we need are no new spectacular discoveries about our lives but rather a complete epistemic shift in knowledge making: the time has come for *us* to pose the questions and invert the microscope.[34]

In his extensive work with first-person narratives of physical illnesses, Canadian sociologist Arthur Frank argues for a shift "from needing more knowledge to needing values that allow us to take a stand with respect to what we know."[35] But even though the CRPD offers a clear value framework and demands that we take a stand, the post-CRPD era is characterized by a bloom of inquiries into the personal impact of coercive measures as if there were new discoveries to make on this topic.[36] The explanations of the incidence of coercive measures focus primarily on insufficient staffing levels in psychiatric services.[37] This new wave of investigations, predominantly conducted within the fields of mental health and psychiatric research, is usually directed toward minimizing the occurrence of certain coercive practices such as restraint and seclusion. These practices are certainly the most tangible expressions of psychiatric violence, but they are in fact all being employed in order to provide standard "health care," which equals the administration of psychiatric drugs. That (forced) medicalization of social realities remains a main feature of current mental "health" provision is rarely being problematized. Broadening the definition of what constitutes human crises and figuring out ways to de-medicalize our lives and mobilize largely unexplored community potential to provide different responses do not seem to be urgent topics of interest. Organizing true and sustainable support systems for people undergoing psychosocial crises could greatly benefit from practices that are already in place but continue to be marginalized and ignored. Many survivor groups and communities of people with psychosocial disabilities have their own knowledge-making traditions that approach a breakdown as a potential breakthrough and know how to "carry each other" in times of crises.[38] Activists in the Global South are developing new knowledge through their community inclusion programs. [39] They are using the CRPD as a framework to build a new paradigm through their practical work on the ground. People deemed mad have also been documenting their knowledge for centuries, but we are not collectively owning and advancing that knowledge. Learning from us, from our sources, and from our movements cannot occur if we are approached as "one-dimensional objects of a knowing gaze."[40]

The social model of disability as a model grounded in the lived realities of disabled people has demonstrated an enormous emancipatory potential. An equivalent achievement by psychiatrized people could finally relocate madness and distress from their conventional placement within our bodies and minds and back into the structures in our lives where these phenomena emerge from. And most importantly, such change of focus would enable us to *jointly* start targeting and improving those structures instead of letting ourselves be targeted and intervened on. Such a comprehensive shift is quite different from the simple recognition of the social determinants of mental health. Beresford, who has done considerable research and theoretical work toward developing a social model of madness and distress, reminds us of this important distinction:

> *There is no question that there has been an awareness of social issues in some mental health disciplines and professions for some time. But this has tended to focus on social issues as factors in the creation of mental health problems. It has tended still to take mental illness or disorder as a given—to accept the idea—rather than attempting to reconceptualise mental health within a social framework.*[41]

If our societies aim to one day achieve a fundamentally different understanding of madness and distress and above all fully transform conventional approaches that seek to isolate and medicate these human experiences, first-person knowledge cannot just be inserted as an additional or optional resource, as is now the case. The time has come for collective and diverse survivor knowledge to become a central resource, and this hour is long overdue. If treated with due respect and with very different methodologies than the present ones, our own accumulated knowledge holds the key emancipatory potential to facilitate the paradigm shift that is urgently needed to implement the CRPD. As envisioned by Canadian survivor Irit Shimrat, this could lead us to "a society brave and moral enough to eschew the whole paradigm of mental health and illness, replacing it with a creation of real community, and real help."[42]

Concluding remarks

It was a year ago that we drafted an "Open Letter to WPA" in reaction to the debate on the CRPD published in its official journal.[43] We ended that letter with an explicit call for psychiatrists willing to take a *new* departure to speak up. The year that followed has seen a few initiatives that are far from the impression that the WPA establishment left in its journal. However, taking a closer look at those initiatives has made us understand that it takes much more than a decision and a will to "break from the old, controlling paradigm."[44] With due respect for all the efforts to move in this direction, we hope to have demonstrated why the implementation of the CRPD is not just a matter of another reform of psychiatry. We also hope to spur many more opportunities for extensive and *diverse* first-person knowledge to take the lead on the way to CRPD provisions becoming a reality for people currently undergoing psychiatric treatment.

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A Key, Not a Straitjacket: The Case for Interim Mental Health Legislation Pending Complete Prohibition of Psychiatric Coercion in Accordance with the Convention on the Rights of Persons with Disabilities

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Abstract

The practice of coercion on the basis of psychosocial disability is plainly discriminatory. This has resulted in a demand from the Committee on the Rights of Persons with Disabilities (the CRPD Committee) for a paradigm shift away from the traditional biomedical model and a global ban on compulsion in the psychiatric context. However, that has not occurred. This paper considers conflicting pronouncements of the CRPD Committee and other United Nations bodies. Assuming the former's interpretations of the Convention on the Rights of Persons with Disability (CRPD) are accurate, involuntary psychiatric detention and enforced treatment on the basis of psychosocial disability are *prima facie* discriminatory and unlawful practices. However, dedicated mental health legislation both permits discrimination and protects and enhances rights. This paper proposes a practical way out of the present impasse: the global introduction of interim "holding" legislation lacking full compliance with the CRPD. While imperfect, such a framework would facilitate a move toward a complete ban on psychiatric coercion. The paper outlines four essential ingredients that any interim legislation ought to contain, including clear timebound targets for full CRPD implementation. It concludes by urging the CRPD Committee to take the unprecedented step of issuing a general comment providing reluctant "permission" for the progressive realization of respect for articles 12 and 14 of the CRPD.

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Competing interests: None declared.

"[L]iberty and security of the person is one of the most precious rights to which everyone is entitled."[1] Accordingly, it is enshrined in numerous international treaties, including the Convention on the Rights of Persons with Disabilities (CRPD).[2] It is, however, subject to exceptions, such as punishment for certain criminal offenses and hospitalization for the purpose of treating mental illness. Involuntary hospitalization and enforced treatment for those with severe mental illness have become so normalized globally that few question their lawfulness, much less the likely success of their purpose. Yet they have been held to amount to torture and cruel, inhuman, or degrading treatment or punishment under article 15 of the CRPD.[3] They are also the springboard for further degrees of restriction, such as seclusion and physical, chemical, and mechanical restraint. Legally endorsed hospital coercion can lead to systemic and other human rights violations, including "unlawful or arbitrary institutionalization, over-medicalization and treatment practices that fail to respect … autonomy, will and preferences."[4] Psychiatric compulsion reduces trust, breaks down the therapeutic relationship, and often leads to cyclical hospital admissions and the "revolving door" patient.[5] The United Nations (UN) Special Rapporteur on the right to health has observed that it causes "enormous psychosocial pain and hopelessness," with numerous studies highlighting its extremely traumatizing impact.[6]

This acceptance of coercion stems from a protective and paternalistic biomedical model of mental health that gives insufficient attention to the psychological and social causes of mental illness. Although coercion is "mostly carried out with the noble desire to reduce suffering and improve the human condition," the fact that it is applicable solely to those with mental disorder makes it wholly discriminatory.[7] By contrast, compulsory hospitalization on the basis of a physical health issue is permissible only in rare circumstances, such as where an unconscious person cannot provide consent to life-saving medical treatment, or to curb a pandemic such as COVID-19, which which has required unprecedented quarantines and country-wide lockdowns.[8]

The CRPD, adopted 14 years ago, embraces a social model of disability, viewing mental disorder not as an intrinsic medical issue requiring cure, but as an *extrinsic* inequity caused by structural barriers that prevent the equal societal participation of all. Requiring the full integration of human rights in all laws and health-related policies and services, it seeks a significant alteration of the normative landscape. The Committee on the Rights of Persons with Disabilities (CRPD Committee) has repeatedly labeled non-consensual psychiatric care as discriminatory and hence contrary to the treaty. Peter Bartlett emphasizes that "CRPD ratification means acceptance of the need for a paradigm shift … [which] does not occur without the challenge to fundamental assumptions about how we have acted in the past."[9] Yet, to date, no country has attempted to comply fully with the CRPD Committee's pronouncements, as demonstrated by the fact that all recently amended mental health legislation permits coercion. Further, many low- and middle-income countries (LMICs) that have no such legislation use coercion nonetheless, without legal basis.

This article assumes the CRPD Committee's interpretations to be accurate and does not debate their validity. Since the CRPD forms part of international law, involuntary psychiatric detention and enforced medical treatment are unlawful practices, for they are *prima facie* discriminatory. Highlighting some of the reasons for the global community's tardiness in ending coercion, this paper examines the utility of mental health laws within the contextual framework of the CRPD. I argue that the current impasse is inexcusable and that the option of incremental change would be an inadequate response to the CRPD Committee's pronouncements. Finally, I propose a practical way out of the deadlock through the use of stop-gap measures.

The current landscape

The CRPD's aims are "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity." Importantly, those with "long term … mental … impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" are included in the definition in article 1. In its reports, the CRPD Committee prefers the term "psychosocial disability" for those with a mental health diagnosis, which refers to those who have experienced negative social factors, including stigma, discrimination, and exclusion.

Key CPRD provisions for those with psychosocial disabilities

Article 14 of the CRPD requires states to ensure that persons with disabilities enjoy the right to liberty "*on an equal basis with others*" and indicates that "*the existence of a disability shall in no case justify a deprivation of liberty.*" Article 25 clarifies that this applies "[a]t all times, *including in crisis situations.*"[10] Those subject to detention are "entitled to guarantees in accordance with international human rights law … including by provision of reasonable accommodation."[11] Yet, many countries' mental health legislation permits coercive treatment provided that various criteria exist—usually related to perceived risk or a specific degree of illness severity. Other relevant CRPD principles violated by psychiatric coercion include article 3(a), which demands "[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons," and article 5(2), which requires the prohibition of "all discrimination on the basis of disability," guaranteeing to persons with disabilities "equal and effective legal protection against discrimination on all grounds." The duty not to discriminate *per se* is found in article 28. Article 12 governs the equal right of those with psychosocial disabilities to make decisions about their own treatment and care "on the basis of free and informed consent" with appropriate support and "reasonable accommodation" where needed.[12] Controversially, the CRPD Committee has interpreted article 12 as requiring the complete prohibition of substitute decision-making—a view with some support from other UN bodies, such as the UN Working Group on Arbitrary Detention.[13]

CRPD Committee interpretation

The CRPD Committee has emphasized, in country reports from 2011, that compulsory hospitalization and enforced medical treatment violate the convention.[14] This is reiterated in General Comment 1 on article 12, issued in 2014, and in the committee's guidelines on article 14 concerning the right to liberty, issued in 2015.[15] The committee's interpretations have been supported by the Special Rapporteur on the right to health, Dainius Pūras; the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar; and the Special Rapporteur on torture, Juan Méndez, who has called on states to "impose an absolute ban on all forced and non-consensual medical interventions … including the non-consensual administration of psychosurgery, electroshock and mind-altering drugs [and] the use of restraint."[16] However, among UN institutions, there is by no means a complete consensus. In its General Comment 35 on liberty and security of person, the Human Rights Committee outlines a set of conditions and safeguards under which both non-consensual *and* coercive treatment might be permissible under the International Covenant on Civil and Political Rights, in part based on disability.[17] In its view, legal procedures permitting coercion must merely "ensure *respect* for the views of the individual and ensure that any representative genuinely *represents and defends* … [their] wishes and interests."[18] Such open disagreement between treaty bodies within the UN human rights system has been "remarkably rare," as W. Martin and S. Gurbai note.[19]

Fallback on the status quo and impossibility of an immediate coercion ban

Even though the cost of psychiatric inpatient treatment is extremely high, maintenance of the status quo is nearly always cheaper—and easier—than developing new pathways of care. In accordance with the right to health (first articulated in article 25 of the Universal Declaration on Human Rights), ending involuntary hospitalization and treatment will require alternative care and treatment within the community, with levels of support tailored to individual disability.[20] Intensive community health care, including supportive accommodation with fully qualified staff, is expensive, even for higher-income countries.[21] In many LMICs, staffed residential placements do not exist, and mental health remains embedded in tertiary care. The absence of sufficiently available, accessible, adequate, and affordable alternatives to involuntary hospitalization in the community globally, as the right to health requires, means that fully CRPD-compliant legislation introduced at this juncture would likely be ignored.[22] For example, research by H. Liebling and L. Davidson et al. found that the Ugandan Mental Health Treatment Act of 1964 had never been properly implemented because a lack of infrastructure made adherence impracticable, with some key informants admitting that "they deliberately ignored requirements under the legislation."[23] Respect for the law is essential for any functioning society, and occasional circumvention might regress to purposeful avoidance, particularly in LMICs with inadequate checks and balances. Furthermore, "[i]t would be an unhappy state of affairs if regard for the CRPD were undermined by the Committee's interpretation."[24] Accordingly, setting the standard too high and too soon risks rendering the rights to health, autonomy, and liberty meaningless. Thus, even if the requisite political will existed, immediate and full compliance with the CRPD would be impossible in any country without compromising the right to health or potentially the right to life. For example, in Gauteng province in South Africa, at least a hundred patients discharged from psychiatric detention in 2016 to inadequate and un-monitored community care died within a year.[25]

The impasse

There has been considerable pushback against the CRPD Committee's pronouncements, with many scholars, clinicians, commentators, and politicians maintaining that a ban on coercion in the psychiatric context would be folly.[26] While the committee's interpretations are authoritative and hold significant weight, they are not considered legally binding.[27] Additionally, no real consequences flow from non-compliance, other than censure in a CRPD Committee's concluding observation or a Special Rapporteur's country report—both of which are likely to receive scant heed from other equally blameworthy states. Of course, not all states have ratified the CRPD, and some have made reservations to articles 12 and 14 (although the validity of such reservations may be contestable, as article 46 of the CRPD prohibits reservations that are contrary to its object and purpose).[28] There is general agreement, nonetheless, on the need for well-formulated mental health laws to protect the human rights of those with psychosocial disabilities.[29] "All over the world, governments and legislatures are considering whether and how to reform mental health and mental capacity legislation in order to ensure greater respect for human rights."[30] In 2017, the Special Rapporteur on the rights of persons with disabilities reported that at least 32 countries had either undertaken or were in the process of implementing legal reforms on the right to legal capacity of persons with disabilities. However, it is important to note that these reviews excluded mental health legislation.[31] Furthermore, since legislative amendments can take several years, laws passed within a few years of General Comment 1 would have been drafted prior to the CRPD Committee's May 2014 interpretation. Nonetheless, there has been some progress, the majority of which relates to the incorporation of supported decision-making—an important and necessary step in CRPD compliance—into legislation. Unfortunately, "most of these laws and bills are not in full compliance with article 12 of the Convention," as the Special Rapporteur on the rights of persons with disabilities has pointed out.[32] For example, in Northern Ireland, the Mental Capacity Act came into force in 2019 and makes decision-making capacity the trigger for all non-consensual interventions, but the act remains discriminatory because it still has a greater impact on those with psychosocial disabilities. Thus, six years after the publication of General Comment 1, no country has banned involuntary detention and treatment, and some have specifically rejected the CRPD's interpretation.[33]

The way forward: The case for interim "holding" legislation

This stasis negatively affects the lives of millions of psychiatric patients worldwide who remain subject to involuntary confinement and enforced treatment. To overcome the stalemate, I propose the following unprecedented step as a proportionate and justifiable response: all states should introduce or amend their mental health legislation in a way that significantly reduces coercion, with a clear intention to comply with the CRPD fully in due course. Signatory states must "refrain from adopting any retrogressive measures that directly or indirectly affects [*sic*] persons with disabilities," but legislative amendments that improve on the status quo will not be a backward step.[34] Where no current law exists, mental health legislation should be introduced urgently to provide a legal framework to prevent violations, protect and promote human rights not previously enshrined, and provide a justiciable framework for those with psychosocial disabilities.[35] The use of interim legislation finds support in the Human Rights Committee's General Comment 35, which recommends the revision of "outdated laws and practices in the field of mental health in order to avoid arbitrary detention."[36] Admittedly, the repeated amendment of legislation within a short time frame is unlikely to find favor with many governments. Nonetheless, reducing compulsion and increasing individual empowerment to protect and promulgate the rights of those with psychosocial disabilities is at the very least a moral imperative.

Progressive realization

The use of "holding" legislation with the intention of improving safeguards and strengthening rights while alternatives to coercion are scaled up is, in essence, "progressive realization." This concept permits states to take appropriate (including legislative) steps to introduce rights as quickly and effectively as possible within the confines of their finite resources. "Appropriate" steps "should be deliberate, concrete and targeted."[37] Such a process appears to be supported by the CRPD Committee itself, given its sometimes ambivalent language. For example, in its General Comment 5 on living independently and being included in the community, published three years after General Comment 1, the committee urges states to "*take steps* to the maximum of their available resources" "to ensure the full implementation of article 19."[38] They are exhorted to "[a]dopt clear and targeted *strategies* for deinstitutionalization, with *specific time frames* and adequate budgets, in order to eliminate all forms of isolation, segregation, and institutionalization of persons with disabilities."[39] D. Pūras and J. Hannah use comparable language, calling for "the progressive move towards an end to all forced psychiatric treatment and confinement."[40] Similarly, the terminology in a 2018 report by the Special Rapporteur on the right to health acknowledges the practicality of gradual change.[41]

Yet, progressive realization is permitted only with respect to social, cultural, and economic rights (such as the right to health), rather than civil and political rights (such as the right to liberty); and it does not apply to discrimination.[42] There is no real answer to that conundrum, other than to recognize that improved protection, promotion, and fulfilment of rights is preferable to the status quo. The lawfulness of any new or amended legislation will depend on its amplification of the rights of those with psychosocial disabilities, its restriction of the scope for human rights violations, and a clear aim of an eventual total ban on coercion. Such improvements are unlikely to amount to the kind of "retrogressive measures" that UN bodies preclude.[43]

Legislation versus soft law

It might be argued that updating "soft law"—such as codes of practice, rules, and regulations—would be as equally effective as amending legislation.[44] However, this would be insufficient. First, citizens (and busy clinicians) are more likely to respect and utilize source legislation than the soft law extrapolating it. Second, resort to the law will be the default upon any mismatch, resulting in little reduction in coercion—particularly in LMICs where under-funding may mean that legislative guidance in hospitals is unavailable or difficult to obtain. Third, in 2011 the World Health Organization (WHO) found that 15% of countries had mental health legislation enacted before 1970.[45] Such laws contain highly stigmatizing language. For example, Gambia's Lunatic Detention Act of 1917 was criticized for its dehumanizing terminology by the African Commission on Human and Peoples' Rights in *Purohit and Moore v. Gambia*.[46] Similarly, in 2017, section 5 of Zambia's Mental Disorders Act of 1951 was held unlawful by the country's Constitutional Court partly due to its discriminatory language.[47] Regrettably, for centuries, those with psychosocial disabilities were considered dangerous or comical, and legislation framed them as nonentities requiring removal from the rest of society. An approach so fundamentally contrary to current human rights standards means that extra-statutory guidance seeking to reduce coercion and enhance autonomy would make little sense; such laws require urgent repeal and replacement. However, since international human rights standards evolve over time with cultural normative change, some quite recent legislation may also require amendment. While an arbitrary cut-off point is not ideal, some guidance is needed. Taking the year of the publication of General Comment 1 as a starting-point (2014), I propose the amendment of laws over five years old, as they are highly likely to be non-compliant with current international human rights standards.

Guidance on legislative amendment

The first step in eventual adherence to the CRPD is to undertake a "comprehensive legislative review" to identify violations of international human rights law, as advocated by the Special Rapporteur on the rights of persons with disabilities.[48] This should encompass different relevant areas of law, including family, criminal, mental health, tort, and contractual law. Thereafter, mental health policies must be updated and should state a clear intention to ban coercion on the basis of psychosocial disability within a specified period. Until General Comment 1, there was relatively clear agreement on the necessary key components of mental health legislation, with WHO's 2005 *Resource Book on Mental Health, Human Rights and Legislation* widely utilized.[49] With this resource book now withdrawn for non-compliance with the CRPD, WHO's QualityRights training and guidance materials may instead prove useful for policy rethinks and legal drafting. These materials cover broad topics such as "freedom from coercion, violence and abuse," "strategies to end seclusion and restraint," and "supported decision-making and advance planning."

The reduction and ultimate exclusion of force will require innovative thinking. This paper is not intended as a complete guide to all principles necessary in internationally compliant mental health legislation; rather, it highlights key requirements and the law's role in driving up standards with a view to eventual conformity. I propose that core legislative change focus on four essential aims: (1) building on procedural and substantive protections; (2) reducing coercion and unnecessary interferences with liberty and bodily integrity; (3) non-discrimination and empowerment; and (4) target-setting to reduce and eventually eliminate coercion within a specific and reasonable period.[50]

(1) Building on procedural and substantive protections

Mental health legislation encapsulates substantive and procedural rights and may cover a broad array of issues. Laws have always specified the circumstances in which the involuntary admission and treatment of those with psychosocial disabilities is permitted, including seclusion and restraint. To such compulsion attach procedural rights—such as the rights to legal representation and to regular and swift independent review of any detention criteria—in accordance with the right to fundamental fairness. Protective negative rights guaranteeing freedom from torture, from cruel, inhuman, and degrading treatment, from abuse, and from discrimination are frequently set out, and offenses specific to hospital and care staff may be described, along with criminal penalties. Positive rights such as the promotion and protection of human rights are often enshrined, as are the legal mechanisms to enforce them. The creation and powers of independent review bodies to oversee hospital admission and treatment, as well as the establishment of independent monitoring, inspection, and complaints bodies, may be incorporated into either legislation or regulations. Another frequently included positive right is the right to affordable quality mental health care, support, and services. There may be provision for the accreditation of facilities and professionals, including their training, although these may be contained in rules or regulations. More recently drafted legislation often aims at the integration of mental health into primary health care and demands community rehabilitation options for those with psychosocial disabilities. In addition, laws may contain provisions on rights to social protection, such as freedom of association, privacy, citizenship, and marriage. All such provisions enhance disability rights and should continue to be included in mental health legislation.[51]

(2) Reducing coercion and unnecessary interferences with liberty and bodily integrity

The principles of least restriction and detention as a last resort are so universally accepted that arguably they now form part of customary international law and are binding.[52] However, in many resource-poor countries, institutionalization is the default pathway of care for those with psychosocial disabilities, with Paraguay, for example, recently admonished by the Special Rapporteur on the right health for investing in tertiary care.[53] Despite WHO's call for reduced institutional care almost 20 years ago, the number of beds available in psychiatric wards in general hospitals increased globally by 60% between 2011 and 2014.[54] In 2017, high-income countries had 52.6 psychiatric hospital beds per 100,000 population, compared to 1.9 beds per 100,000 population in LMICs.[55] Yet, there is a powerful argument that "[e]mpowerment and recovery cannot happen in closed settings."[56]

Increasing community options

Less restrictive alternatives to confinement are vital, as General Comment 35 states.[57] The embedding of strong community mental health services in law is an indispensable aspect of any deinstitutionalization program.[58] Article 19 of the CRPD provides for the right to live independently and to be included in the community, and article 26 requires signatory states to "organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes" to ensure that those with disabilities enjoy "full inclusion and participation in all aspects of life." However, care in the community should not be coercive. The Special Rapporteur on the rights of persons with disabilities has complained about an expansion of "mandatory outpatient treatment, which not only increases involuntary interventions, but also allows for other forms of abuse such as illegal curfews" and similarly discriminatory practices such as tagging.[59] There is increasing evidence that non-coercive models of care within the community are more efficacious than traditional biomedical notions of compulsive support and treatment.[60] They better protect human rights, are easier to access (particularly for those from rural communities), and reduce stigma. There is no interruption to family relationships, friendships, or employment during treatment, with studies reporting better continuity of care, increased adherence to treatment, and greater user satisfaction.[61]

Where community-based alternatives to hospitalization are not already available, states must be obligated to create them. This will require strategic change to mental health priorities, with policies focused on building the necessary structures. Planning should emphasize the mainstreaming of mental health into primary care and community rehabilitation to enable local access, as Rwanda, for example, has done to good effect.[62] Plainly this cannot happen overnight. Presently, no country has sufficient community-based options to meet the collective need, and there is vast variability worldwide.[63] Indeed, high-income countries have approximately 200 times more financial resources for their mental health services than low-income countries.[64] Accordingly, no single model of care is replicable globally. However, the principle of least restriction requires all mental health legislation to include initial consideration of community-based alternatives to involuntary hospitalization, including available support from family members or friends.

The precise mechanics of a country's preferred community care structures need not necessarily be incorporated into law, but should be embedded in both policy and strategy to ensure implementation. WHO is currently compiling human rights-based guidance to help community-based mental health services (including acute services) promote autonomy, community inclusion, and the involvement of people with lived experience of psychosocial disability at all levels of decision-making. Peer and circle-of-support methods, which foster the recovery approach through needs-based, people-centered services, are growing, with the open dialogue model of Finland and the personal ombudsman introduced by Sweden both reaping rewards.[65] The "Soteria paradigm" enhances the autonomy of those with schizophrenic spectrum disorders through small, community-based therapeutic environments with significant lay support, social networks, and communal responsibilities.[66] The UK's crisis resolution and home treatment teams have proved effective even for those in crisis.[67] Trieste in Italy has had considerable success in its "shift from hospitalization to hospitality," which was initiated in the 1970s through a "whole life vision" and participatory health care at community mental health centers with limited beds for "guests" rather than inpatients.[68] Every country must develop its own accessible and culturally adapted community-based psychosocial interventions that best meet people's needs.[69]

Ringfencing community care budgets

Without proper planning and budgeting, the prohibition of coercion could herald a reduction in the quality of life and morbidity of some patients and trigger a rise in the mortality rate.[70] However, "where bed reduction is done responsibly … the overall costs of community-based care are similar to those of hospital-based services for long-term patients, while the quality of life and satisfaction among individuals receiving residential care in the community are higher."[71] Globally, median spending on mental health is approximately 2% of total government health spending, with expenditure per capita only US$2.50 in 80 countries.[72] Small mental health budgets in LMICs are spent mainly on inpatient care, with "significant financial and human resources pouring into mental health services that are, by design, constructed to violate human rights," as decried by D. Pūras and J. Hannah.[73] A shift to community rehabilitation programs requires an inevitable initial outlay—with government buy-in often difficult to obtain.[74] Yet, plenty of efficacious alternatives to coercive care can be implemented relatively cheaply through "task-shifting" via non-specialized lay staff "with a rich understanding of the socio-cultural context."[75] Interventions focused on mental health promotion and prevention in LMICs have been shown to be cost-effective."[76] However, absolutely crucial to the success of such programs is ringfenced health budget finance, which will require considerable lobbying globally; current government spending on mental health worldwide in terms of percentage of the health budget is woeful.[77]

Restricting the availability of hospitalization

Until the abolition of involuntary hospitalization and medical treatment, mental health legislation will remain the gatekeeper governing admission to psychiatric facilities and consent to treatment. Traditionally, the right to liberty has been subject to exceptions based on criminality, dangerousness (to self or others, necessarily judged subjectively rather than "watertight safeguards"), or necessity.[78] In some countries, such as Malawi, a hospital order may be lawfully obtained on the opinion of a "relative, partner or assistant" of the person with disabilities solely on the basis of "unsoundness of mind," with no need for a medical diagnosis or a particular degree of illness severity.[79] General Comment 35 suggests that "any deprivation of liberty must be necessary and proportionate, for the purpose of protecting the individual in question from serious harm or preventing injury to others," but the Special Rapporteur on the right to health has criticized such "broad and subjective grounds."[80] Any such legislative justifications must be further circumscribed, be based on objective criteria, and include the procedural protection of at least two professional opinions except in a clearly and tightly defined "emergency."[81]

International cooperation

Wealthier nations with significant community care infrastructure already in place have little excuse for delay in the implementation of policy and legislation prioritizing community rehabilitation with a view to phasing out compulsion. UN Sustainable Development Goal 17 requires states to provide, seek, and accept international cooperation where necessary.[82] However, "[i]nternational assistance should not support … health systems that are discriminatory or where … human rights violations occur …, particularly … large psychiatric institutions and other long-term segregated care institutions."[83]

Restraint

Draconian practices such as seclusion and physical or chemical restraint frequently occur in psychiatric detention. They are often used too hastily to prevent anticipated aggression instead of de-escalation techniques, to control or punish, or merely for staff convenience.[84] It is strongly arguable that restraint lacks any therapeutic justification, and M. Chieze et al. recently estimated a 25–47% incidence of post-traumatic stress disorder after intervention.[85] Accordingly, the Special Rapporteur on torture has advocated for the immediate and total cessation of all restraint measures.[86] However, some argue that this is not viable.[87] Certainly, any inclusion of restraint and seclusion in mental health legislation prior to a complete ban on coercion must be severely curtailed. It must be permissible only in an emergency for the shortest period of time commensurate with any risk. Other procedural protections required are swift and regular reviews of restraint after commencement. Legislation should also demand that careful records be kept of such interventions, with an independent review of all such decisions to discourage their use and increase staff accountability.

(3) Non-discrimination and empowerment

Non-discrimination requires those with psychosocial disabilities to be treated in the same way as others, including with regard to their choices on whether and where to accept treatment, and what type of treatment they desire. It is tied to the principle of empowerment, which in the psychiatric context means maximizing the choice, influence, and control of those with psychosocial disabilities over events in their lives, thereby enabling self-management of disability to the highest degree possible.[88] This fits with the biopsychosocial model of care, which is based on relationships of therapeutic reciprocity, rather than one-sided domination and control. The UN recognizes that "[e]mpowerment is a basic precondition for the recovery of many persons who struggle with critical psychosocial challenges," and respect for autonomy has been evidenced to improve health outcomes. K. Sugiura et al. usefully list a number of mental health laws passed between 2011 and 2017 with innovative provisions intended to increase the autonomy of those with psychosocial disabilities.[89]

Consultation with service users

Under article 4(3) of the CRPD, states must "consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" in strategic planning on mental health and the development and implementation of legislation and policies. Any new law should crystalize such rights. Those with psychosocial disabilities should be appointed to monitoring bodies and involved in decisions affecting psychiatric patients at the individual and strategic levels. For example, panelists of the UK's first-tier tribunals reviewing compulsory hospital detention have traditionally comprised a psychiatrist, a lawyer, and a lay member who is usually a social worker. Instead, the latter could be someone with lived experience of psychosocial disability to provide a service user's perspective.

Respecting will and preferences

The right to the highest attainable standard of health enshrined in article 25 of the CRPD must be "on the basis of free and informed consent," which must be obtained *prior* to any treatment.[90] However, substitute decision-making is the prevalent treatment model and often overrides the wishes of those with psychosocial disabilities, usually on the basis of their "best interests." This concept "contradicts respect for the will and preference of individuals."[91] General Comment 1 demands the complete prohibition of substitute decision-making in favor of supported decision-making, since those with disabilities "enjoy legal capacity on an equal basis with others in all aspects of life" under article 12(2).[92] Such capacity must be respected "at all times, *including in crisis situations*."[93] Plainly this is not the case anywhere at present; doctors, social workers, and sometimes family members have legal powers to compulsorily detain people on the basis of mental disorder, with patients forced to take psychotropic medication. Mental health laws must maximize empowerment, with supported decision-making the rule, not the exception. Any divergence from a person's wishes should always be explained (to both the individual concerned and any staff involved in their care), recorded, and regularly reviewed. Useful global examples of context-appropriate approaches to implementation of supported decision-making in mental health care have been highlighted in recent research.[94] Different models include formal and informal networks, support agreements, an independent advocate who "genuinely represents *and defends* the wishes and interests of the individual" in accordance with General Comment 35, advance directives, legal capacity assistance from a trusted person of the individual's choice, and peer support.[95] The Special Rapporteur on the rights of persons with disabilities has called specifically for more recognition and integration of the latter into legislative frameworks.[96]

States have a duty to provide support to those with psychosocial disabilities where necessary. Paragraph 17 of General Comment 1 views "support" as a broad term encompassing both informal and formal support arrangements of various types and intensity. The Special Rapporteur on the rights of persons with disabilities cautions against a "one size fits all" approach to supported decision-making as being discriminatory and likely ineffective, and lists various possible types of necessary support, such as sign language expertise.[97] A code of practice or regulations can be drafted to flesh out further details.

Advance planning

Advance planning provisions complement the empowerment approach and should be included in mental health laws, as recommended by the Special Rapporteur on the right to health.[98] Unfortunately, current legislation tends to permit the overruling of advance decisions in various circumstances. For example, the validity and applicability of "advance directives" permissible under section 24 of the UK's Mental Capacity Act of 2005 can be challenged under section 25 on several subjectively assessed bases. Proposed new mental health legislation would also permit deviation from such directives for "compelling reasons."[99] Joint crisis plans include elements of advanced directives through shared decision-making between service users and professionals. There is some evidence of their cost-effectiveness and ability to improve therapeutic relationships.[100] Any new legislative criteria for overriding decisions on hospital treatment made prior to admission must be unequivocal and limited in scope. Advance decisions made after the abolition of coercion will require respect even when a refusal of hospitalization or medication is contrary to clinical opinion.

Guardianship

Also contrary to article 12 of the CPRD are guardianship provisions, obliging those with psychosocial disabilities to reside in a particular place and sometimes to follow a particular treatment regime.[101] Current procedural protections include limiting guardianship to a remedy of last resort, selection of the guardian by the person with psychosocial disability, periodic review of guardianship orders, and the right to appeal decisions that remove or restrict legal capacity. Nonetheless, "[a]ll such reforms fall short in respecting the rights of persons with disabilities."[102] Many of the efforts toward introducing supported decision-making regimes maintain elements of substitute decision-making, or coexist with regimes.[103] However, Costa Rica's Law No. 9379 of 2016 has abolished all forms of guardianship, creating instead the legal figure of "guarantor of equality before the law of persons with disabilities." Similarly, Peru recently abolished both guardianship and substitute decision-making through a bill drafted by multi-stakeholder commissions.[104] Guardianship—and consent provided for hospitalization, treatment, or accommodation contrary to the wishes of a person with psychosocial disability by legal guardians or family members—cannot be justified and should be banned immediately.[105]

(4) Target-setting to reduce and eventually eliminate coercion within a specific and reasonable period

While consensus on the eradication of compulsion in psychiatry is unlikely any time soon, CRPD implementation must be conscientious. This requires timebound targets for the reduction and elimination of force in health care settings. Time frames for the introduction or national rollout of community rehabilitation options should be incorporated into both policy and legislation. A US federal court recently criticized the state of Mississippi for "policy changes that both decrease and increase institutionalization," with citizens "trapped in a snail's-pace deinstitutionalization" process.[106] A specific and reasonable time limit for an end to coercive measures within legislation and policy makes justiciable any failure to abide by the specified period. The total prohibition of coercion within 10 years is suggested as a reasonable time frame which all signatory states should aim to meet, with high-income states having little excuse for failing to comply earlier. States should create or empower a body to police the meeting of policy and legislative targets. Although each state must set goals and targets within the parameters of its own particular context and resources, an outer time limit set by the CRPD Committee itself would greatly assist in preventing drift.

Other benefits of updating mental health legislation

Improving care standards and reducing stigma

WHO's Mental Health Gap Action Programme (mhGAP) emphasizes that "[m]ental health law codifies and consolidates the fundamental principles, values, aims, and objectives of mental health policies and programmes."[107] An often undervalued benefit of mental health law is its more subtle and less measurable effects. As H. Liebling and L. Davidson et al. have observed, "mental health legislation also has an important symbolic as well as functional role, and can progress a moral imperative for improved mental health systems."[108] Laws can gradually change the understanding, values, and discriminatory beliefs of the general public and mental health professionals alike. Codifying strict parameters for control and requiring a partnership approach between clinician and beneficiary will slowly change attitudes on the acceptability of custodial settings and coercion, reducing the stigma surrounding psychosocial disability. Decreasing compulsion will significantly alter the status quo, even if full compliance with international human rights standards remains unfeasible for some years to come.[109] Legislative change should coincide with public awareness campaigns explaining legal intentions and rights. Training and professional development components should include legal rights and obligations for all clinical staff, ensuring reconsideration of the levels of acceptable risk to others. Gradually, pervading and long-held paternalistic views and prejudices will alter. Thus, paradoxically, mental health laws that legitimize compulsory detention and medical treatment on the basis of disability—for a limited and tightly circumscribed period—can be a powerful tool for change.

Conclusion

In 2018, the Special Rapporteur on the right to health declared the field of mental health to be "on the verge of freeing itself from a pattern of coercion and institutionalization."[110] Any cause for celebration was somewhat premature. However, he correctly observed that "[w]e are at a crucial point in terms of influencing how we … shape the next [decade] as regards ending the cultural dependence on confinement and incarceration."[111] P. Bartlett highlights the practical repercussions of the present impasse succinctly thus:

> *However important the new human rights paradigm may be, and however much the new paradigm should be promoted, the existing, non-compliant structures will be around for many years to come. For the people enmeshed in those structures, the substantive and procedural protections of the old paradigm may well still bring considerable benefits.*[112]

That is, of course, if there are any such protections. Almost a third of 111 countries reporting to WHO in 2017 had no stand-alone mental health legislation whatsoever, and such legislation existed in only 36% of low-income states. Countless vulnerable patients residing in the other 64% continue to be subjected to compulsory psychiatric detention and treatment without legal basis or procedural protection.[113]

This paper has argued that mental health legislation remains essential worldwide to protect the international human rights of those with psychosocial disabilities. While to date such laws have legitimized psychiatric compulsion, they can simultaneously (1) reduce coercion through stringent substantive and procedural protections and empowering provisions that enhance the right to autonomy and (2) enshrine the principles of least restriction and last resort. New or improved laws can help drive up standards of mental health care, increase protection for human rights, and reduce prejudice and stigma. A global commitment to "holding" legislation as a precursor to a complete ban on coercion would be an antidote to the current stalemate regarding full implementation of the CRPD. The global pandemic makes the need for an end to psychiatric compulsion even more pressing. It is already having a substantial impact on people's mental health, with a significant rise in stress and anxiety across the globe. Long-term psychological effects are likely from the prolonged strain caused by severe restrictions on liberty resulting from quarantines and lockdowns. In the pandemic's aftermath, the use of compulsion as a method of treatment is highly likely to be re-traumatizing.

The current inertia is inexcusable. The CRPD Committee has the wherewithal to end the current stasis by endorsing the updating of mental health legislation that, while not fully compliant with the CRPD, significantly *improves* compliance and thus rights protection for those with psychosocial disabilities. Small steps toward goals are always more realizable than huge leaps, and advanced adherence to international human rights and good practice standards through such legislation would improve the lives of millions. Accordingly, the CRPD Committee should issue a general comment to that effect as a matter of urgency, thereby providing the necessary "reluctant permission" for the progressive realization of respect for articles 12 and 14 of the CRPD. It should set a specific and pragmatic target date for full compliance (for example, within a decade), with earlier fulfilment where possible. In accordance with article 4(3) of the CRPD, those with psychosocial disabilities must be consulted about and involved in all modernizing processes. Only with the CRPD Committee on board with staged progress will there be any real global advance in the promotion, protection, and fulfilment of the rights of those with psychosocial disabilities, rooted in respect for human rights and individual empowerment, rather than compulsion.

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The Great March of Return: Lessons from Gaza on Mass Resistance and Mental Health

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Abstract

The Gaza Strip is under an Israeli land, sea, and air blockade that is exacerbated by Egyptian restrictions and imposes an enormous cost in terms of human suffering. The effects of blockade, poverty, and frequent attacks suffered by the population have taken a significant toll on people's mental health. The Great March of Return, a mass resistance movement begun in March 2018, initially provided a positive impact on community mental health via a sense of agency, hope, and unprecedented community mobilization. This improvement, however, has since been offset by the heavy burden of death, disability, and trauma suffered by protestors and family members, as well as by a failure of local and international governments to alleviate conditions for Palestinians in Gaza. Reflecting on the ephemerality of the material and political gains of this movement, this paper shows that Palestinian and international health practitioners have an opportunity to develop an understanding of the psychosocial consequences of community organizing and mass resistance while simultaneously providing holistic mental and physical health care to community members affected by the events of the Great March of Return and other efforts.

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Competing interests: Bram Wispelwey and Yasser Abu Jamei direct community health programs in Palestine (Health for Palestine and Gaza Community Mental Health Programme, respectively).

Conditions in the Gaza Strip

For 13 years, the Gaza Strip has been under a land, sea, and air blockade, imposed on top of a decades-long Israeli military occupation and with an enormous cost in terms of human suffering.[1] The blockade has limited the movement of people, goods, and services in and out of Gaza and has contributed to a chronic humanitarian crisis entailing a lack of sufficient electricity, sanitation, and health services for Palestinians in the Strip.[2] Israel has intentionally calibrated its occupation and blockade measures to maintain Gaza on "the brink of collapse."[3] The humanitarian stress placed on Gaza has prompted the United Nations (UN) to warn that the area will be "unlivable by 2020."[4] More than 4,400 Palestinians, including more than 1,100 children, have been killed, and tens of thousands have been injured over the course of three military assaults by Israel in the last 12 years.[5] Commonly considered "the world's largest open-air prison," Gaza has a population of two million people, 70% of whom are refugees whose right of return to their homes in present-day Israel has been systematically refused since 1948.[6] All political attempts to resolve the refugee crisis over the past seven decades have failed, leaving millions of displaced Palestinians in Gaza, the West Bank, Israel, and elsewhere in inadequate "temporary" living conditions, and—perhaps more harmfully—with an ever-waning hope for refugee return.

Exacerbating this context has been an economic crisis characterized by high levels of unemployment and poverty. For example, unemployment rose from 44% to 52% between 2017 and 2018; young adults aged 19–29 are the most affected, with a 69% unemployment rate as of early 2018.[7] Over the same period, 53% of the population in the Strip was thought to be living below the poverty line (up from 39% in 2011), with deep poverty affecting more than a third of the population.[8] With a dismal outlook on prospects for the future, a sense of both helplessness and hopelessness has escalated among the people.[9]

Mass resistance as mental health intervention

In March 2018, hope was reignited in the form of large-scale demonstrations in Gaza. Protests were triggered by collective anger surrounding Palestinians' refused right of return, the ongoing military occupation and blockade, the dire economic situation, and US policy decisions that included the move of its embassy from Tel Aviv to Jerusalem and the defunding of the United Nations Relief and Works Agency for Palestinian Refugees (UNRWA) from US$364 million (30% of the agency's entire budget) in 2017 to zero.[10] Palestinians in the Strip began what became known as the "Great March of Return" (GMR) protest on March 30—Land Day—in solidarity with Palestinian citizens of Israel. Land Day commemorates the protests of Galilean Palestinians against the appropriation of their land by the Israeli state in 1976, an event that led to the killing of six protestors and the injury of dozens of others.[11] Every Friday since, Palestinians in Gaza have massed at the border for GMR protests to assert their right to return to their homelands, as outlined in UN Resolution 194.[12]

The GMR demonstrations, conceptualized by a group of young Palestinians through social media, quickly developed into a grassroots community organizing effort.[13] The GMR's organizers reached out to a cross section of the Palestinian community to foster support and participation. The initial atmosphere was festival-like in its exuberance and multigenerational family inclusion.[14] All the richness of Palestinian life was present: food vendors, *dabke* dancing, clowns, acrobats, and even wedding celebrations. The protests, which included chanting and mass movement toward the separation fence between the Gaza Strip and Israel, were faced by tear gas and live sniper fire from Israeli security forces.[15]

With the large and united scope of these demonstrations, and broad international interest in them, Palestinians found a renewed sense of hope that active resistance in the form of large-scale protest could precipitate a fundamental change in the grim situation in Gaza. Additionally, collective organizing infused participants with a sense of dignity and self-efficacy in the face of immense political challenges to well-being. One of the GMR's early organizers noted that "we stood against all the powers telling us to break and die in silence and decided to march for life … we are fighting back peacefully with our bodies and our love for life, appealing to the justice that remains in the world."[16] Mental health practitioners began noticing that protestors felt, for the first time, that they had agency in challenging the structures determining their conditions.[17] They had refocused the global media story on their goals and actions, developing a perception that a collective Palestinian voice was being heard again. The achievement of a positive and meaningful international response felt possible, bringing hope and what mental health practitioners noted as significant improvements in mood and response to trauma.[18]

Mental health in the Palestinian context: Where Western models fail

While mental health has traditionally been pathologized at an individual level in Western psychological discourse, it is clear to Palestinian mental health professionals that the alarming rates of mental illness among Palestinians are driven first and foremost by the historical and ongoing political context. Mental illness rates in the occupied Palestinian territory, according to standard Western measurements, are some of the highest in the world.[19] Compared to Americans, Palestinians have three to four times the rate of post-traumatic stress disorder (PTSD), and their depression rates significantly exceed those of any other people in the Eastern Mediterranean.[20] But many health professionals in the occupied Palestinian territory believe that this Western mental health methodology is capturing just the tip of the iceberg, below which there exists community-wide social suffering related to occupation, blockade, violence, ethnic cleansing, land theft, daily humiliation, and a loss of faith in local and global leadership to resolve the crisis.[21] In other words, health professionals are drawing a distinction between an end diagnosis of depression and underlying, justified communal misery. In order to avoid reducing community-wide experiences of political violence to individual trauma, some Palestinian investigators have abandoned Western mental health frameworks in favor of those that highlight the roles of political power and settler-colonialism in shaping an intergenerational resistance praxis.[22]

Some have posited that these Western mental health diagnoses, when more appropriately redefined in the Palestinian context as social suffering, require a human rights-informed and political advocacy approach to therapy.[23] The false categorization of mental health illness from a Western and individualized diagnostic lens may lead to ineffective care that is not tailored to context, which poses serious ethical concerns and the possibility of harm.[24] In particular, therapeutic psychosocial approaches that assume that people suffering from trauma are now *post*-trauma are destined to fail in a region where trauma is continuous and the triggering context is often unavoidable. For example, Palestinian children being treated for behavioral or mood disorders as a result of a wartime trauma experience delayed progress through their treatment course, with persistent anxiety and fear due to a lack of security and concern for imminent harm to themselves or family members. These patients are at high risk of relapse and further pervasive psychosomatic manifestations given their inability to escape the traumatizing context. Within such a trapped and colonized condition, Frantz Fanon's framework connecting social subjugation to mental health distress is wholly apposite.[25] The GMR is thus an example of Fanon's *Les Damnés de la Terre*, for its protestors are collectively empowering themselves to become architects and agents for change.[26] Acknowledging the structural oppression and systematic violence that affect all levels of society is fundamental to identifying how political advocacy, collective resilience, and mass protest should form an integral part of mental health treatment, particularly when protection from political and military violence is, as in the case of Gaza, unavailable.

Palestinian health professionals have long noted the links between meaningful resistance and activism efforts, on the one hand, and psychological well-being and health protection, on the other. This observation framework is in line with decades of decolonial, subaltern, antiracist, Global South, Black, and indigenous mental health praxis and literature.[27] A growing radical healing movement and framework in US psychology draws on a similar legacy, seeking an activist approach to "healing and transformation that integrates elements of liberation psychology, Black psychology, ethnopolitical psychology, and intersectionality theory."[28] As activism, community organizing, and protest are gaining renewed interest in the United States and elsewhere as means of resistance, antiracism, decolonial praxis, and political change, evidence is mounting that these actions have beneficial effects, via increased agency, on people's well-being and mental health.[29] A recent US study found that political activism was a protective factor for Latinx college students against stress and depressive symptoms, and organizations such as City Life/Vida Urbana in Boston have long touted the positive connection between community organizing and mental health.[30]

With the social suffering thesis put forward by Palestinian health professionals such as Rita Giacaman and Samah Jabr—which links structural racism and systematic violence to all forms of well-being, including psychological—these "new" results should not surprise us.[31] And this Palestinian conception offers a coherent answer to why mental health practitioners in Gaza recognized a profound positive impact on psychological well-being at the beginning of the GMR. These practitioners had already explicated the importance of including the voices of the oppressed in the healing process, and the GMR is, among other things, a bold example of the traumatized and oppressed—*les damnés*—taking hold of the therapeutic reins at a community level.[32]

Two years on: Where do we go from here?

Despite engaging in a weekly mass protest stretching for two years now, and recognition from the UN that Israel's response to the GMR may include numerous war crimes or crimes against humanity, the situation for Palestinians in Gaza has not improved.[33] In addition to the hundreds of deaths and tens of thousands of injuries since the GMR began, Palestinians have watched their political leadership and the international community fail to leverage this activism into material or political improvements.[34] The broadly experienced sense of promise at the GMR's commencement has begun to fade.

The initial positive mental health effects of mass resistance have been displaced by a significant increase in patients diagnosed with PTSD, depression, and anxiety, as well as relapsing mood and behavioral disorders in children.[35] Further burden has been placed on the collective social fabric given the limited economic resources and increasing physical and mental trauma experienced by family members. A sharp uptick has occurred in Palestinians accessing mental health services across all genders and ages, especially young adult men, the group most likely to experience direct or observed trauma during the GMR.[36] The Gaza Community Mental Health Program (GCMHP), a community-based organization that grounds its work in a social justice-based approach to mental health treatment, has been at the forefront of the response to addressing the downstream effects of the GMR crackdown on Gaza's citizens. Psychological first aid, telephone counseling, and crisis-oriented community interventions strive to protect vulnerable groups in response to escalating crises. GCMHP aims to treat these acute mental health manifestations while also assisting patients in reclaiming their role as productive members of the community, but the situation has become increasingly difficult.[37]

Current developments on the ground—including the United States' withdrawal of funding to UNRWA and other entities, the US Embassy's move to Jerusalem, the fragmentation of Palestinians into disconnected populations with different rights and legal statuses, the ongoing destruction of Palestinian homes and villages, deliberate material deprivation in Gaza, and political plans for West Bank annexation—represent further entrenchments of occupation, colonization, and international abandonment of Palestinians' rights and well-being.[38] These facts, coupled with total territorial control by one the world's most powerful militaries and systematic violence readily unleashed on protestors, make effective resistance difficult to sustain.

As the Gaza Strip becomes increasingly unlivable, sociopolitical stressors will mount and exacerbate the suffering that manifests, among other ways, as poor mental health outcomes. Humanitarian intervention and treatment strategies that do not embrace the political realm risk being ineffective at best and may inadvertently prolong suffering by eschewing root causes. Palestinian health practitioners and researchers continue to connect the biomedical to the political sphere, combining health work with broader efforts to support communities struggling against occupation as the most rational and effective approach.[39] Palestinian health workers, at times intentionally targeted and killed by snipers, have lived out this attitude during the GMR.[40]

Given the dispiriting lack of material change as a result of the GMR, and its significant toll on Palestinians' lives and well-being, we are left with difficult questions about the ephemerality of the mental health benefits that accrue from collective organizing and resistance. Despite repeated setbacks, however, Palestinians have mounted numerous and often unexpected resistance charges over the last century, leading to the development of a highly cultivated intergenerational means of coping and renewal.[24] In this sense, the benefits of resistance on mental health are not purely contingent on whether demands are achieved in the short term, but are passed from generation to generation in order to keep the political struggle afloat and community hope alive. This steadfastness is in turn met with oppression designed to extinguish resistance, including, in the case of the GMR, potential war crimes or crimes against humanity committed by the Israeli army in the form of targeting and killing children, health workers, journalists, and people with disabilities.[41]

The extremeness of responding to mass protest with brutal violence rather than negotiation—the confirmation of an oppressor's immovability—requires an international response. Given that many of the geopolitical factors that contribute to social suffering are within the political and advocacy realms of international health professionals, these professionals must organize on behalf of Palestinian justice and liberation in their home countries if they hope to positively affect Palestinians' mental and physical health. Groups such as the Health Advisory Council of Jewish Voice for Peace are organizing within US communities to promote health-related avenues for activism in support of Palestinians' health. Those of us from countries with historical responsibility and geopolitical leverage—the United States and United Kingdom, first and foremost—have a special responsibility, as we do toward citizens of our own countries, to contribute to achieving Palestinians' rights to health and liberation. Financially, clinically, and programmatically supporting grassroots Palestinian initiatives, such as GCMHP and Health for Palestine (a community health program in West Bank refugee camps), represent tangible opportunities for Western health professionals.[42] The GMR is an opportunity to recognize and add to the evidence linking mass resistance and activism to therapeutic and salutogenic effects, and to follow this exemplary Palestinian framework in both theory and practice.

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Understanding US Immigration Detention: Reaffirming Rights and Addressing Social-Structural Determinants of Health

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Abstract

A crisis of mass immigration detention exists in the United States, which is home to the world's largest immigration detention system. The immigration detention system is legally classified as civil, rather than criminal, and therefore non-punitive. Yet it mimics the criminal incarceration system and holds detained individuals in punitive, prison-like conditions. Within immigration detention centers, there are increasing reports and recognition of civil and human rights abuses, including preventable in-custody deaths. In this paper, we propose understanding the health impacts of detention as an accumulation of mental and physical trauma that take place during the entirety of a detained immigrant's experience, from migration to potential deportation and removal. Further, we explore the social-structural determinants of health as they relate to immigration detention, contextualize these determinants within a human rights framework, and draw parallels to the larger context of US mass incarceration. Realizing the right to health requires addressing these social-structural determinants of health. For the care of immigrant patients to be effective, clinicians and public health professionals must incorporate an awareness of the health risks of the immigration detention system into trauma- and human rights-informed models of care during and after detention.

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Competing interests: None declared.

Background

Approximately 7% of the US population, or 22.8 million people, are non-citizens.[1] In 2017, nearly 260,000 people sought asylum, or protection from persecution, within the United States.[2] These immigrant populations experience unique risks to health, including pre-migratory trauma, unsafe and stressful migration experiences, and post-migration discrimination.[3] Human rights abuses can occur across this spectrum of the immigrant experience. Once in the United States, immigrants may experience fears of deportation or mistrust of health services, dissuading care-seeking behavior.[4] Health outcomes associated with increased immigration enforcement and fear of deportation include increased cardiovascular risk factors, lower birth weights, and worsened mental health.[5] In addition, these health behaviors and outcomes ripple throughout the communities to which immigrants belong.[6] Twenty million children living in the United States have at least one immigrant parent, and more than 16.7 million people have at least one undocumented family member living with them, among whom nearly 50% are US born or naturalized citizens.[7]

Medical and public health research and practice has increasingly addressed the negative health impacts of anti-immigrant policies.[8] However, the health impacts of immigration detention beyond preventable deaths have received comparatively little attention, even though immigration detention has become increasingly prevalent and increasingly in violation of human rights standards.[9] In 2018, the US government detained nearly 400,000 people in the 200 immigration jails across the country, with a total average daily population of 42,000.[10] In 2019, this reached a total daily population of 55,000, the largest in American history, reflecting a steady and steep rise in the immigration detention population over the past few years.[11] At least one in four Latino/Latinas say they personally know someone who has been detained or deported for immigration reasons in the last 12 months.[12] Knowing a deported person is associated with adverse mental health outcomes, irrespective of one's own legal status.[13]

For the care of immigrant patients to be effective and their right to health realized, clinicians and public health professionals need a working understanding of the immigration detention system and the various ways it may affect a person or family unit's health and well-being. This article uses a framework based on the social-structural determinants of health to offer an orientation to the US detention system and calls for incorporating this awareness into trauma- and human rights-informed models of care for immigrant patients. The social determinants of health, as defined by the World Health Organization, are "the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life."[14] Underpinning this framework is recognition of health as a right for all individuals, irrespective of immigration status, alleged criminality, or detention, as laid down in international human rights treaties such as the International Covenant on Economic, Social and Cultural Rights and other human rights conventions specific to refugees, migrants, and asylum-seekers.[15]

Understanding the US immigration detention system

Federal immigration enforcement policy changes paved the way for an expansive rise in detention rates over the past several decades.[16] In 1973, the US government detained a daily average of 2,370 migrants; this number rose to 5,532 by 1994, surged to 34,000 by 2009, and as of 2019 had risen to a record 55,000.[17] These numbers are dramatically out of proportion to the rate of unauthorized immigration during these same time periods; for example, from 2007 to 2017, there was actually a drop in national estimates of unauthorized immigrants.[18]

Federal policies that were central to this expansion were the 1996 Antiterrorism and Effective Death Penalty Act and the Illegal Immigration and Immigrant Responsibility Act, which established minimum daily detention numbers and lowered the bar for deportable offenses; many crimes categorized as "aggravated felonies" in the immigration context are considered neither aggravated nor felonies in the *criminal* context.[19] Notably, both undocumented and legal permanent residents are subject to detention.

The immigration detention system, unlike criminal jails or prisons, operates under civil law. Consequently, many constitutional protections available under criminal law do not exist in the detention system. For example, immigrants can be detained indefinitely; there is no federal right to legal representation for detainees; and most immigrants are not entitled to government-appointment lawyers, greatly reducing their chances of winning their case.[20]

Yet detention conditions are often similar to those of prisons or jails.[21] Detained individuals are held in secured facilities, wear prison uniforms, and subjected to strict control of time and movement. Indeed, many local jails contract bed space to Immigration and Customs Enforcement (ICE), and for-profit, stand-alone immigration detention facilities use corporate prison models.[22]

Further, there is significant fragmentation of responsibility and accountability among the agencies managing the immigration detention system. The Office of Refugee Resettlement, housed in the Department of Health and Human Services, oversees the detention of children and unaccompanied children, whereas Customs and Border Protection (CBP) and ICE, within the Department of Homeland Security, administer adult detention. The structure and quality of health services in detention settings is similarly fragmented. Approximately 25% of detainees receive care from the ICE Health Service Corps (staff detailed from US Public Health Service), while others are cared for by direct employees of for-profit health staffing vendors. The policies and procedures that govern health care in ICE and CBP detention settings—the ICE Performance Based National Detention Standards and the CBP National Standards on Transport, Escort, Detention, and Search—are unevenly applied across the various detention settings, and quality assurance is often subcontracted to for-profit vendors. For health professionals working in detention centers, law enforcement security may dictate the scope of care, unlike hospitals and ambulatory settings, where medical experts inform those decisions.[23] Analyses of documented preventable deaths reveal gross deficiencies in access to care, quality of care, and transparency in death review.[24] This fragmented system of care operates without clear or transparent oversight, falling short of both human rights and other legal standards.[25]

Human rights and the social-structural determinants of health in the US immigration detention system

The social determinants of health in immigration detention include direct physical and mental health outcomes from neglect, abuse, poor conditions of confinement, and challenges to economic stability and social networks—adverse effects that continue long after detention ends and that reach beyond the individual. Experiences of discrimination, racialization, and criminalization are structural determinants of health that further shape immigrant patients and exacerbate health inequities. Realizing the human rights and inherent dignity of migrants, including their right to health, requires addressing these social-structural determinants of health.[26]

Multiple forms of abuse

Recent reports indicate that physical abuse and sexual assault in detention centers are frequently ignored. For example, the Department of Homeland Security received 33,126 complaints of sexual and physical abuse from January 2010 to July 2016 but investigated only 570.[27] Rape and sexual assault are often underreported in immigration detention due to fears of retaliation, social isolation, language barriers, and knowledge that allegations are not seriously investigated.[28] Many detention facilities use solitary confinement as punishment or to monitor individuals who experienced victimization or are mentally ill, despite its detrimental impact on physical and psychological well-being.[29] Because some security personnel and private prison officials are responsible for developing and managing health services, there is often a punitive instead of therapeutic approach to mental health care.[30]

Conditions of confinement

Detention center medical systems have limited health care services, are frequently under-staffed, and are focused on managing acute care needs rather than chronic medical problems, resulting in medical neglect, delayed diagnoses and care, and severe negative consequences, especially among trauma-exposed individuals.[31] As the daily population of detained adults and children has increased, overcrowding has become a risk to the health of detained individuals. Epidemiologic investigations by local and state health departments and the Centers for Disease Control and Prevention have documented outbreaks of mumps and measles, pneumonia, influenza, and other respiratory disease in several detention facilities.[32] Other conditions of confinement that affect health include facility practices such as continuous lighting and sleep deprivation, lack of privacy, sanitation deficiencies, restricted recreation time, dirty or inadequate clothing (particularly for weather changes), inadequate meals, deprivation of autonomy and security, and verbal harassment and physical mistreatment by detention officers.[33] In one review of more than 7,000 asylum cases, one-third of detained asylum-seekers reported poor conditions, treatment, or medical issues. Among them, 61.8% reported issues related to food and water, 34.5% reported issues related to hygiene, and 45.6% reported issues related to the inability to sleep, overcrowded conditions, confinement, and the temperature being too cold.[34]

Economic and social stressors

Immigration detention compounds preexisting social determinants of health, such as language barriers, economic inequalities, and disrupted social networks. For example, lost wages, steep prices for phone calls, having to purchase necessary items from commissary (such as toiletries), legal fees, and exorbitant bond prices all exacerbate the economic burden on immigrants and their families, who may already be from low socioeconomic backgrounds.[35] The absence of appropriate interpretation services to meet the diverse language needs of immigrants in detention centers also contributes to poor and devastating health outcomes, as does the disruption of social networks and social ties due to distance from immigration detention centers and separation from family and support systems in the United States and native countries.[36] Legal noncitizen residents—who are the most likely to have work and family ties—are likely to be detained longer than other noncitizens and may therefore be especially vulnerable.[37] Undocumented family members lack additional freedoms of mobility relative to other immigrants. Due to fears of "entering the belly of the beast," many undocumented immigrants do not visit detained family members, weakening family and social cohesion.[38] Lastly, the social determinants of health are compounded by the legal context of immigration detention centers—for example, the absence of a lawyer and the reality of indefinite detention with lengthy backlogs and unclear timelines—adding uncertainty to the immigration detention process, which itself is associated with anticipatory stress detrimental to health.[39]

Racialization and criminalization

These social determinants of health are reinforced by structural determinants of health—conditions further "upstream"—such as systemic racism. In the immigration detention context, racism and the dual racialization-criminalization of immigrants are particularly poignant forces. Male Latino immigrants have been especially subjected to criminal stereotypes and scapegoating; nearly 90% of detained individuals are men, and more than 97% are Latin American or Caribbean.[40]

Black immigrants are also disproportionately affected due to the immigration enforcement system's reliance on police and courts to funnel immigrants who have committed crimes into immigration detention.[41] Racial discrimination in law enforcement and criminal sentencing leads Black immigrants to be more likely than any other population to interact with law enforcement and to be arrested, convicted, and imprisoned.[42] As a result, although only 7% of non-citizens in the United States are Black, they make up 20% of those facing deportation on criminal grounds.[43] Further, Black immigrants are more likely than other immigrants to be detained for criminal convictions and to be deported due to a criminal conviction.[44]

Like police officers in criminal law enforcement, immigration enforcement agents may also use racial profiling as an enforcement strategy. This can lead to the arrest and detention of US citizen Latino/as in addition to those who are undocumented, serving as a significant psychosocial stressor with consequent health impacts among both immigrants and citizen communities of color perceived to be immigrants.[45]

Immigration Intercept Model: A conceptual framework

Given the impact of immigration detention on the health outcomes of detainees, their families, and communities, health care professionals outside the immigration detention system must be prepared to approach patients' history of immigration detention as an important health risk factor.[46] Further, the health impacts of detention must be understood as embedded within the accumulation of mental and physical trauma that take place over the spectrum of the immigration experience, often in violation of human rights standards. The range of experiences prior to and following detention include adjusting to life as an immigrant in US communities, coping with preexisting trauma, dealing with the pain of family separation immediately following apprehension, and adapting to new social and economic circumstances after detention. Understanding these factors allows health care professionals to intervene at different stages of an immigrant person's or family's immigration journey. We propose the Immigration Intercept Model (Figure 1), adapted from the Justice Intercept Model used to identify community interventions for individuals with substance use and mental health disorders as they move through the criminal justice system.[47]

The Immigration Intercept Model identifies points, or intercepts, at which social-structural determinants of health play a role and where health care professionals could advocate for interventions. Some immigrants (such as asylum-seekers) are immediately detained after crossing the border and do not experience life in the United States; some experience deportation or removal while others do not. As a result, it is critical to consider these intercepts and how a social-structural determinants of health framework, based in human rights, intersects with each intercept.

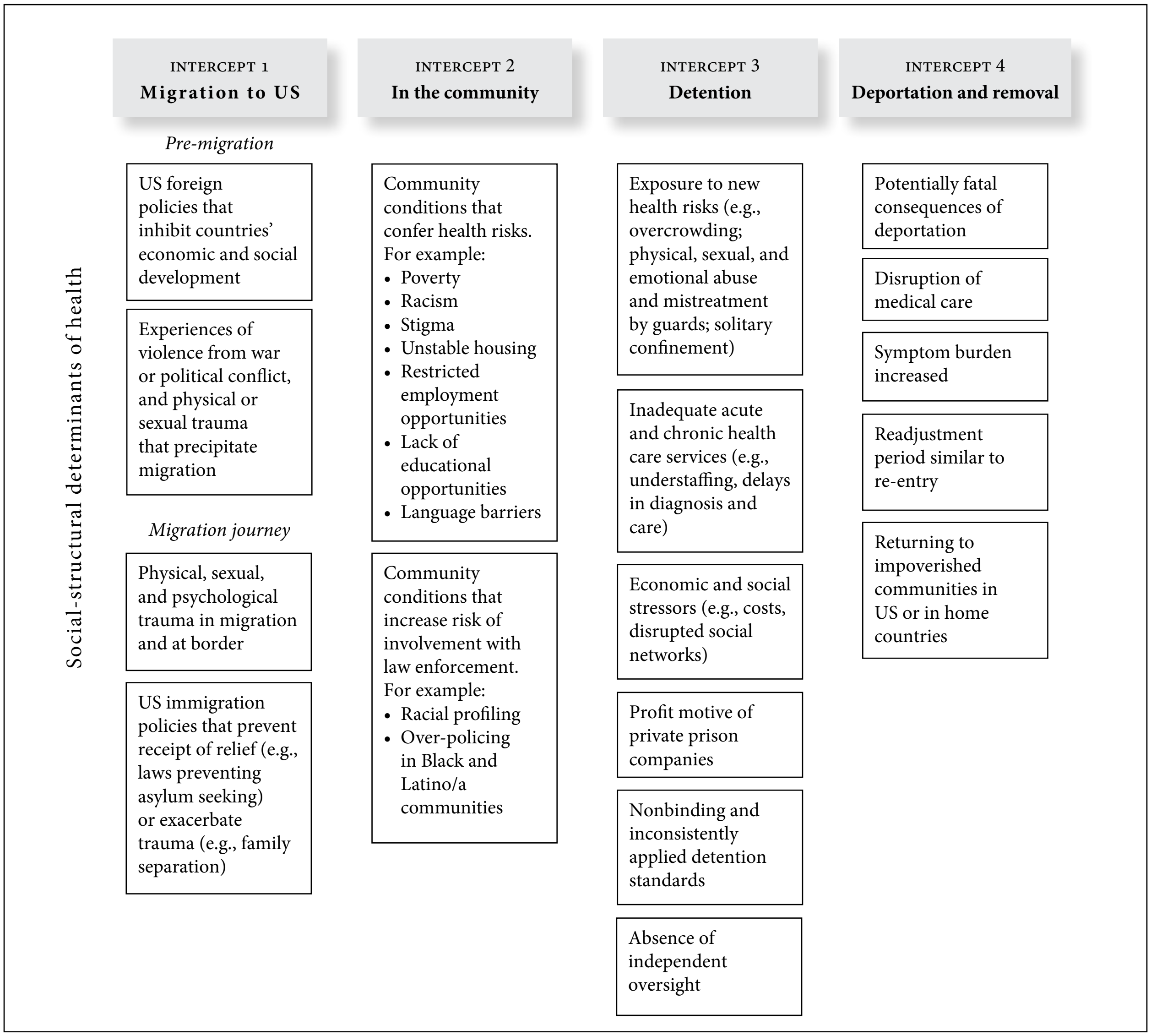
Pre-detention factors include (1) experiences of trauma in one's home country that precipitated the migration (such as domestic violence, gang violence, poverty, and war); (2) experiences during the migration journey (such as physical trauma, sexual trauma, and trafficking), which can be compounded by dehydration or malnutrition; and (3) community conditions such as poverty, racism, housing instability, and employee exploitation that confer independent health risks.[48] These experiences vary depending on an individual's legal status—a structural and racialized determinant of health in itself, with a host of collateral consequences such as restricted employment prospects, housing instability, and stigma.[49]

After detention, immigrants may be released due to receiving an immigration benefit, being released on bond, or being deported. The end of detention, however, does not terminate an individual's contact with negative aspects of the immigration system. Many formerly detained immigrants experience a readjustment period similar to re-entry following incarceration.[50] They also disproportionately return to impoverished communities of color in the United States or economically struggling communities in their home countries, further exacerbating existing health inequities. Whether released into a US community or deported, they may experience a disruption of medical care as they attempt to connect to health care professionals to address new or chronic medical issues. The consequences of deportation can be fatal, especially when individuals are removed to countries without adequate health systems or where they are at risk of persecution.[51]

From a clinical perspective, heeding the Immigration Intercept Model might mean screening for a history of immigration detention as one of the factors that compounds health risks and leads to trauma accumulation among immigrant patients.

Follow-up questions should center on the patient's duration in immigration detention, whether they developed a medical or psychological condition while in detention, and whether a condition worsened while in detention (Figure 2). Clinicians can use communication strategies similar to those described to obtain incarceration history. For example, health care professionals can implement a structural vulnerability "checklist" to engage all immigrant patients equally, or they can directly screen by asking questions that destigmatize and normalize detention experiences.[52] For example, they could say, "A lot of my immigrant patients and their family members have experienced detention in immigration detention centers in the past, and this can affect how healthy people and their families are. Has this ever happened to you or to a loved one?"[53] Given the psychological and financial toll that immigration detention can have on the entire family unit, screening for a family member in detention is relevant. At the same time, health care professionals should take care to ask these questions in a manner that reduces, rather than amplifies, fears, trauma, and stigma; similarly, they should

Figure 1. Immigration Intercept Model



Social-structural determinants of health

intercept 1
Migration to US

Pre-migration

US foreign policies that inhibit countries' economic and social development

Experiences of violence from war or political conflict, and physical or sexual trauma that precipitate migration

Migration journey

Physical, sexual, and psychological trauma in migration and at border

US immigration policies that prevent receipt of relief (e.g., laws preventing asylum seeking) or exacerbate trauma (e.g., family separation)

intercept 2
In the community

Community conditions that confer health risks. For example:
- Poverty
- Racism
- Stigma
- Unstable housing
- Restricted employment opportunities
- Lack of educational opportunities
- Language barriers

Community conditions that increase risk of involvement with law enforcement. For example:
- Racial profiling
- Over-policing in Black and Latino/a communities

intercept 3
Detention

Exposure to new health risks (e.g., overcrowding; physical, sexual, and emotional abuse and mistreatment by guards; solitary confinement)

Inadequate acute and chronic health care services (e.g., understaffing, delays in diagnosis and care)

Economic and social stressors (e.g., costs, disrupted social networks)

Profit motive of private prison companies

Nonbinding and inconsistently applied detention standards

Absence of independent oversight

intercept 4
Deportation and removal

Potentially fatal consequences of deportation

Disruption of medical care

Symptom burden increased

Readjustment period similar to re-entry

Returning to impoverished communities in US or in home countries

Adapted from Physicians for Human Rights, Webinar on immigration detention (May 14, 2019). Available at https://www.youtube.com/watch?v=neHEjVJ_W94.

avoid documenting their patients' immigration status in medical records.[54] Health care professionals can then refer patients to legal or other health services as appropriate. Notably, clinicians should also consider detained immigrants' resilience and agency as potential protective factors for health.

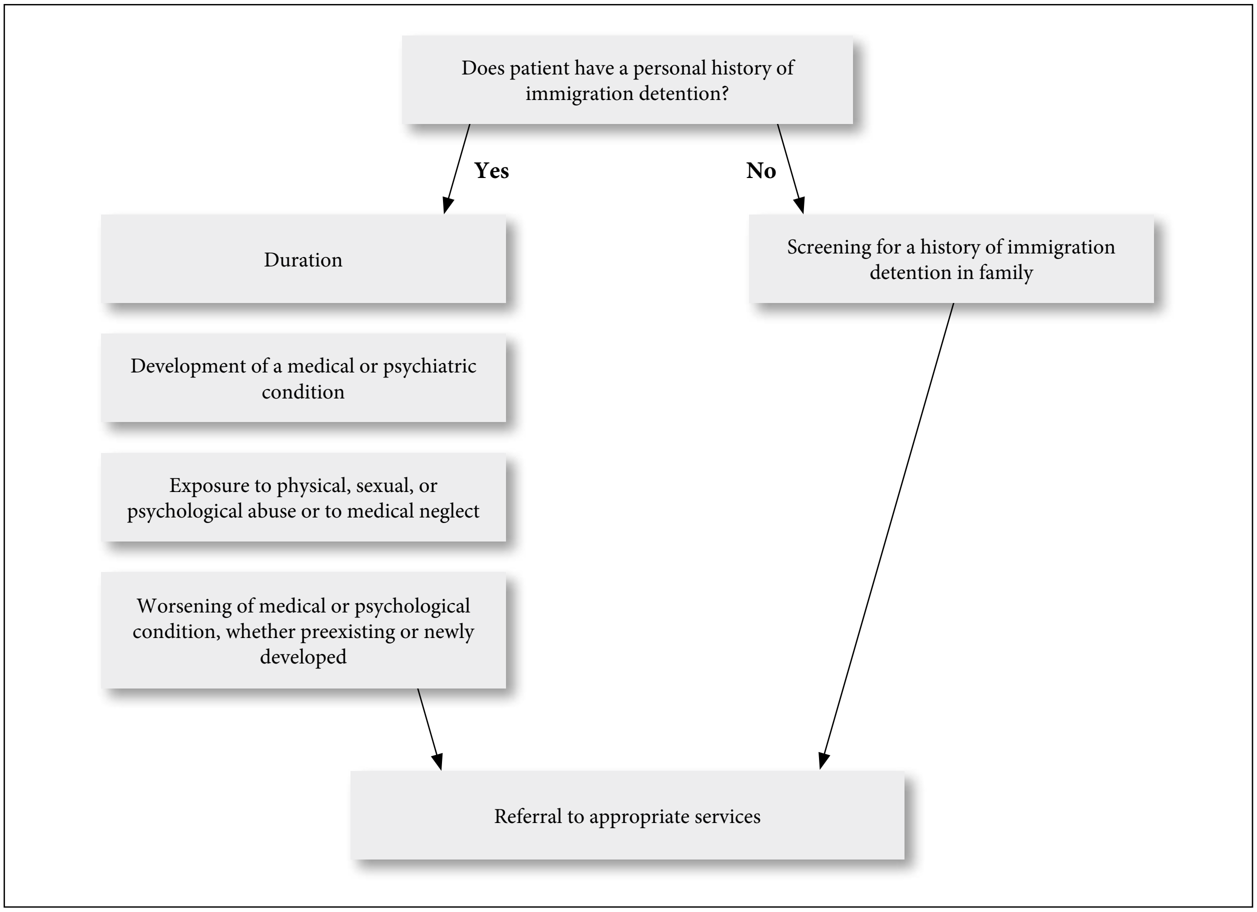
Call to action and future directions

The immigration detention system has a significant negative impact on immigrant patient and community well-being. Health care professionals have a critical role to play in addressing the health impacts of detention—both by ensuring that issues related to detention are explicitly incorporated into immigrant health and human rights efforts and by developing new strategies to address the social-structural determinants of health in detention in order to better promote health.

A human rights-based approach emphasizes the meaningful participation of individuals and communities in decisions that directly affect them. Thus, health care professionals' efforts must be centered on the experiences and perspectives of people who are directly affected by the detention system despite the challenges inherent in engaging with this vulnerable group. Detained individuals have limited rights and are at risk of retaliation for engaging in activism or advocacy efforts. Similarly, those released on bond face the continued burden of fighting their deportation case, while those who are deported—although no longer legally vulnerable in the United States—may face stigma and violence in their native countries.

The Immigration Intercept Model provides a framework for identifying points at which health care professionals can address health and detention. Many clinical and public health efforts already exist

FIGURE 2. Components of health care screening for history of immigration detention



at these points—trauma-informed care models offer ways to elicit information about pre-migratory, migratory and post-migratory trauma in a clinical encounter, and clinicians broach stressors and discrimination faced by immigrants while living in communities. But the impact of detention should be explicitly incorporated into these efforts to care for immigrant patients, with clinicians aware of, and comfortable addressing, the possibility of patients having experienced detention. Additional recommendations tailored to the detention context may be an area of future focus.

Finally, because this is an emerging area at the confluence of immigrant health, human rights, and public policy, it is critical to develop new partnerships and approaches. Legal and human rights groups are key stakeholders that provide individual support to those who are detained and that conduct monitoring of detention centers. Given the challenges of entry into detention centers, health care professionals should collaborate with legal experts who have developed relationships with detained individuals. Further, states such as California have taken steps to conduct evidence-based oversight of ICE detention, and these efforts should be widely expanded until alternatives to detention and more structured oversight are developed at the federal level.[55] These practices are crucial in the current political context, in which immigration laws are becoming increasingly punitive, indefinite detention is ever more commonplace, and human rights standards are not prioritized.

Acknowledgments

Caitlin Patler acknowledges support of the University of California–Mexico Program and the Russell Sage Foundation (award no. 93-16-15; any opinions expressed are those of the authors alone and should not be construed as representing the opinions of the Russell Sage Foundation). Maria-Elena De Trinidad Young acknowledges support from the National Institute on Minority Health and Health Disparities (grant no. R01MD012292-02). Altaf Saadi acknowledges support from the National Clinician Scholars Program at the University of California, Los Angeles.

Addendum

In this paper, we proposed a call to action to incorporate awareness of the health risks of immigration detention into trauma- and human rights-informed models of care. Harmful conditions and inadequate health care provision within detention facilities have taken on new urgency in the COVID-19 pandemic, representing significant risks to both detained people and the rest of US society by driving the national epidemic curve upward.

COVID-19, like other infectious disease outbreaks before it, enters detention settings where disease mitigation efforts are minimal or nonexistent: crowded and close quarters make social distancing enormously challenging, unsanitary conditions often include a lack of access to hygienic hand washing, and inadequate health services are all well documented by medical professionals and human rights organizations.[56] The introduction and spread of COVID-19 in detention facilities is facilitated by staff who come and go each day across two or three shifts. Once inside a facility, the virus cannot be contained and can then easily spread outside to surrounding communities. The reality of immigration detention centers makes them a ticking time bomb for the spread of COVID-19, which will result in preventable illness and death among detained immigrants, staff, and wider communities.

We have already seen the harm of COVID-19 in other carceral settings: in just a two-week span, the New York City jail system went from two confirmed cases to more than 500.[57] We can expect to see this trajectory replicated throughout the US immigration detention system.

In maintaining this civil detention system, the US immigration enforcement system is not only exposing thousands of detained people to heightened risk of serious illness and death but also doing the same for the staff who work in these settings—all the while wasting precious health care resources. Indeed, as hospital workers and paramedics face severe shortages of personal protective equipment to care for patients, ICE has requested thousands of N95 masks to continue apprehensions in the community.[58] The primary response in these circumstances must be release, especially given the complete lack of a public safety rationale for continuing to hold most people currently in immigration custody. ICE and other immigration enforcement agencies can contribute to nationwide mitigation measures by releasing detained people, with a special focus on those who possess risk factors for serious illness and death from COVID-19 infection. ICE officials report having released more than 160 people already as part of such efforts.[59] A perspective based on the social determinants of health helps us understand the social factors that contribute to the spread of viral diseases such as COVID-19. A human rights perspective compels us to respect the human dignity of each individual detained while upholding international standards and the values of equality, transparency, and humanity.

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Global Health in the Age of COVID-19: Responsive Health Systems Through a Right to Health Fund

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Competing interests: None declared.

Abstract

We propose that a Right to Health Capacity Fund (R2HCF) be created as a central institution of a reimagined global health architecture developed in the aftermath of the COVID-19 pandemic. Such a fund would help ensure the strong health systems required to prevent disease outbreaks from becoming devastating global pandemics, while ensuring genuinely universal health coverage that would encompass even the most marginalized populations. The R2HCF's mission would be to promote inclusive participation, equality, and accountability for advancing the right to health. The fund would focus its resources on civil society organizations, supporting their advocacy and strengthening mechanisms for accountability and participation. We propose an initial annual target of US$500 million for the fund, adjusted based on needs assessments. Such a financing level would be both achievable and transformative, given the limited right to health funding presently and the demonstrated potential of right to health initiatives to strengthen health systems and meet the health needs of marginalized populations—and enable these populations to be treated with dignity. We call for a civil society-led multi-stakeholder process to further conceptualize, and then launch, an R2HCF, helping create a world where, whether during a health emergency or in ordinary times, no one is left behind.

Imagine a world where advocates successfully moved governments to greatly increase health systems funding and ensure that those health systems were equitable and of good quality, and where civil society and the public could monitor progress and hold their governments accountable. Health systems would be well resourced and universally accessible, and they would have sufficient numbers of health workers operating in environments safe for themselves and their patients. Imagine that advocacy and broad public and government understanding of people's right to water and sanitation accelerated efforts to enable all people to follow good hygienic practices. And imagine that participatory policymaking, empowered community-based organizations, and regular, open dialogues with policy-makers led to trust in health information from both governmental and nongovernmental sources.

In short, imagine a world where health rights advocacy received robust support, and the core right to health principles of equality, accountability, and participation were being realized. It would have been a world better prepared to meet the immense health and social demands of the coronavirus disease 2019 (COVID-19) pandemic. And it could yet be a world that is ready to meet the next outbreak of a novel or emerging infection.

When vaccines are developed, as they will be, and made available to everyone, COVID-19 will slowly recede into the past. Yet the weak health systems, lack of sufficient hygiene, and frequent lack of trust in health and political authorities that contribute to the toll of infectious diseases will remain. As will the regular toll of disease and death these take because systems are not in place to protect people's health, especially that of the marginalized among us. For as of 2017, more than half of people globally were not covered by essential health services.[1] What is more, over a quarter of people globally did not have access to basic sanitation (2017), 10% lacked access to drinking water (2017), and slightly more than 10% did not have enough food to eat (2018).[2]

The 2019 United Nations Political Declaration on Universal Health Coverage reaffirms the human right to health.[3] Yet, more than 70 years after the Universal Declaration of Human Rights, with so many states failing to deliver quality health services to all, will still another commitment to the right to health make a difference?

Global pledges can be transformative, but only if backed by political action and resources. In 2001, for example, the United Nations General Assembly Special Session on HIV/AIDS launched the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), which has developed national health system capacities and helped save 32 million lives.[4]

Particularly as countries respond to and begin to recover from COVID-19, with its tremendous economic and social harm, it might be too big a political lift to expect the creation of a global fund for health on the multi-billion-dollar scale required to create universal health systems, however needed such a fund may be. But imagine the potential impact if the responses to COVID-19 and the Political Declaration on Universal Health Coverage led to a Right to Health Capacity Fund (R2HCF) focused on strengthening civil society's ability to advocate for the right to health, as well as fortifying the mechanisms to achieve this right—including inclusive participation, accountability, and equality. Imagine how this could help secure health for all and better prepare the world for the next disease outbreak.

Inclusive participation is critical for ensuring that health policies and programs are attuned to the realities of communities, and it empowers people to advocate for their own health. Meaningful participation respects human dignity and agency, a major contribution to well-being, and can promote affordability, accessibility, and quality. Accountability requires political leaders to answer for their failures in delivering universal health coverage (UHC). Equitable health systems leave no one behind, evincing special concern for marginalized populations.[5] An R2HCF could be a foundational component of a reimagined post-COVID-19 global health infrastructure. And it would become a powerful counterweight to nationalist populism, breathing life into the right to health, and helping restore the mutual solidarity that is ever more urgent as the world confronts the pandemic and its aftermath.

A right to health capacity fund

Mission and scope

The R2HCF's mission would be to promote inclusive participation, equality, and accountability for advancing the right to health. Funds would be directed to civil society, especially community-based organizations, to build their capacities to advocate for health rights and strengthen mechanisms to increase accountability and participation (see Box 1). These vital health funding needs receive only a miniscule proportion of health funding (discussed below). Reasons include funders' preference for supporting direct health services and not sufficiently appreciating the contributions made by advocacy efforts and accountability and participation mechanisms to improved health; a narrowing civil society space, including fundraising restrictions on human rights organizations; the sometimes oppositional nature of advocacy; and governments' reluctance to share decision-making powers or to be held accountable.

Beyond this core focus, the R2HCF might directly support health services provision for highly marginalized populations who continue to be left behind (see Box 2). The line between these two sets of activities might sometimes seem blurry; guidance on eligible activities will need to be clear. The R2HCF would aim to enable even the most marginalized populations to fall within the ambit of UHC, and it would advance the social determinants of health, including nutritious food, clean water, sanitation, safe housing, education, and gender equality.[6]

Eligibility and prioritization

The R2HCF would concentrate on entities with the least access to global health financing: community-based and grassroots organizations, and other civil society organizations. While the R2HCF would focus on lower-income countries (where health indicators are the worst and where each dollar could go the furthest), funding would also be available to civil society organizations in higher-income countries, since extreme disparities and marginalization exist there as well. As governments may themselves need right to health capacity building, civil society organizations and developing country governments could partner to jointly access funds to strengthen the capacity of governments and national human rights institutions, such as through educating legislators and judges on the right to health. Partnerships with the government will also be key to sustaining programs that should receive government financing, such as multi-stakeholder participation and accountability mechanisms, right to health education, and any direct services for marginalized populations that the R2HCF supports.[7]

The R2HCF could develop a set of principles to prioritize grant-making, including activities that benefit especially marginalized populations, are likely to create sustained change, and are least likely to secure alternative funding.

Governance

We envision the R2HCF as an independent nonprofit organization modeled on the GFATM, GAVI, and Unitaid, perhaps based in the Global South, where most of the communities whose rights it supports would be located. Its governing structures could include governments, civil society, international institutions, and foundations. Civil society and community leaders would have a leading role in R2HCF governance. Governments on the board would have to be committed to the right to health. Both civil society input and objective assessments

Box 1. Strengthening right to health capacities: Types of activities an R2HCF would support

Advocacy
- Human rights organizations' advocacy, policy analysis, and strategic litigation
- Right to health advocacy training for community members

Community-based and -driven accountability and participation
- Local health service and other social accountability measures, such as village health committees and health facility monitors

Participatory policymaking
- Community-driven health impact assessments for policies, programs, and projects that affect the right to health, whether adversely (such as mines, fossil fuel subsidies, and deforestation) or positively (such as parks, public transportation, and healthy school meals)
- Participatory health planning to ensure that urban and other community designs promote health for all and that pandemic preparedness plans protect marginalized populations
- Participatory budgeting for health-related budgets
- Participatory processes to develop health equity programs of action*

Right to health capacity building
- Community members' and civil society organizations' capacity to participate in health policymaking processes
- Right to health literacy and education, including for community members, public officials, health workers, educators, judges, lawyers and paralegals, law enforcement officers, and journalists
- Partnerships between legal services organizations and health providers to increase patients' understanding of their rights and their access to justice
- Information exchanges on successful right to health advocacy strategies
- Government capacity to enforce standards on quality, non-discriminatory, acceptable, and accessible health care in the private sector and to carry out environmental safety testing and enforcement in marginalized communities
- National human rights institutions' capacity to investigate and resolve complaints about right to health violations

Legal empowerment
- Access to justice programs to support claims centering on the right to health

Monitoring
- Right to health monitoring, such as through national human rights institutions, parliamentary right to health investigations, and community platforms
- Public expenditure tracking of health-related budgets

In addition to funding activities such as these, the R2HCF could have targeted strategic initiatives. These could include supporting innovative mechanisms for accountability and participation and accelerated grants for right to health emergencies. The R2HCF could also reserve a small sum for technical support aimed at helping smaller organizations strengthen their financial systems and monitoring and evaluation capacity and ensure that their programming is well designed and based on best practices. Such support would help these organizations overcome key barriers to their effectiveness, namely limited capacity and experience, along with their simply having insufficient funds.†

* O'Neill Institute for National and Global Health Law, Health equity programs of action. Available at https://oneill.law.georgetown.edu/projects/tuberculosis-law-and-human-rights-project/health-equity-programs-of-action.

† Personal communication (e-mail) with Ralf Jürgens, Senior Coordinator, Human Rights, Global Fund to Fight AIDS, Tuberculosis and Malaria, March 25, 2020.

could be used to determine which governments have the requisite level of commitment. Objective assessments might involve a set of indicators with clear criteria, much as Freedom House uses in its annual assessment of the level of political rights and civil liberties in every country.[8] Global institutions such as the World Health Organization and the Office of the United Nations High Commissioner for Human Rights could be board members, along with foundations experienced in human rights advocacy and financing.

The R2HCF could be either independent or housed within an existing organization, where it could gain efficiencies by leveraging the organization's administrative, communications, and other expertise and infrastructure (such as financial auditing). One potential host organization could be the Robert Carr Fund, which strengthens civil society networks that support the health and rights of inadequately served populations—though it is focused regionally and globally, with a particular emphasis on HIV.[9] Another option is the GFATM, although its existing governance would pose challenges, among them that only three of twenty GFATM board members are from civil society and affected community.[10]

Whether independent or linked to an existing organization, the R2HCF could become part of a consortium of interested right to health funders.[11] Collaboration could enable them to best compensate for their respective limitations, share lessons, develop a joint evidence base, and share resources, such as technical guidance and expertise.

Income sources

Like other global health funding mechanisms, the R2HCF would be funded through contributions by governments, foundations, and other donors. The GFATM and other health funds may even choose to offer a small solidarity contribution, given the R2HCF's contributions to their own missions.

In addition, an innovative financing window would help ensure the fund's viability and sustainability, and could be inspired by several countries' dedicated airline ticket tax to support Unitaid.[12] Innovative funding for the R2HCF could come, for example, from willing governments levying a tax on goods, services, or profits of corporations whose activities undermine the right to health, including tobacco, alcohol, sugary beverages, and highly processed unhealthy foods. Even a very low tax rate could raise significant sums. Many governments already tax certain unhealthy products.

Filling the gap: The size of the R2HCF

Currently, data are insufficient to accurately estimate existing funding levels for civil society right to health advocacy and other functions that the R2HCF would fulfill. Indeed, the absence of

Box 2. For debate: Directly funding health initiatives to protect marginalized populations from further neglect

Should a secondary function of the R2HCF be to directly support health services for neglected populations? The R2HCF could prove a literal lifeline for politically marginalized and stigmatized populations by funding, for example:

- Syringe exchanges for users of injected drugs
- Mobile health clinics to bring health care to remote, rural villages
- Clean water for indigenous communities
- Community health centers for vulnerable migrant populations
- Community-based support for people with disabilities

However, such funding would have drawbacks and risks. Direct support for health services would reduce already inadequate funding available for the fund's core mission—civil society action and structural changes advancing participation, accountability, and equality. Further, health services that depend on the R2HCF might not be sustainable. Governments might even use the R2HCF as a justification for not providing these services themselves.

If the R2HCF were to support direct services provision, it could be accompanied by measures to mitigate these concerns, such as agreements with the governments of countries receiving this funding on co-financing and on gradually assuming and sustaining domestic funding responsibilities, ensuring a sense of ownership.

data highlights the importance of the R2HCF. It is frequently said that we measure what we value; the lack of data suggests a low global priority. We recommend that such assessments be carried out.

Nonetheless, the data points that do exist suggest both a paucity of funding and a considerable unmet need. First, the GFATM is the main multilateral funder of right to health activities, with a strategic objective to "promote and protect human rights and gender equality" and with an unprecedented Breaking Down Barriers initiative aimed at removing human rights barriers to HIV, tuberculosis, and malaria services.[13] Yet between the 20 countries that were part of this initiative and other human rights grants secured through the ordinary grant process, the GFATM invested only about $123 million toward human rights in 2017–2019, or approximately US$41 million per year.[14] While countries exceeded the GFATM's target that middle-income countries allocate at least 2.85% of HIV grants to breaking down human rights barriers, only 0.72% of tuberculosis grant funding addressed human rights, below the GFATM's 2% target.[15]

Beyond the GFATM, funding is sparse. Major foundations such as Gates, Rockefeller, and Ford do not focus on the right to health. The Open Society Foundations is the most significant foundation funder of human rights activities, with US$47 million spent on health and human rights activities in 2019.[16] The Robert Carr Fund, operating on a three-year funding cycle, provided nearly US$33 million for 2019–2021.[17] The largest foundation focused exclusively on frontline human rights activism is the Fund for Global Human Rights, which currently provides grants totaling US$9 million annually.[18] Only US$225 million in development assistance went to nongovernmental women's organizations per year in 2015–2016, including a mere US$38 million annually for those in developing countries.[19] A comprehensive review found that US$170 million was available to civil society organizations in Latin America from 2014 to 2017 for human rights activities—only 10% of which was for advocacy and lobbying.[20] Limited bilateral right to health funding is focused on sexual and reproductive health rights—vital, yet only one of many needs.

It is apparent, then, that right to health funding is far below existing and future needs. We envision an R2HCF with an initial annual target of US$500 million, which would represent a transformative infusion of new funds. While we believe that this is a reasonable target, it is not based on a rigorous data-driven assessment. The R2HCF could adjust its funding target based on demand and research to better understand the right to health funding landscape.

The economic case: The power of rights

While it might not seem it during the wave of multi-billion and even multi-trillion dollar COVID-19 rescue packages, in ordinary times, even US$500 million per year would be considered a significant investment. What is the case for the R2HCF, then, including in light of the alternative of simply increasing direct health system investments?

First, the R2HCF would be far more achievable than a health systems fund that could have a major global impact. While we strongly support massive new investments in health systems, a transformative R2HCF is possible at a much lower price. A US$500 million annual fund would vastly scale up resources for the right to health. By contrast, billions of dollars annually will be required to make significant inroads into filling health systems gaps: The funding gap to achieve the targets of the third Sustainable Development Goal (SDG), which is focused on health and includes UHC, is at least US$20–54 billion per year for low- and middle-income countries, with 75% of investments needed for health systems.[21]

Second, the R2HCF would valuably complement current domestic and international health investments. It would enhance accountability, contributing to policies that ensure the most effective and efficient use of funds, and it would ensure that policies and programs are developed through inclusive participation, tailored to people's needs and realities.

Third, advocacy can leverage new money, particularly increases in national health budgets. This is especially important because the vast majority of funds for health systems and underlying determinants of health will come from domestic resources.

Fourth, right to health initiatives can be transformative. For example, a study in Uganda reported that using community score cards—a form of community monitoring of local health services that includes an action plan that community members and health workers develop jointly—led to a 33% reduction in child mortality.[22] A grant from the Fund for Global Human Rights was critical in securing Tunisia's first law on domestic violence.[23] The Treatment Action Campaign's social mobilization and litigation led South Africa to offer antiviral treatment for people living with HIV.

Fifth, even with vastly scaled-up health systems funding, without dedicated efforts, marginalized populations will likely be left behind. Civil society's ability to document rights violations, develop sharp analyses and recommendations, mobilize political constituencies, generate media attention, bring neglected perspectives to lawmakers, and seek accountability through courts can drive policy reform and resource allocation that new health systems funding alone might not. Even with significant new health system funds, an R2HCF would be critical to ensure health coverage that is truly universal and that systems are in place to protect marginalized and other vulnerable populations during disease outbreaks.

Finally, the R2HCF would contribute to human dignity in ways that strengthening health systems alone cannot. It would enable people to be active agents in decisions affecting their health and lives, and to be respected. The value of enabling people at the margins to experience being treated with dignity is incalculable.

Finding—and creating—political will

The chief obstacle to an R2HCF is the political will to create it. Creating a new international right to health financing mechanism of significant magnitude is a tall order. The global recession that the COVID-19 pandemic will cause will make funding scarce in the near term. Yet the global health community has demonstrated strong interest in innovative new financing models, such as the Pandemic Emergency Preparedness Facility and the Coalition for Epidemic Preparedness Innovations. And a powerful constituency would advocate for the R2HCF.

There is a growing body of evidence—including case studies, randomized control trials, literature reviews, and the forthcoming mid-term assessment of the Global Fund's Breaking Down Barriers initiative—on the public health impact of funding advocacy and other health and human rights programming.[24] And in time, the R2HCF could contribute to this evidence, with regular publications on the impact of its investments, including toward rights-based UHC and global health security.

The high-level political commitment to UHC and the commitment to improving global health security that will surely follow COVID-19 open a window of opportunity for the R2HCF, which would make major contributions to SDG3—from accountability and participation to advocacy that unleashes significantly increased and more effective domestic health funding.

In an era of nationalistic populism, civil society space is narrowing and the world is experiencing an erosion of human rights, including through growing xenophobia and discrimination. The fund could be of major interest to countries that remain deeply committed to human rights, the rule of law, and global solidarity. Funders might view the R2HCF as a powerful antidote to the nationalism and lack of global collaboration that is almost surely worsening the harms of COVID-19, from too little funding for lower-income countries to the global scramble to find manufacturers of medical equipment and supplies and win the international bidding war, rather than sharing scarce supplies equitably and based on need.[25]

The added urgency of human rights, combined with a renewed commitment to UHC and global health security, could make the R2HCF a compelling possibility. And there is a global constituency to support it—communities whose health rights are not respected, and civil society seeking to push for the right to health. We envisage civil society organizations undertaking meticulous policy analysis, doing sustained lobbying, and campaigning in the streets to create a R2HCF. We hope for the support of major global institutions, such as the World Health Organization and the Office of the United Nations High Commissioner for Human Rights, given that the R2HCF would support their core missions.

The path ahead

Accordingly, we call on other civil society advocates, international organizations, governments, and foundations to join us in a multi-stakeholder process, one led by civil society and that includes current right to health funders, to conceptualize the R2HCF, to advocate for it, and to create it. The need to, as United Nations Secretary-General Antonio Guterres has put it, "recover better" from COVID-19, together with the political declaration on UHC, provides a vital window of opportunity to launch the fund rapidly.[26] If the transformative SDG agenda and the promises to achieve UHC by 2030 and to leave no one behind are to be more than lofty declarations, we cannot wait to develop a powerful R2HCF.

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HHR Health and Human Rights Journal

The Waitangi Tribunal's WAI 2575 Report: Implications for Decolonizing Health Systems

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Abstract

Te Tiriti o Waitangi, a treaty negotiated between Māori (the Indigenous peoples of Aotearoa) and the British Crown, affirmed Māori sovereignty and guaranteed the protection of *hauora* (health). The Waitangi Tribunal, established in 1975 to investigate alleged breaches of the agreement, released a major report in 2019 (registered as WAI 2575) about breaches of *te Tiriti* within the health sector in relation to primary care, legislation, and health policy. This article explores the implications of this report for the New Zealand health sector and the decolonial transformation of health systems. The tribunal found that the Crown has systematically contravened obligations under *te Tiriti* across the health sector. We complement the tribunal's findings, through critical analysis, to make five substantive recommendations: (1) the adoption of *Tiriti*-compliant legislation and policy; (2) recognition of extant Māori political authority (*tino rangatiratanga*); (3) strengthening of accountability mechanisms; (4) investment in Māori health; and (5) embedding equity and anti-racism within the health sector. These recommendations are critical for upholding *te Tiriti* obligations. We see these requirements as making significant contributions to decolonizing health systems and policy in Aotearoa and thereby contributing to aspirations for health equity as a transformative concept.

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Competing interests: None declared.

Introduction

Māori have challenged breaches of *te Tiriti o Waitangi* (*te Tiriti*) since shortly after its signing in 1840.[1] *Te Tiriti* is the Māori text of a short but far-reaching agreement that allowed the British Crown to establish government over its settlers in New Zealand, affirmed Māori *rangatiratanga* (sovereignty) over their own affairs, including natural resources, and granted them the rights and privileges of British subjects.[2] An English text, which differed significantly, was also drafted, but it was the Māori version that was presented and signed by most *rangatira* (leaders) and the version we argue should therefore take precedence. While First Nations' treaty rights to health are recognized in Canada and may be negotiated into treaties being contemplated in Australia, Aotearoa New Zealand is a single jurisdiction with a single treaty, giving its experiences the particular context that we demonstrate in this article.

Māori have pursued diplomatic, legal, and political channels to address breaches through, for example, delegations to British monarchs, the League of Nations, and, later, the United Nations. Military action, as well as peaceful measures such as land occupations, have been used to resist the alienation of *whenua Māori* (land).[3] Petitions continue to be presented to Parliament.[4] Since the election of the first Māori members of Parliament in 1867, members have introduced legislation and otherwise lobbied for measures to give effect to the agreement and remedy its breaches by the Crown.[5]

In 1975, after much Māori (and some non-Māori) political agitation and lobbying, a legal process to support the enduring *mana* (prestige and authority) and place of *te Tiriti* in public life was agreed. The Treaty of Waitangi Act 1975 was passed to establish the Waitangi Tribunal and other mechanisms for hearing, researching, and settling grievances.[6] The tribunal influences reconciliation efforts between Māori and the Crown through recommendations to remedy Crown breaches. The tribunal has a mandate to investigate alleged breaches of either the Māori text (*te Tiriti o Waitangi*) or the English version (the Treaty of Waitangi). Over recent decades, it has produced a significant body of work assessing evidence presented by thousands of Māori claimants about *te Tiriti* breaches and Crown defenses of government action and inaction.[7]

Issues surrounding Māori health fall within the remit of the Waitangi Tribunal, and in 2016 the claim WAI 2575 was opened to hear grievances about the health system, including health equity, health care, disability, and substance use. Neglect of Māori health, and state undermining of Māori efforts to exercise authority over their own health, have distinguished public health policy at least since 1907, when the Tohunga Suppression Act was passed. This Act criminalized certain Indigenous health practices and removed the centrality of culture to health policy.[8] By this time, the silencing of Māori voice in both policy and clinical practice was entrenched, though consistently resisted by Māori health professionals and political actors. By the 1980s, the Treaty of Waitangi Act was beginning to influence policy thinking. Scope was emerging for more effective Māori assertion of their rights under *te Tiriti,* particularly the guarantees of *tino rangatiratanga* in article 2 and of social equity in article 3. For example, in 1988, the director-general of health under the newly established neoliberal regime, George Salmond, directed the health sector to authentically engage with its treaty obligations through the mechanism of partnership and acknowledgment of health as a *taonga* (treasure).[9]

Since 1988, the health sector has attempted to engage with these responsibilities. However, despite some examples of success, the tribunal found profound colonial system failure that has resulted in major, persistent health disparities across all conditions between Māori and other New Zealanders.[10] Over 200 grievance claims were filed with the tribunal specifically in relation to the administration of the health system. The complexity, breadth, and depth of the health claim led the tribunal to hear the evidence in three stages. Stage one focused on systemic issues and the primary health care sector. The tribunal's stage one report was released in 2019 and is the subject of this article. Stage two (yet to be concluded) will address mental health, disabilities, alcohol, tobacco, and substance abuse. Stage three (also yet to be concluded) will work with any remaining issues of national significance and eligible historical matters.

On its own, the stage one report is a substantive scholarly contribution to Māori health policy development.[11] It makes an important contribution to the monitoring of the effectiveness of the Crown's policy in Māori health by defining the Crown's responsibilities and obligations under *te Tiriti* and evaluating its successes and failures in relation to these responsibilities and obligations.

The tribunal found that the Crown was responsible for ensuring equitable policy outcomes and for the active protection of Māori health and well-being.[12] Inequities in the burden of disease and inaccess to effective primary health care show that these outcomes remain elusive for Māori.

The WAI 2575 report argues that the Crown has failed to deliver equitable health outcomes for Māori and is therefore in breach of *te Tiriti*.[13] In response, we argue that there are at least five key implications for all health-related legislative and policy instruments. These instruments should (1) be compliant with *te Tiriti*; (2) recognize *tino rangatiratanga*; (3) ensure accountability to Māori; (4) ensure that investment in Māori health is commensurate with equitable outcomes; and (5) embed equitable and non-racist practices in policy development, delivery, and evaluation. These requirements are vital to the decolonization of the hegemonic health system of Aotearoa in pursuit of health equity and social justice.

Primary health care is strategically important for achieving improvements in Māori health and is, as noted by the World Health Organization in its Declaration of Alma-Ata,

> *essential health care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation … It is the first level of contact of individuals, the family, and community with the national health system bringing health care as close as possible to where people live and work and constitutes the first elements of a continuing health care process.*[14]

Methodology

This article is written from a critical perspective, as the authors are invested in understanding where power resides and the ways it can be located to maximize justice and human rights.[15] Feminist and Indigenous scholars alike have long argued that privilege and lived experiences shape how we see the world.[16] As researchers, who we are influences our research questions and what we hear and see when we collect and analyze data. By way of *whanaungatanga* (relationship building), we take the unusual position of introducing ourselves so our standpoints are transparent to the reader.[17]

Heather Came is a Pākehā (of settler descent, *Tangata Tiriti*) activist-scholar with expertise in *Tiriti* application, institutional racism, and critical policy analysis. Her professional background lies in health promotion and public health, as well as the dynamics of institutional racism. Heather Came and Timothy McCreanor were both expert witnesses on behalf of claimants to the stage one Waitangi Tribunal WAI 2575 hearings.

Dominic O'Sullivan belongs to the Te Rarawa and Ngāti Kahu *iwi* (tribes). He is a political scientist interested in Indigenous self-determination. He writes from a liberal theoretical perspective to examine the recognition *te Tiriti* has under New Zealand's prevailing liberal democratic arrangements.

Jacquie Kidd is Māori, belonging to the Ngāpuhi *iwi*. Her professional background is in nursing, and her current work involves community-based research to identify and address health inequities at the local level. Her focus is on amplifying the strengths and solutions found within *whānau* (family), *hapū* (family groupings or subtribes), and *iwi* through co-designing research and associated health messages.

Timothy McCreanor is a Pākehā public health researcher with a longstanding interest in the ways in which language shapes and reflects relations among Māori and Pākehā. Health as a key domain in such discursive relations is a current focus of his contributions to research and action for social justice.

Overview: WAI 2575 report

The stage one WAI 2575 hearings saw evidence presented by Māori health providers and other interested parties relating to the period from the enactment of the New Zealand Public Health and Disability Act (NZPHDA) in 2000 to the present. The tribunal agreed to an urgent hearing because of the seriousness of the issues raised and the extent of the health inequities that the claimants described. All parties agreed that the legacies of colonization had an impact on health inequities.[18]

Systemic issues in the legislative and policy framework

The tribunal found that the policy and legislative framework failed to consistently state a commitment to achieving health equity for Māori and that the treaty clause in the NZPHDA was reductionist: "it simply does not go far enough in ensuring that the whole health system complies with the Treaty."[19] It also found that the principles of participation, protection, and partnership that inform Māori approaches to health policy were "outdated and need to be reformed."[20] For example, despite structural mechanisms in place for Māori participation in the health sector, the tribunal found that Māori were not afforded "Treaty-consistent control of decision-making in relation to health design and delivery."[21] The tribunal was concerned by the omission of reference to the treaty in lower-level policy documents and recommended the development of a new treaty clause for the NZPHDA to give greater authority to the requirement to achieve equitable health outcomes for Māori.

The tribunal found that the primary health care framework under the NZPHDA was not designed in partnership with *mana whenua* (local Māori) or other Māori communities. It found that the primary health framework did not "recognise and properly provide for *tino rangatiratanga* [sovereignty] and *mana motuhake* [autonomy] of *hauora Māori* [Māori health]."[22] It argued that the current partnership arrangements need to be reviewed at all levels.

With concern, the tribunal noted the underrepresentation of Māori within the health workforce and the disestablishment of *Te Kete Hauora* (the Māori group within the Ministry of Health). It noted that Māori health managers within district health boards (DHBs) were "hamstrung by the ambit of their role and the very minimal budget holding functions they often hold."[23] In these respects, the Crown was in breach of *te Tiriti*. The tribunal also recommended exploring the establishment of an independent Māori Primary Health Authority.

Primary health care funding

The tribunal found that Māori primary health organizations "were underfunded from the outset."[24] Funding arrangements disadvantage primary health organizations that serve high-needs (often Māori) communities. In addition, it found that the "Crown has been aware of these failings for well over a decade but has failed to adequately amend or replace the current funding arrangements."[25] Over NZ$200 billion has been spent on health since 2012, with little measurable improvement to Māori health outcomes. The tribunal noted that NZ$167 million (less than 0.1%) was allocated for the primary care of Māori patients, with only NZ$28.7 million going to Māori primary health organizations during this period.

The tribunal recommended an assessment of the extent of underfunding since 2000, and a review into the funding of the primary health system. It recommended that the claimants and Crown agree on a methodology for conducting this assessment. To reflect this matter's underlying urgency, the tribunal directed the parties to report progress by January 2020. We argue that this review is essential to improving health outcomes and should take a holistic approach to addressing the determinants of improved health outcomes, including the inter-generational impacts of sustained underfunding. Justice requires that the assessment consider that supporting equitable outcomes may necessitate an allocation to Māori health that is more than proportionate to the Māori share of the population.

Accountability

The Crown argued that the primary health care system was deliberately "permissive and semi-devolved."[26] On the one hand, this devolution, which occurred as part of public sector reforms during the 1980s, allowed the Crown to shift its direct responsibility for primary health care to private providers. On the other hand, it created opportunities for Māori entities to seek contracts with the Crown to provide primary care with greater reference to Māori epistemologies and community priorities. While devolution does provide a foundation for Māori authority (*rangatiratanga*) in health policy delivery, the tribunal found that the Crown did not collect enough qualitative or quantitative data to fully inform itself, or the public, of how the sector was performing in relation to Māori health. Māori health outcomes were not systematically measured or reported on, and *Te Puni Kōkiri*, the Ministry of Māori Development, failed to carry out its statutory duty to monitor the health sector's effectiveness for Māori.

The tribunal recommended that the Crown commit to reviewing and strengthening accountability mechanisms and processes. To this end, it proposed that the Crown, in conjunction with Māori health experts, co-design a research agenda. It recommended the reintroduction of annual Māori health plans for DHBs, the inclusion of treaty references in policy documents, and external monitoring of the Ministry of Health.

Implications of the WAI 2575 report

Our argument is that the tribunal's recommendations may be given substantive effect through reframing the ways in which the Crown uses legislative and policy instruments in relation to Māori health. The reframing that we propose is to ensure that these instruments are consistent with *te Tiriti*, recognize *rangatiratanga*, ensure accountability to Māori citizens, receive public funding sufficient to support equitable outcomes, and entrench non-racist practices at all levels of the policy process—development, implementation, and evaluation.

Tiriti-compliant legislation and policy

The tribunal's findings and recommendations for amending the NZPHDA and for reforms to policy administration are based on the conceptual perspective that policy decisions are not ideologically neutral. Rather, such decisions are both the product of the dominant culture in which they are formed and a political compromise among competing stakeholders. This means that equitable outcomes are more likely, and the policy process is more just, if Māori aspirations, values, and epistemologies are guaranteed influence at every stage of the policy process.[27] However, government discourses often privilege the Treaty of Waitangi (the English version) and guiding treaty principles (developed by the executive and judicial branches of government) over *te Tiriti o Waitangi* (the Māori text). Use of the English text reinforces the government's assertion that Māori ceded sovereignty to the British Crown, an argument that the tribunal found against in 2014.[28]

Privileging the English text over the Māori—when the Māori text was the instrument that most *rangatira* signed and when the international legal doctrine of *contra proferentem* maintains that in the event of dispute, the instrument should be interpreted against the drafting party—justifies a diminished regard for substantive Māori presence and leadership in the policy process.[29] It also justifies diminished space for Māori to exercise independent authority over their own affairs. If, however, the Māori text is privileged and the instrument is not upheld as a cession of sovereignty, a different political dynamic is created in which Māori, as citizens, are shareholders in public sovereignty and, at the same time, holders of an independent authority that should be recognized in public policy.[30]

We therefore argue that the Māori text is the definitive text. Correspondingly, there is an argument for legislation and policy development to occur with exclusive reference to the Māori text. Research into what it may mean for the Treaty of Waitangi Act 1975 to be amended to ensure that the tribunal conducts its inquiries with exclusive reference to the Māori text is also justified as a way of admitting that Māori did not cede sovereignty to the British Crown.

Critical policy analysis on these themes could be developed through scholarly attention to the role of ideology in health policy, especially on the implications that sovereignty was not ceded and that, instead, Māori retain the rights of *rangatiratanga* and citizenship.[31] The nature of sovereignty in a liberal democracy, as distinct from the authority that the concept implied in 1840, and how this is both distinct from and related to *rangatiratanga*, is an important question for how policy decisions are made, who makes them, and whom they are made for. In this respect, Heather Came et al. have developed a new methodology specific to analyzing health policy entitled "critical *Tiriti* analysis."[32] This methodology outlines a five-phase process to review policy in relation to the Māori text of *te Tiriti o Waitangi*. With the finding that contemporary health policy is not consistent with *te Tiriti*, we argue that this methodology will become standard operational practice and ensure that Māori participate and lead future policy development as a matter of course.

One of the inherent features of critical *Tiriti* analysis is that policy development is transparent—that is, who is claiming to make policy, whom are they making it for, and which philosophical aspirations and epistemological preferences are being used. This does not mean that individuals writing on behalf of governments must be named, but it does mean that the processes being used and their justifications should be explicit. Critical *Tiriti* analysis assumes that published policy documents will include a methodological description showing that there has been Māori leadership in the development process. For instance, was there Māori participation in policy writing, was there wider Māori consultation, was there an advisory committee, and, if so, who was on it? Reference lists should be included so the quality of the evidence can be reviewed by Māori and other interested parties. Evidence of academic and other forms of Māori scholarship should be present to demonstrate engagement with Māori perspectives of what works and why in health policy.

Currently, Māori epistemologies are not consistently present in policy design and implementation. The WAI 2575 report implies that their inclusion would require a fundamental shift in policymaking, implementation, and evaluation. However, there is a gap between what policy might want to achieve (or know that it needs to achieve) and the ability to do so. This is why the tribunal recommended that the Crown and Māori co-design a responsive research agenda.

There are several different ways to approach co-design, ranging from including Māori representatives on policy and planning committees, to consulting with stakeholder communities, to a power-sharing community engagement process.[33] A *Tiriti*-focused co-design approach to service development and delivery involves the latter, beginning with building relationships between the employees of Crown agencies and traditional *hapū* as well as urban-based Māori communities. *Tikanga* (customary protocols), including Māori practices such as *pōwhiri* (welcome ceremony) and *whanaungatanga* (relationships with people, land, and ancestors), provide mechanisms for establishing relationships, which is fundamental to co-design.

Recognizing tino rangatiratanga

In colonial contexts, the nation-state imposes and assumes unitary political sovereignty. Indigenous sovereignty is contested by the colonial state despite prior incumbency, natural justice, and even the Crown's acknowledgement of prior Māori sovereignty as a precondition for the conclusion of a treaty.[34] The United Nations Declaration on the Rights of Indigenous Peoples recognizes extant Indigenous political authorities that remain in spite of the erection of colonial government.[35] Within *te Ao Māori* (the Māori world), *rangatiratanga* is a power subordinate to no other, so it cannot be ceded. The concept itself encompasses terms such as authority, control, and the right of Māori to make decisions for Māori.[36]

Liberal democracy, which was not the prevailing political arrangement in 1840, but is in 2020, means that sovereignty is not held by the state, Crown, or Parliament in its own right. Nor is it an authority over and above the people. It is, instead, a repository of citizens' collective authority, and it is exercised by governments only through citizens' consent.[37]

Citizenship belongs to Māori as much as it belongs to anybody, but it does not supersede or diminish *rangatiratanga*. *Te Tiriti* is explicit. The two co-exist as interrelated spheres of political authority and have implications for health policy's form, purposes, development, and implementation. This gives the sovereignty that Māori did not cede a heterogenous nature, meaning that Māori are simultaneously part of the nation-state while also standing outside of it. Therefore, *tino rangatiratanga* and the collective public sovereignty that Māori share with other citizens needs to be expressed within public agencies, as well as through *hapū* and other Māori entities. For Māori health, equity, community thriving, and personal health and well-being are legitimate aspirations that public budgets must fund.[38] One of the critical enablers of these aspirations and of just service provision is the fact that Māori leaders are present in senior management positions within Crown agencies and on DHBs. To this end, it is significant (but insufficient) that in 2019 the minister of health appointed Māori people to chair four of the country's nineteen DHBs, compared with none in previous years.[39] While it is not possible to establish a causal link between an exact number of Māori people holding office in the administration of the public health system and equitable outcomes, it is fair to say that the system must ensure sufficient substantive Māori participation for Māori to be able to recognize that their values and priorities influence the provision of primary health care and that they are able to make meaningful decisions about how, by whom, and to what end that care is delivered.

Recognizing *tino rangatiratanga* means that it must be evident to Māori citizens that every substantive decision about the design of the health sector, the prioritization of resources (see later section on funding), and the setting of policy directions needs to have been made with equitable and empowered Māori leadership. This leadership needs to be nurtured and developed, without constraint or interference from the Crown. Administrative reforms ought to be made to ensure that the practice of making policy decisions without reference to Māori cannot occur. Given the depth and urgency of addressing health disparities, public decisions need to systematically consider and prioritize measures that advance Māori aspirations to deliver improved holistic Māori health outcomes. Critical *Tiriti* analysis has been developed to support this objective and support the implementation of structural mechanisms at all levels that are monitored and strengthened over time as part of ongoing sector-wide quality assurance efforts. Māori leadership of these mechanisms needs to be resourced so as not to overburden Māori. Health sector leadership needs to embrace Māori leaders and leadership styles.[40]

An independent Māori Primary Health Authority was proposed by the tribunal.[41] However, this potentially underplays the magnitude of the challenge, and it would make more sense to have an overarching Māori-led and -governed holistic authority that rejects the current siloing. Such a broad configuration would bring together a critical collective mass of Māori knowledge and leadership. In a recent *whaikōrero* (speech), Professor Sir Mason Durie articulated his vision for an independent Māori health and well-being authority (Te Rūnanga Whakapiki Mauri). This authority

> *would be defined by the norms of te ao Māori. It would favour Māori decision-making at all levels and would foster an integrated approach that saw all Kaupapa Māori Organisations working towards the same goals and with the same values. It would bring together mental health, child health, health generally, kōhanga reo [language nest], kura kaupapa [Māori primary school], whare kura [Māori school], housing and other aspects of wellness.*[42]

Durie has called for collective Māori endorsement of his proposal, though this does leave unresolved the question of generic health funding that currently resources existing health services. One model that could be re-introduced and integrated into Durie's proposal is the Māori co-purchasing organizations (MAPOs) that were formed in the 1990s under the Northern Regional Health Authority and operated in the Te Tai Tokerau and Auckland regions. The

MAPO strategy was a structural co-funding mechanism to enable *iwi* input into all health service purchasing decisions.[43] If integrated into Durie's proposal, a nationwide localized MAPO system could consolidate Māori control and authority in relation to health funding.

Strengthening accountability

The tribunal report explained at length the lack of public accountability in relation to Māori health outcomes.[44] Existing structural mechanisms need to be consistently applied. For instance, the tribunal reported that the Crown has never withheld money through the Crown funding agreement, nor sacked a DHB board, nor rejected an annual plan, in relation to poor performance in relation to Māori health. Critically, Te Puni Kōkiri (Ministry of Māori Development) needs to resourced to a level where it can fulfill its statutory responsibility to monitor the health sector. Existing Ministry of Health and DHB monitoring of health providers' delivery of Māori health outcomes also need to be strengthened.

One response is to strengthen Māori health performance indicators at every level of the system, including individual and collective accountabilities. Ministerial insistence and support for specific performance indicators in all relevant Crown agencies may sharpen bureaucratic and clinical focus.

Transparency in practice and outcomes are critical to strengthening accountability to Māori. Various DHB and Ministry of Health reports are publicly available, and Māori members may question ministers in Parliament in relation to these reports. However, the data presented are usually high level and frequently not reported by ethnicity. George Gray's independent website, Trendly, offers analysis of some indicators by DHB; however, as the tribunal recommended, effective monitoring requires more comprehensive data.[45]

The Indigenous data sovereignty movement has clearly articulated the aspiration that Indigenous people should control Indigenous data.[46] Others have argued that more work needs to be done to develop and strengthen measures that are meaningful for Māori.[47]

To achieve this policy reorientation, more Māori-led production and analysis of Māori health data is needed. This requires a focused investment in health research and increased efforts at recruiting and training Māori scientists and policy makers. Māori-specific measures, alongside quality and quantity of life, should be key outcome measures for the health sector.

Investing in Māori health

The Waitangi Tribunal report noted a pattern of systemic underfunding of Māori health.[48] Funding to Māori health providers from the Ministry of Health and DHBs in 2015–16 was 1.86% of Vote Health.[49] Clair Mills and Papaarangi Reid have quantified the cost of "doing nothing" in relation to child health inequities, for example, by estimating that inaction in relation to Māori health in this one area costs between NZ$62 million and NZ$200 million per annum.[50]

Current investment levels in Māori primary services do not reflect population parity, with Māori making up 15% of the total population.[51] However, raising investment levels to 15% does not address the inter-generational effects of disparate morbidity and mortality that the tribunal attributes to colonial practices—an association corroborated by others.[52] In finding that Māori primary health care is underfunded, the tribunal recommended that the Crown and claimants cooperate to establish a methodology for working out how an appropriate level of funding is to be determined. This is a significant opportunity for Māori to influence future appropriations and policy settings.

The presumptions that would usefully inform the development of such a methodology include recognizing that although underfunding is ultimately the outcome of government budget priorities, it is also enabled by wider investment strategies, procurement policies, prioritization processes, and contracting practices. Pending the development of Te Rūnanga Whakapiki Mauri or something similar, the health sector's funding and contracting infrastructure needs to be reviewed with a focus on identified sites of institutional racism and the broader inconsistencies with *te Tiriti* that the tribunal found.[53] An action research process could then be instigated by systems change teams within public entities to design and progressively implement anti-racism interventions focused on specific sites of racism that would contribute to a broadening community of anti-racism praxis.[54]

Historical trauma, entrenched disparities, and ongoing disinvestment in Māori health knowledge, human capital, and operational systems means that a larger proportion of Vote Health will be required to acknowledge both *rangatiratanga* and the substantive equality of opportunity that citizenship implies.[55]

Health equity is not simply a matter of levels of public funding. The ways in which decisions are made and implemented, by whom, and for whom are also important. *Rangatiratanga*, for example, suggests the replication of models of Indigenous-owned and -run health services that exist nationally and for Indigenous peoples elsewhere that are consistent with Māori aspirations and operate on the assumption of both clinical and cultural safety.[56]

Embedding equity and anti-racism

The intellectual debate about whether institutional racism exists in the New Zealand health system appears to have been resolved, and there is agreement that it is a major impediment to health equity.[57] This is a profound agreement and presents a unique opportunity for a transformative response from the Crown in relation to upholding *te Tiriti* within the health sector. The debate now needs to focus on how to eradicate institutional and other forms of racism long embedded in the sector and on how Māori wish to express *tino rangatiratanga*.

The achievement of health equity in Aotearoa will require a significant political commitment at the policy, systems, and individual levels. While *rangatiratanga* in the form of Te Rūnanga Whakapiki Mauri or similar may be some years away, it is important that change occurs immediately.[58] This can be achieved by engaging in action research as outlined above, but also through adopting a *kaupapa Māori* methodology to address inequity.

Came et al. have consistently argued for a systems change approach that embraces a relational, holistic, and intergenerational analysis to eliminate institutional racism and secure active engagement with *te Tiriti o Waitangi*.[59] These works maintain that anti-racism efforts need to be planned, sustained, systematic, and multi-leveled to be successful. Short-term effects are otherwise produced when what is needed is long-term sustained change. There needs to be high-level political will, a commitment to organizational cultural change, and genuine Māori leadership.

Marshall Chin et al., referring to equity rather than racism, have argued that policy should be specifically designed for equity.[60] They also emphasize the importance of adequate resources in Māori health, accountability, and frank and fearless conversations about the drivers of inequity: institutional racism and colonial assumptions in the policy process. Fiona Cram has developed an evidence-based framework that outlines particular actions for the health sector, but it does not yet appear to have been implemented.[61]

The evidence is overwhelming with regard to the fact that achieving equity also requires consideration of the other political and historical determinants of health.[62] It is well accepted that there is a considerable population-level health gain to be achieved by raising the level of health of those with the most compromised health.[63] Lifting people out of poverty into meaningful work with a living wage will raise the level of household incomes and subsequently improve health.[64] Investment in Māori public health, with a focus on keeping *whānau* well and living in conditions that do not compromise *hauora* (health), is cost-effective, ethical, and equity enhancing.[65]

Conclusion

As critical scholars, we are interested in the right to health. For Māori, *hauora* and *oranga* (health) are inclusive terms for the physical, spiritual, and cultural well-being of Māori as individuals and collectively. It is widely accepted that there are long-standing significant disparities in health outcomes for Māori, fueled by the intergenerational legacy of colonization. Along with many health professionals, we do not accept that such inequalities are acceptable, just, necessary, or fair in a developed country such as Aotearoa. Breaches of *te Tiriti* are unacceptable breaches of the social contract between Māori and non-Māori—and often also breaches of human rights agreements.

Human rights are interdependent, indivisible, and interrelated. Māori have an equal and inclusive right to the highest standards of health. The right to health is articulated in the constitution of the World Health Organization, the Alma-Ata Declaration, and the Universal Declaration of Human Rights.[66] The government of New Zealand is responsible for ensuring that this right is achieved under article 5(e)(iv) of the International Convention on the Elimination of All Forms of Racial Discrimination, article 12 of the International Covenant on Economic, Social and Cultural Rights, articles 11(1)(f), 12, and 14 (2)(b) of the Convention on the Elimination of All Forms of Discrimination against Women, article 24 of the Convention on the Rights of the Child, article 25 of the Convention on the Rights of Persons with Disabilities, and article 24(2) of the Declaration on the Rights of Indigenous Peoples, all of which it has ratified.[67]

The WAI 2575 report raises urgent imperatives for the New Zealand health sector—a sector that has failed to uphold the right to health for Māori. The strategy of one or two Māori seats at the decision-making table has proven ineffective. We argue that what constitutes equitable needs to be defined by Māori and will require substantive Māori participation in policymaking and implementation. Indeed ultimately, the transformations called for by WAI 2575 will require Māori leadership of the changes in order to give effect to *tino rangatiratanga* as well as substantive and distinctive citizenship.

This Māori leadership might take the form of Te Rūnanga Whakapiki Mauri, as Durie proposes, which is a reasonable response to the tribunal's recommendation for an independent Māori Health Authority. Certainly, it needs decision-making authority in relation to policy development, implementation, and evaluation, as well as fiscal decisions and clinical governance. A decolonized and *te Tiriti*-compliant health system would necessitate a reallocation of power and health investment. Policy needs to be realigned to engage with the Māori text, rather than the English version or the treaty principles. We support the tribunal's recommendation that a more than proportionate allocation of Vote Health to Māori health may be necessary over several generations to acknowledge the current inequitable burden of disease and the legacies of colonization that are reflected in the conditions in which many Māori *whānau* currently live.

Existing structural mechanisms need to be utilized and new ones developed to ensure sector-wide transformation toward accountability for Māori health. This needs to occur at ministerial, bureaucratic, and clinical levels of the sector. We need a planned approach to achieve health equity and to eliminate institutional racism

Clearly, there needs to be early and substantive inclusion of Māori evidence in health planning. The significant contributions of Māori scholars should be recognized and trusted, and Māori scholarly work should inform health policy and decision-making. Māori leadership and the application of critical *Tiriti* analysis could become structured into the development of health policies and services that respect both *rangatiratanga* and distinctive Māori citizenship.

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HHR
Health and Human Rights Journal

Right-to-Medicines Litigation and Universal Health Coverage: Institutional Determinants of the Judicialization of Health in Brazil

MARIANA P. SOCAL, JOSEPH J. AMON, AND JOÃO BIEHL

Abstract

Over the past three decades, Brazil has developed a decentralized universal health system and achieved significant advances in key health indicators. At the same time, Brazil's health system has struggled to ensure equitable and quality health services. One response to the broad promises and notable shortcomings has been a sharp rise in right-to-health litigation, most often seeking access to medicines. While much has been written about the characteristics of patient-plaintiffs and the requested medicines in right-to-health litigation in Brazil, little research has examined potential community-level and institutional drivers of judicialization and their role as mechanisms of accountability. To explore these dimensions, we used a mixed-effects analytical model to examine a representative sample of lawsuits for access to medicines filed against the state of Rio Grande do Sul in 2008. We found that the presence of a Public Defender's Office was associated with a sevenfold increase in the likelihood of a municipality having a medicine-requesting lawsuit. This effect was maintained after controlling for a series of municipality characteristics. As low- and middle-income countries seek to achieve universal health coverage within the framework of the Sustainable Development Goals, Brazil's experience may be illustrative of the challenges that health systems will face and the institutional mechanisms that will emerge, advancing accountability and individual patients' interests in response.

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Competing interests: None declared.

Introduction

Universal health coverage (UHC) has become a rallying cry and pillar of the Sustainable Development Goals. Operationally, it can mean both focused reforms and sweeping health system changes. In its simplest formulation, UHC is understood as access to affordable, quality health services for all.[1]

Over the last three decades, among low- and middle-income countries, Brazil has been at the forefront in creating a universal health system (*Sistema Único de Saúde*, or SUS) grounded in the recognition of a right to health for all.[2] With significant investment, Brazil has increased life expectancy (from 65 to 75 years), reduced infant mortality (from 53 to 14 per 1,000), and pioneered pharmaceutical access initiatives.[3] In recent measures of UHC, Brazil received a 77 out of 100 in its UHC service coverage index, with scores for different services including 88 (family planning), 90 (antenatal care), and 96 (child immunization).[4]

Alongside these achievements, the country has faced major challenges: sustaining funding, building robust institutions and regulatory mechanisms, and ensuring equitable quality of care. The decentralization of care delivery has often occurred without adequate technical capacity, and the growing privatization of services has jeopardized efficiency and entrenched inequalities around the axes of race, gender, and region.[5] These trends are especially evident around pharmaceutical access: many Brazilian patients go to public pharmacies only to find that the medicines they were prescribed are out of stock or are not included in governmental drug formularies.[6]

One mechanism that emerged to address some of these challenges has been the phenomenon of right-to-health litigation (often referred to as the "judicialization of health").[7] Highly contested and methodologically constrained, the debates over the whys, the hows, and the effects of this ever-expanding phenomenon have been marked by polarized arguments about equity, bureaucratic autonomy, resource allocation, and efficiency.[8] Many scholars and government officials have advocated for the containment and management of right-to-health litigation.[9] In contrast, our previous work has advanced an understanding of such litigation as a heterogeneous phenomenon and as a critical dimension of the country's democratic life, enabling legal empowerment, fostering social mobilization, and working as a mechanism (albeit precarious) of accountability.[10] From this perspective, judicialization contributes to the struggle to define the contours and components of the country's constitutionally mandated right to health alongside subsequent laws, Ministry of Health policies, and Supreme Court rulings that have advanced an expansive right to access to treatments.

While past studies of judicialization in Brazil have emphasized individual characteristics of patient-litigants and the types and costs of the medicines requested, in the present study we seek to identify how community-level and institutional determinants might influence right-to-health-litigation. As low- and middle-income countries invest in and develop stronger health systems, more attention should be paid to understanding Brazil's experience in developing a universal health system and to the governmental and civil society mechanisms that arose to address its shortcomings and constraints. With hundreds of thousands of lawsuits seeking access to medicines annually, judicialization has played a central role in Brazil by mediating individuals' access to health care. As low- and middle-income countries expand their efforts to establish UHC, and their populations face an increasing burden from non-communicable diseases, the potential role (and limits) of judicialization as a mechanism of accountability deserves close scrutiny, especially in light of current trends in pharmaceutical globalization and the privatization of health care.[11]

Neoliberal reforms, access to medicines, and judicialization in Brazil's national health system

Two concurrent and paradoxical trends informed the structure of Brazil's universal health care system in the early 1990s. On one hand, there was a trend toward a greater recognition of the government's role in the fulfilment of social rights in a democratizing Brazil. On the other hand, a neoliberal theory of government emphasized decentralization and the outsourcing of state functions to the private sector.[12] Nowhere was this conflicting direction more evident than in the question of pharmaceutical access.

From its inception, access to medicines was an integral part of Brazil's national health system, SUS. Over time, with the introduction of drug-specific programs and policies and patient activism, access to medicines became an even larger component.[13] In the 1990s, community health boards (*Conselhos de Saúde*) were created at local, regional, and national levels to ensure accountability within SUS. They were designed to set priorities and to monitor the implementation of health policies.[14] These participatory mechanisms, however, have not alleviated major problems related to the lack of infrastructural investments (with public services outsourced to private providers) and the effective regulation of public and private health care actors. Thus, the country still sees large regional disparities in health care delivery and in health outcomes, with poorer regions and lower socioeconomic population groups disadvantaged the most.[15]

Even outside SUS, access to medicines has remained a core responsibility of the state. Private health insurance plans were introduced in the country in the late 1980s to complement SUS and to provide specialized and expedited care for higher-income segments. However, privately insured individuals (who now constitute about 24% of the population) have continued to benefit from SUS through access to state-subsidized medicines, since private insurance plans do not cover outpatient drugs.[16] This benefit, combined with the tax deductibility of health insurance premiums, puts a strain on state health expenditures while also lowering tax revenues. Of particular demand are increasingly high-priced specialty drugs such as treatments for diabetes, hepatitis C, and cancer.

In the mid-1990s, after Brazil signed the TRIPS agreement and began to see a successful response to HIV/AIDS with expanded access to antiretroviral drugs, an understanding of a right to medicines emerged. With exponentially increasing drug costs (due to tightening intellectual property laws for medicines and Brazil becoming a major market for global medicines), judicialization expanded to new patient populations, with people using the courts to seek access to medicines they were unable to find in public pharmacies. The arguments advanced in lawsuits drew on those used by HIV/AIDS activists, and the phenomenon grew especially quickly in the southern and southeastern regions.[17] Recognition of a right to medicines was endorsed by a ruling by the Supreme Court in 2000 concerning a patient's access to a new antiretroviral drug and describing the HIV/AIDS pharmaceutical assistance program as the actualization of the government's duty to implement programmatic norms that secure the health of the population.[18] With such programs, as Justice Celso de Melo argued, the right to health ceases to be "an inconsequential constitutional promise."[19]

Patient-plaintiffs in Brazil obtain legal representation from private lawyers or public legal services, such as the independent Public Prosecutor's Office (*Ministério Público*) and local branches of the Public Defender's Office (*Defensoria Pública*). The Public Prosecutor's Office operates at both the federal and state levels and is charged with defending the rights of minorities and civil society more broadly. The Public Defender's Office promotes individual rights and provides free legal representation to individuals who earn below a certain income threshold (three times the minimum wage). Public Defenders' Offices are present in all Brazilian states and in most large cities and are meant to guarantee the constitutional promise of a right to access to justice. Historically, lawsuits for access to medicines have been filed against the state, even when the drug has not been part of SUS's formularies or when the plaintiff had a private health insurance plan. Since the early 2000s, courts have continued to consistently rule in favor of patient-plaintiffs, based on the interpretation that the right to state-provided medicines is part of the constitutional right to health.[20]

The state of Rio Grande do Sul, where we have been carrying out research for the past decade, has the highest number of right-to-medicines cases in the country.[21] In 2016, for example, this state of over 11 million inhabitants had 61,000 legal cases for access to medicines, costing 4% of the state's entire health budget that year.[22]

Case study: Institutional determinants of judicialization in southern Brazil

Numerous investigations have described the characteristics of right-to-medicines litigation in Brazil. While some studies have found that judicialization is driven primarily by better-off individuals seeking expensive off-formulary treatments, others have found that judicialization serves mainly low-income individuals who are seeking inexpensive medicines that should have been available in SUS pharmacies.[23] When examining the legal and medical services most frequently involved, some scholars have suggested that judicialization is driven largely by physicians seeking to promote high-cost treatments and private lawyers specializing in health-related lawsuits, while other scholars have highlighted the important role played by SUS doctors and public defenders in encouraging patients to file lawsuits.[24]

Less closely examined has been the influence of community-level characteristics (such as socioeconomic development) and institutional factors (such as the presence of health and legal systems).[25] For example, some studies have suggested that regional differences in health budgets and in SUS's administrative capacity might be drivers of judicialization.[26] From this perspective, judicialization could be seen as a response to a population's health needs being insufficiently or inadequately fulfilled by state services at the local level.[27] Alternatively, the characteristics and accessibility of the legal system at the local level may influence individuals' ability to "enter justice" (*entrar na justiça*, as plaintiffs generally call it—that is, to have their health claims addressed by the judiciary).[28]

In the context of what has been at times a polarized and overly narrow debate, broadening the understanding of judicialization beyond individual cases, types of medicines requested, and their immediate costs is timely and analytically significant.

Methods

To assess the possible influence of community-level and institutional factors on judicialization, we re-examined lawsuits for access to medicines filed against the state of Rio Grande do Sul in each of the state's 496 municipalities in 2008. This representative sample was collected through a systematic survey of lawsuits on which we have previously reported. Methods from our research are described in detail elsewhere.[29] Briefly, the survey collected data from the State Health Secretariat's electronic registry, a database that records all medicine-related lawsuits filed against the state and includes information on plaintiffs' municipality of residence. In this analysis, we used plaintiffs' municipality of residence as the unit of analysis and considered municipalities with at least one medicine-requesting lawsuit to be positive cases. The research was reviewed and approved by the Institutional Review Board of Princeton University and by the Health Secretariat and the General Attorney's Office of the state of Rio Grande do Sul.

Our analysis focused on the availability of health services and the presence of a Public Defender's Office at the level of the municipality and health administrative region (HAR, or *Coordenadorias Regionais de Saúde*). Each HAR is responsible for managing and implementing state-sponsored health service delivery, including medicines, in the municipalities it covers.[30] The location of Public Defender's Offices was obtained from the Rio Grande do Sul Public Defender's Office website.[31] Availability of health services, defined as the number of facilities providing health services per 1,000 inhabitants, was obtained from a national health services survey known as the *Pesquisa Assistência Médico-Sanitária*.[32] We also examined several demographic, socioeconomic, and health characteristics of the municipalities, which we obtained from the Brazilian Census and the Ministry of Health's epidemiologic surveillance system.[33] All 496 municipalities had full information, and there were no missing data.

Although the decision to submit lawsuits is made by patients and their sponsors (such as physicians and legal representatives), a patient's likelihood of filing a lawsuit depends on the availability of such services in their community. Higher availability of health services in a given locale, for example, could be associated with a greater demand for pharmaceuticals and the increased likelihood of judicialization. Lower availability of health services could also be associated with a greater likelihood of judicialization as a means to fulfill the unmet health needs of a local population. In turn, higher availability of legal services could be associated with a higher likelihood of judicialization through increased access to legal representation.

In this study, we focused our analysis on outcomes and determinants at the community (municipality) level. Our analysis assumes that patients with the same individual characteristics would have different likelihoods of filing a medicine-requesting lawsuit, depending on the community level determinants and the characteristics of the health services and legal system of the municipality where they live.

Figure 1 displays the conceptual framework that guided our analysis. This theoretical scheme was adapted from Ronal Andersen and John F. Newman's framework entitled "Societal and Individual Determinants of Medical Care Utilization" and is used here to represent the "claims formation stage" of the litigation process.[34]

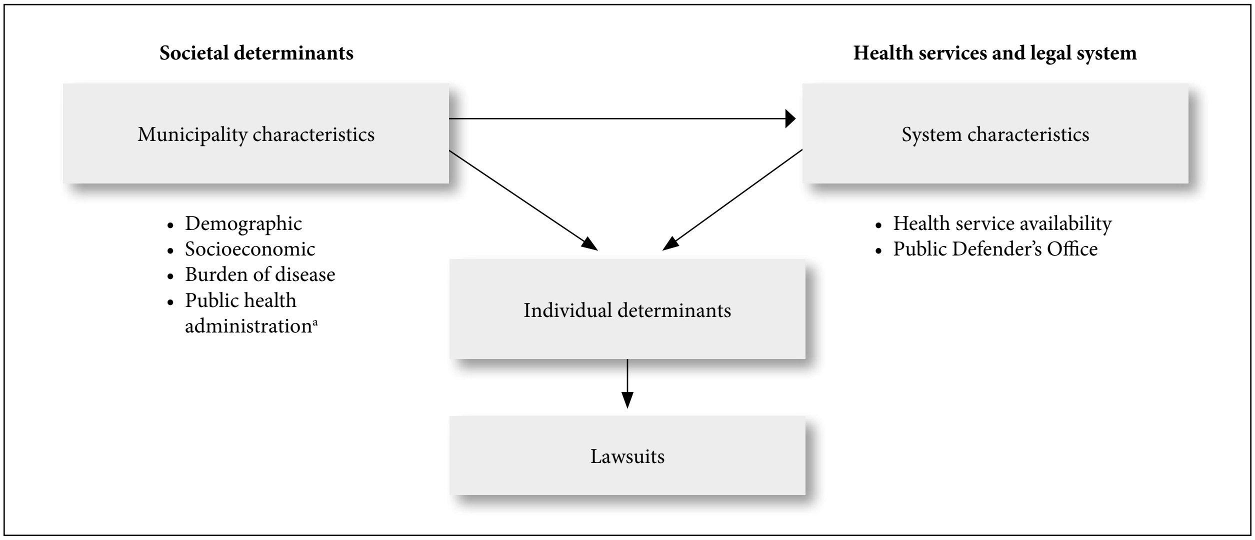
Controlling for demographic and socioeconomic characteristics, we implemented multi-level random effects logistic regression analyses grouped at the HAR level. The adjustment for municipality characteristics was implemented because these characteristics may simultaneously influence the likelihood of a municipality having a medicine-related lawsuit and the municipality having greater availability of health services or a Public Defender's Office. There is also the possibility that the administrative capacity of the health system at the municipality level may play an independent role, as indicated by the municipality's membership in a given HAR.

We tested the robustness of our results with sensitivity analyses using fixed-effects models for HAR and by repeating all models without the capital city of Porto Alegre (population of about 1.4 million), the only municipality with more than one Public Defender's Office. All statistical analyses were implemented using Stata statistical package release 12 (StataCorp, College Station, TX).

Results

In 2008, over half of Rio Grande do Sul's 496 municipalities were classified as urban (N=275, 55.5%), with an average of 21,000 inhabitants per municipality (range: 1,200–1.4 million) (Table 1). The state

FIGURE 1. Conceptual framework: Institutional determinants of medicine-related lawsuits



[a] In Brazil, public health administration is represented at the local level by health administrative regions (*Coordenadorias Regionais de Saúde*).

had a higher level of socioeconomic development than most states in Brazil, with an illiteracy rate among adults of 6.8% (range: 1–20% among municipalities) and monthly income of R$742.83 (US$462.50) (representing 1.8 times the national monthly minimum wage of R$415.00, or US$ 258.39, at the time).[35] The state had a crude mortality rate of 703.2 per 100,000, which varied between 120 and 1,200 deaths per 100,000 population among municipalities. Overall, 153 Public Defender's Offices were present in the state, with at least one Office present in 31% (N=153) of the municipalities. There were, on average, 59 health services per 100,000 inhabitants (Figure 2).

Ninety-two percent of lawsuits were found outside the capital city of Porto Alegre. About 45% (N=223) of municipalities had at least one lawsuit for access to medicines (Figure 3). Municipalities with lawsuits had an average of 28.5 lawsuits per 100,000 inhabitants (range: 1.5–168.6). Although the state capital had the highest number of lawsuits, when adjusted for population size it ranked 20th in lawsuits per 100,000 people. The municipalities with the highest density of medicine-requesting lawsuits were smaller municipalities, geographically scattered across the state.

In a bivariate analysis, municipalities with medicine-requesting lawsuits had higher populations (40.9 ± 109.9 vs. 6.0 ± 7.5 thousand inhabitants, p<0.0001) and higher mortality rates (7.23 ± 1.47 vs. 6.87 ± 1.85 deaths per thousand, p=0.014) than municipalities without lawsuits (Table 2). Municipalities with lawsuits were more likely to be urban (26% vs. 59%, p<0.0001) and had lower illiteracy rates (6.2% vs. 7.3%, p=0.0006) and higher income levels (R$765.4 ± 199.7 vs. 724.4 ± 213.1, p=0.028) than those without lawsuits. Municipalities with lawsuits were more likely to have a Public Defender's Office (59% vs. 8%, p<0.0001) and had lower availability of health services (0.52 ± 0.26 vs. 0.64 ± 0.38 services per 1,000 inhabitants, p<0.0001) than those without lawsuits.

When controlling for all other characteristics in a multi-level random effects logistic regression model, municipalities with at least one Public Defender's Office were about seven times more likely

TABLE 1. Descriptive characteristics of Rio Grande do Sul's 496 municipalities

Characteristic	Metric	Value
Demographics		
Population	Avg (sd)	21.6 (75.8)
Mortality rate[a]	Avg (sd)	703.2 (169.6)
Socioeconomic		
Urban[b]	N (%)	275 (55.5%)
Illiteracy rate[c]	Avg (sd)	6.8% (3.3%)
Per capita income[d]	Avg (sd)	R$742.83 (208.00)
Service availability		
Health servicese	Avg (sd)	59.02 (33.6)
Public Defender's Office[f]	N (%)	153 (31%)
Lawsuits		
Has medicine-related lawsuit	N (%)	223 (45%)

Notes: A new municipality was created in the state of Rio Grande do Sul after the data collection for this study, bringing the current total to 497 municipalities. Avg: average; sd: standard deviation.

[a] Crude mortality rate: total deaths per 1,000 inhabitants

[b] Municipality has predominance of urban areas

[c] Percentage of the adult population that cannot read or write

[d] Average per capita income in 2010 Brazilian reais

[e] Health services per 100,000 inhabitants

[f] Municipality has at least one Public Defender's Office

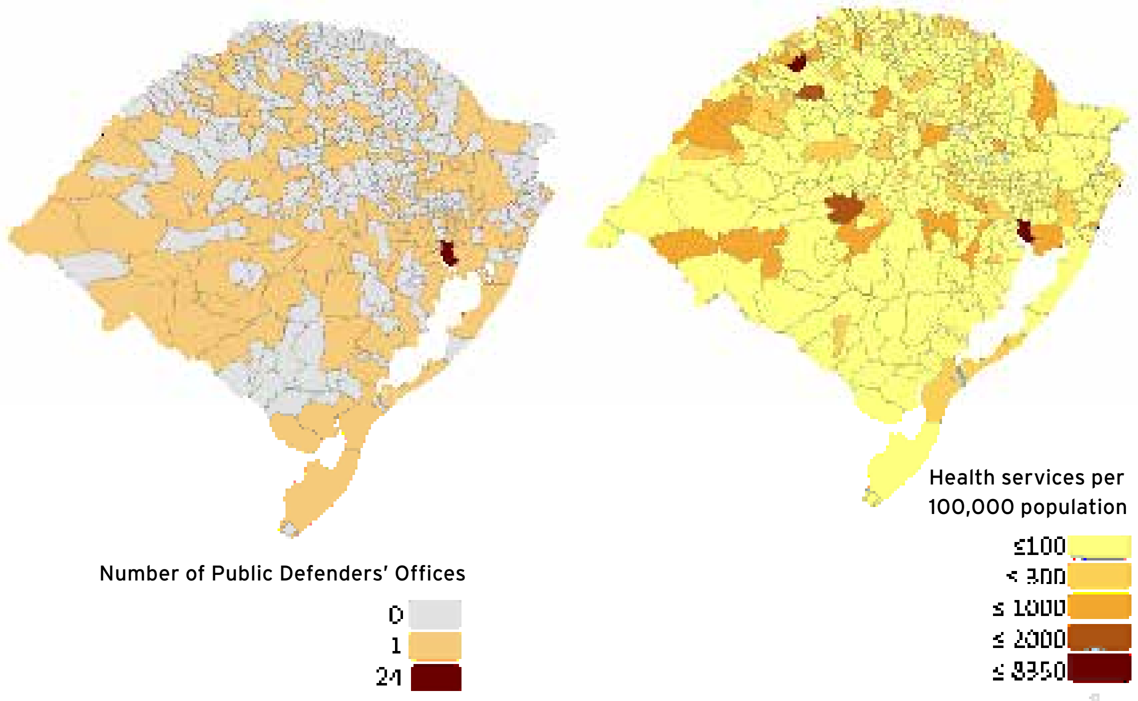
to have a medicine-requesting lawsuit than municipalities without it (odds ratio: 6.95, 95% CI: 3.2–15.1) (Table 3). Municipalities with greater availability of health services were less likely to have a lawsuit, yet this association was not shown to be statistically significant (odds ratio: 0.56, 95% CI: 0.27–1.17). Population size (odds ratio: 1.04, 95% CI: 1.01–1.07 per 1,000 population), mortality rate (odds ratio: 1.17, 95% CI: 1.01–1.34 per 1,000 individuals), and urban characteristics (odds ratio: 1.01, 95% CI:1.00–1.03 as compared to rural) continued to be associated with a greater likelihood of lawsuits. Neither of the variables associated with socioeconomic status, illiteracy, or per capita income was significantly associated with the presence of a lawsuit in the municipality. After adjusting for all characteristics, belonging to the same public health administration region explained 15% of the municipality's likelihood of having a lawsuit (intraclass correlation coefficient: 0.15, 95% CI: 0.06–0.33). The different models implemented in the sensitivity analysis did not significantly change the results.

Analysis

Amidst global efforts to implement universal health care systems, the Brazilian experience of the last three decades is emblematic of the challenges that governments face in ensuring equitable and efficient health systems, while addressing an expansive, constitutionally mandated right to health and dealing with an accelerated political economy of pharmaceuticals.[36] In our previously reported work, we found that judicialization was geographically widespread in southern Brazil and that the majority of litigants were poor and older individuals with chronic diseases, seeking access to medicines that were already on governmental formularies and should have been available in local public pharmacies. Overwhelmingly, local judges ruled in favor of patient-plaintiffs, deeming their demands constitutionally legitimate.[37]

Our empirical findings here suggest that the

FIGURE 2. Distribution of Public Defenders' Offices and health services across Rio Grande do Sul's 496 municipalities



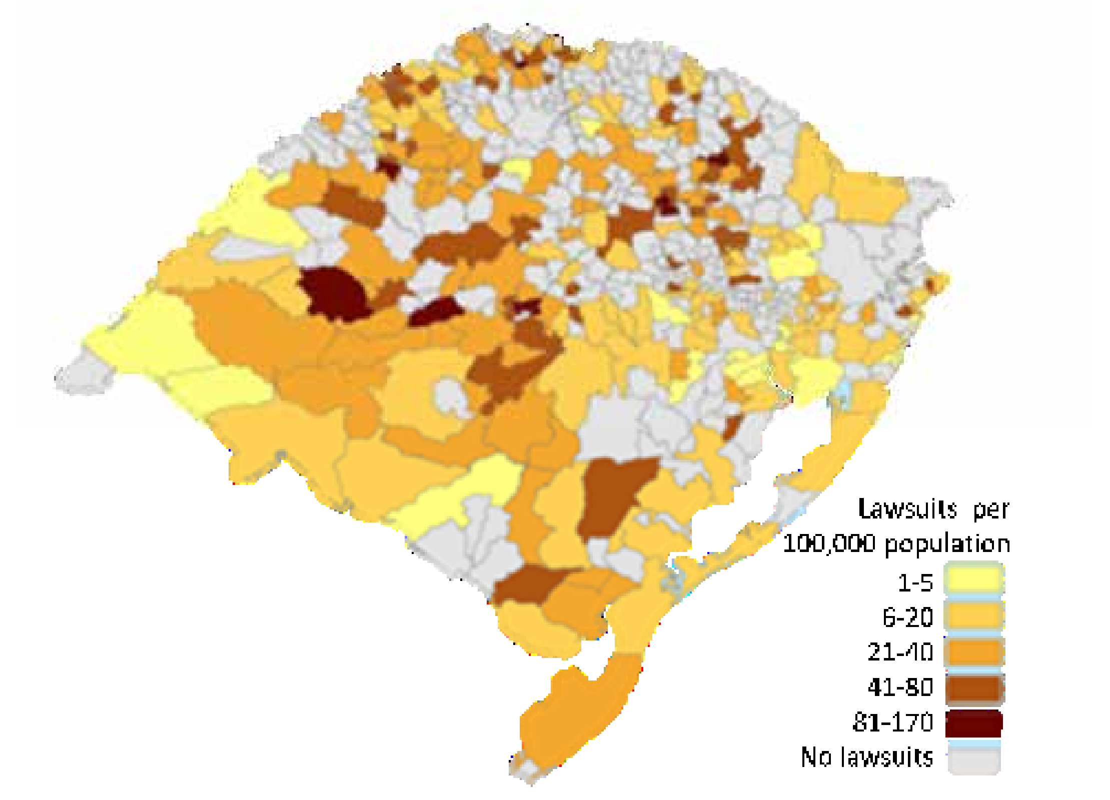
Sources: Defensoria Pública do Rio Grande do Sul. Available at http://www.defensoria.rs.def.br/inicial; Instituto Brasileiro de Geografia e Estatística, Pesquisa de Assistência Médico-Sanitária (2009). Available at https://www.ibge.gov.br/estatisticas-novoportal/sociais/saude/9067-pesquisa-de-assistencia-medico-sanitaria.html.

presence of a Public Defender's Office in a municipality is a major determinant of the likelihood of judicialization. Although this study implemented a cross-sectional analysis—which does not allow for the establishment of causative relationships between the institutional factors that we examined and the occurrence of judicialization—two main findings suggest that it is likely that the presence of Public Defenders' Offices helped enable judicialization, and not the other way around. First, our fully adjusted models indicated that two municipalities with the same characteristics—same population size, mortality rates, and urban/rural characteristics—have significantly different likelihoods of having a medicine-related lawsuit, depending on the presence or not of a Public Defender's Office. Even if the presence of a Public Defender's Office in the municipality was initially a response to population needs, it still plays an important role in enabling patient-plaintiffs to file lawsuits. Second, the Public Defender's Office is not the only form of legal representation available for low-income individuals in Rio Grande do Sul. When filing a lawsuit for access to medicines, low-income individuals may also be represented by a private lawyer and have their legal fees reimbursed by the state, as long as they request it as part of their lawsuit, present proof of need, and the judge approves it.

Judicialization as a mechanism of universal health coverage accountability

Charged with a mandate to represent vulnerable individuals and uphold justice, public defenders have accepted health-related lawsuits as part of their commitment to institutionally sustaining advancements in socioeconomic rights and promoting state accountability.[38] This accountability is

Figure 3. Distribution of medicine-requesting lawsuits across Rio Grande do Sul's 496 municipalities



Source: Authors' analysis of a representative survey of all medicine-requesting lawsuits filed against the state of Rio Grande do Sul (for a full description of the survey, see J. Biehl, M. Socal, and J. Amon, "The judicialization of health and the quest for state accountability: Evidence from 1,262 lawsuits for access to medicines in southern Brazil," Health and Human Rights Journal 1/18 (2016), pp. 209–220).

TABLE 2. Characteristics of Rio Grande do Sul municipalities with and without lawsuits

Characteristic	Municipalities with lawsuits (n=223)	Municipalities without lawsuits (n=273)	p-value
Demographics			
Population[a]	40.6 (109.9)	6.0 (7.5)	<0.0001
Mortality rate[b]	7.23 (1.47)	6.87 (1.85)	0.017
Socioeconomic			
Urban[c]	74% (44%)	41% (49%)	<0.0001
Illiteracy rate[d]	6.2% (2.8%)	7.3% (3.7%)	0.0006
Per capita income[e]	765.4 (199.7)	724.4 (213.1)	0.0286
Service availability			
Health services[f]	52.49 (25.85)	64.37 (37.98)	<0.0001
Public Defender's Office[g]	59% (49%)	8% (27%)	<0.0001

[a] Total population, in thousands
[b] Crude mortality rate: total deaths per 1,000 inhabitants
[c] Municipality has predominance of urban areas
[d] Percentage of the adult population that cannot read or write
[e] Average per capita income in 2010 Brazilian reais
[f] Health services per 100,000 inhabitants
[g] Municipality has at least one Public Defender's Office

TABLE 3. Factors associated with higher likelihood of lawsuits among Rio Grande do Sul municipalities: Results from fully adjusted multi-level random effects

Variable	Coefficient	95% confidence interval	p-value
Demographics			
Population[a]	1.04	(1.01–1.07)	0.02
Mortality rate[b]	1.17	(1.01–1.34)	0.031
Socioeconomic			
Urban[c]	1.01	(1.00–1.03)	0.022
Illiteracy rate[d]	0.97	(0.89–1.06)	NS
Per capita income[e]	0.99	(0.86–1.14)	NS
Service availability			
Health services[f]	0.56	(0.27–1.17)	NS
Public Defender's Office[g]	6.95	(3.2–15.1)	<0.0001
Constant	0.09	(0.01–0.56)	NS
N		496	

Notes: Multivariable multi-level random effects logistic regression model. The independent variable is the presence or absence of medicine-requesting lawsuits in a municipality. All the listed characteristics are included as fixed-effects regressors. The model includes a random intercept for health administrative region (HAR). Coefficients represent expected change in the odds of lawsuits associated with a 1-unit change in the variable, keeping all other characteristics constant. NS: not statistically significant (p-value >0.05). N=496 municipalities.

[a] Total population, in thousands
[b] Crude mortality rate: total deaths per 1,000 inhabitants
[c] Municipality has predominance of urban areas
[d] Percentage of the adult population that cannot read or write
[e] Average per capita income in 2010 Brazilian reais
[f] Health services per 100,000 inhabitants
[g] Municipality has at least one Public Defender's Office

manifest in two ways: first, it provides a measure of whether the state is fulfilling its constitutional obligations and administrative functions; and second, it pressures the state to respond to the rapidly changing landscape of population health needs and transparently and effectively address the incorporation of new technologies in the health system. In focusing on accountability within existing political and economic systems and sustaining hard-fought basic rights, the Public Defender's Office thus elicits a vision of justice and political engagement at a local scale that includes the urgent need for health systems reform.[39]

If universal health coverage goes beyond access to minimum public health services and essential medicines and seeks to address the chronic, non-communicable diseases that are increasingly the cause of morbidity and mortality in low- and middle-income countries, then the increasing "pharmaceuticalization of health" must be anticipated.[40] Innovative treatments are available in the global market at ever-increasing speeds and heftier price tags. Incorporating these technologies into what can be offered to populations is a particular policy challenge for countries such as Brazil, which has become the world's fifth most profitable and rapidly growing pharmaceutical market.[41] In this context, some scholars have argued that judicialization fails to act at the scale needed to combat neoliberally inflected policies.[42] That is, judicialization should focus more on court cases that seek structural changes to the political economy of medicines or on lobbying legislative bodies to take such steps as reforming patent laws and imposing regulations on price.

While judicialization might have the indirect effect of temporarily improving health care delivery, medicines granted by courts are often not fulfilled by the government, leaving patients with a legal victory but no treatment.[43] Or courts are slow to act, while patients suffer waiting for a resolution.[44] In a previous study we documented some responsiveness by the government to litigation, with several of the most sought-after medicines that were initially not on drug formularies later officially included, thus increasing the likelihood of availability.[45] While this is not a direct consequence of judicialization, it is a consequence of the expansion in the services and products provided by the public system that has occurred because of judicialization. Moreover, the lack of private insurance coverage for outpatient drugs in Brazil has left a gap that further challenges public policy and strains government budgets. Small steps have been taken in recent years by advancing regulations requiring private insurers to expand their benefits packages and include some high-cost drugs in their covered services.[46] Having private insurers cover drugs helps expand opportunities for Brazilians to finance the drugs they need, helps open new markets, and helps develop new opportunities for price negotiations with pharmaceutical companies.

It is easier to sue for medicines than for the improvement of public health services, and although massive individual right-to-health litigation may not represent sustainable structural change, it nonetheless helps strengthen the right to health and human rights more broadly, as seen in the institutional work of Public Defender's Offices in southern Brazil. This work recognizes the fundamental importance of the State and its right-to-health obligations. Without establishing these obligations and institutionally sustaining advancements (albeit limited) in socioeconomic rights, pressing for governments to recognize their duty to challenge drug patents and negotiate pricing seems fanciful at best.[47]

There is indeed a sentiment across many sectors in Brazil that there should be a more effective way to address government malfunction and the privatization of SUS other than the judicialization route, but the answer from officials and scholars has often been that the better way is limiting access to justice and hoping that pharmaceutical delivery systems improve, either with expert advisory panels or on their own.[48] While better prioritization (that is, rationing) might be necessary, empowering expert advisory panels to determine what medicines should be provided by the state would not directly change the current dynamic in which courts judge that the state's constitutional obligation to fund UHC at 15% of GDP is not being met and that individuals' right to health includes medicines not on government formularies. If the recommendations of such panels were to constrain access to medicines, this might be considered a failure to progressively realize the right to health and in violation of Brazil's treaty obligations under the International Covenant on Economic, Social and Cultural Rights. Expert panels might alternatively be charged with assessing the efficiency of the government's pharmaceutical supply chain system, the influence of the pharmaceutical industry, the government's use of (or failure to use) TRIPS flexibilities, or potential legislative policies and legal reforms around the coverage of medicines by private insurance. Local accountability efforts such as judicialization may not be the most efficient or all-encompassing political mechanism, but it is a critical element of a progressive rights movement and conduit of legal empowerment and a broader democratization of society.

Lawyers and legal services have played a role in Brazil in defining access to medicines in landmark cases going back to rulings on the free provision of antiretroviral therapy as a component of the right to health. In recent years, the legal pathway for access to medicines has allowed patients with hypertension to receive the basic drugs that were missing in their local public pharmacies, as well as patients with rare genetic disorders to receive the newest treatments in the field before their conditions become irreversible.[49] Although our data is from 2008, the mechanism of judicialization for accountability remains ever more relevant.

Legal empowerment as a grassroots strategy to expand health care has been documented globally, with, for example, *defensores de saúde*, or health advocates, in Mozambique supporting clients at the village level to resolve specific grievances with respect to health services, and "street lawyers" (*Gadejuristen*) in Copenhagen who provide legal education and sterile injecting equipment to drug users.[50] In Brazil, lawyers have also represented patients seeking broader protections such as access to information, transportation, specialized care, and family planning for those affected by the Zika virus.[51] In addition, legal empowerment demonstrates that the assumption that social rights litigation "benefits those in the 'middle' of the social spectrum because the poor have less access to courts" is fundamentally a product of the lack of options for access to legal representation.[52] Such lack can be successfully mitigated by institutions such as the Public Defender's Office, which reinforce the "right to remedies" of individuals left out and left behind as policy makers (and often, international experts and norm-setting organizations) define what is, and what is not, included in universal health coverage.

As mentioned above, the role of public defenders and lawsuits as mechanisms of accountability for a functioning health system have limits—and inefficiencies. In order to effectively improve and expand Brazilians' access to medicines, other accountability mechanisms ought to be engaged as well: the Public Prosecutor's Office (*Ministério Público*), which represents vulnerable communities (including children, the elderly, and traditional populations); the community health boards (*Conselhos de Saúde*) that are SUS's main accountability channel by design; state legislators and government health administrators who have the power to set up stronger mechanisms for prioritization and resource allocation; and civil society organizations, such as those representing Zika-affected families.[53] These mechanisms may target different shortcomings of universal health care systems, such as improving quality of care, transparency of decision-making, responsiveness, and resource allocation. They may also help expand the range of benefits offered from low-cost, low-complexity technologies toward increased access to high-cost and high-complexity ones.

Conclusion

Within global discussions of universal health coverage, the scant attention given to law has focused mostly on enabling legal environments and progressive health laws.[54] There has been little consideration of accountability mechanisms in general or access to legal services in particular. Our study demonstrates that the Public Defender's Office plays an important role in right-to-health litigation, expanding it to geographically and socioeconomically diverse environments.

The volume of court cases is itself pressure on both the judiciary and the legislature to adopt structural reforms. Until now, this pressure has been insufficient to match the power of lobbyists and special interests who oppose such reforms, but it may not always be so. While it may be more strategic in the long term to fight for patent law reforms and hope for timely and effective implementation, those putting forward individual lawsuits seeking medicines actually embody structural vulnerabilities. They speak to the urgent need to strengthen public health systems and guard them against private cooptation.[55] The immediate need for human rights advocacy and legal access for multitudes of individual patients is clear.

The role of judicialization and of the Public Defender's Office in improving accountability in access to medicines and overall health care delivery in Brazil should be further investigated. We contend that a combination of "real-time, comprehensive data collection multi-disciplinary academic research, robust public debate and media attention are needed in order to identify and strengthen these emergent accountability mechanisms aimed at both public and private health care institutions."[56] In addition, policy makers aiming to improve access to care and pharmaceuticals in Brazil should consider the impact of judicialization and improve policy design and regulatory oversight based on the information generated by this process, with the normative ambition of achieving transparent, accountable, and participatory priority setting that promotes substantive human rights.

Acknowledgments

We want to thank Tiago Canelas Ferreira for his assistance with the figures in this article. We are also grateful to the Princeton Open Access Publication Fund Program for financial support for open-access publication fees.

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A Constructivist Vision of the First-Trimester Abortion Experience

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Abstract

How might the abortion experience look in a world without the existing regulatory constraints? This paper critically assesses the evidence about how a high-quality abortion experience might be achieved in the first trimester. There would need to be positive obligations on states in pursuance of women's reproductive rights. The onus would be on states and state actors to justify interferences and constraints upon a woman's right to terminate in the first trimester of her pregnancy. In this vision, abortion is person-centered and normalized as far as possible. High-quality information about abortion would be freely available through multiple sources and in varying formats. Whenever possible, abortion would happen in a place chosen by the woman, and in the case of medical abortion, could be self-managed with excellent clinical backup on hand should the need arise. The overarching purpose of this paper is to highlight the broader environment and framework of state obligations necessary to underpin the lived experience of abortion.

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Competing interests: None declared.

Introduction

Criminalization of abortion has well-known deleterious effects.[1] Much has been written on decriminalization of abortion, specifying what legislation needs to be dismantled.[2] In contrast, we adopt a 'constructivist' approach, looking at what is needed to support a high-quality abortion experience, drawing upon research and literature that includes the lived experience of women who have undergone abortion. We set aside regulatory constraints that could hinder progress toward giving people with a uterus (in the interest of brevity, 'women' is used hereafter) the ability to freely choose how they respond to an unwanted pregnancy. As far as possible, we have used a fresh sheet of paper. We take a ground-up approach, building from scratch and beginning with no abortion-specific laws at all.

Although we use the term 'abortion' throughout this paper, we recognize that this may be construed as a loaded term with preconceived connotations. In keeping with our constructivist approach, we use the term simply to denote the steps necessary to bring about the end of an established pregnancy (that is, after implantation of the embryo). These steps would, in the ordinary course of events, result in ending the life of the unborn entity or entities.

Starting points and core assumptions

In this paper, we make several core assumptions. First, we assume that the state has unlimited resources to address its positive and negative obligations to pregnant women. Second, we assume that those resources are distributed fairly, justly, and equally within society. Third, we make no attempt to accommodate the plurality in this vision. There is no sense that competing views require accommodation or that compromises are necessary in the regulatory rules. Fourth, our vision does not seek to erase the private sphere, or any socio-political objections to, or prejudices against abortion. Rather, our focus is on a world without pre-existing regulatory constraint on the choices that women can make in this context. Fifth, although gestation outside the womb may soon be possible (ectogenesis), we assume that some demand for abortion (as currently envisaged) will persist.[3] Necessarily, these assumptions limit the transferability of this framework in the real world, but our intention is to encourage policy makers and reformers to think critically about the possibilities that a constructivist approach might offer should the opportunity arise for genuine reform. Further, our purpose is to highlight that in the absence of direct regulatory constraints, it is the broader environment and framework of state obligations that underpin the lived experience of abortion.

Defining quality in abortion care is at an early stage, despite abortion being such a commonplace occurrence. There is no standardized, validated set of quality metrics for abortion as there are, for example, for maternity services.[4] This paper does not focus on safety, effectiveness, timeliness, efficiency, and equitability; there is a considerable body of work on these.[5] Instead, we concentrate on person-centeredness as a major ingredient of a high-quality abortion experience. Person/patient-centered care means an approach that informs and engages women (and partners, if appropriate) in their own individual health care and also to engage service users in health care service co-design.[6] We assume that appropriate regulatory mechanisms remain in place to maintain the safety of all abortion services.[7]

We do not assume that women will have direct contact with health services. This is in line with current World Health Organization thinking, the general principles of self-care, and the experiences and perceptions of women who have undertaken self-management of medical abortion.[8] We do, however, acknowledge that there are still some research gaps on self-managed abortion; for example, how best to inform and support women in using the medicines safely and effectively and how to facilitate the community distribution of high-quality drugs and information.[9]

We know that many women have opted, for various reasons, for "informal sector" abortions, even when they are entitled to a legal abortion in the formal (approved) health sector.[10] On the face of it, this may seem like a second-best option, but as some women positively opt for self-managed abortion at home, it is no longer an act of desperation: "self-managed abortion can be a source of reprieve or escape from … indignities of formal settings and experiences of shame and powerlessness within them."[11] We regard self-managed first-trimester medical abortion (that is without attending a health facility)—following evidence-based regimens using drugs from approved sources, with full information—as safe. Self-management could be supplemented by advice from an approved authority such as a pharmacist or an appropriately trained community activist.

Unless appropriately registered, licensed, and trained, procedures undertaken by informal abortion providers such as herbalists, street vendors, and traditional birth attendants are potentially unsafe. For the avoidance of any doubt, we are not seeking to directly constrain the choices of pregnant women. Rather, our concern is to ensure that women are not harmed or subjected to the unnecessary risk of significant harm by the supply of inaccurate/ inadequate information or the provision of deficient abortion services. Accordingly, we suggest that informal service providers, rather than pregnant women, should be the target of any future regulatory constraints. Our aim is to minimize recourse to untrained service providers by delivering improved access to the formal (approved) and publicly funded sector. In our vision, the formal sector and those who work in it are subject to regulation in relation to the standard and quality of pre-/post-abortion care.

When women are asked what they want in abortion services, they identify minimal delay as a priority.[12] Women who have decided to terminate a pregnancy want their abortion procedure to take place as soon as possible, and find a delay distressing.[13] Most say they do not want counseling.[14] Facilitating access to abortion services is an important aspect of our vision.

Although we do not rule out extension of our vision, we limit the immediate scope of this paper to first-trimester abortion due to the current insufficiency of evidence as to safety, effectiveness, and acceptability of second or third trimester medical abortion undertaken outside the formal health system. Although ambulatory (outpatient) medical abortion is generally limited to 10 weeks' gestation, the envelope continues to be pushed on this upper limit. The World Health Organization recommends self-managed medical abortion up to 12 weeks' gestation, conceding that evidence is limited for the upper two weeks.[15] Further, we are on slightly easier ethical ground in the first trimester, whether on a rights, personhood, or relational perspective. Our starting point is that state actors have a much harder time justifying constraints on pregnant women during the first trimester, partly because there is more common ground about the moral status of the unborn entity at this stage of development. Consequently, any margin of appreciation that might be granted to states and their agents ought to be narrowly construed during this stage of pregnancy.[16]

Some of the thinking behind this paper has been stimulated by innovative organizations that provide internet-based abortion services and thereby empower women.[17] Although women choose to use these services, the organizations only provide medical abortion and so by definition offer no choice within their service provision. Although the development of drugs for medical abortion has been a revolutionary scientific advance, in many high-resource countries medical abortion now tends to dominate service provision to the exclusion of surgery.[18] Surgery obviously requires direct contact with health professionals. But first-trimester surgical abortion can be provided safely outside a hospital setting with simple equipment, and satisfaction with manual vacuum aspiration is high.[19] However, unless aspiration is available on demand, it is not a genuine option; for example, a weekly operating list is not sufficient.

The role of the state

All people have the right to expect quality health care from the state. But what exactly are the obligations of the state in pursuance of this right? The reproductive justice framework contends that there is a right to have a child, a right not to have a child, and a right to parent a child in a safe and healthy environment.[20] Access to reproductive services is a key component of this framework because "there is no choice where there is no access."[21] Under existing international human rights law, states have specific obligations to respect, fulfill, and protect human rights, including reproductive rights.[22] These obligations include limitations on the actions that states may take (negative obligations) and on proactive measures that states must take (positive obligations) to give effect to individual rights and freedoms. States must take steps towards fulfilling their obligations by all appropriate means, including particularly the adoption of legislative measures, and should report on these measures and the basis on which they have been considered the most appropriate under the circumstances.

States have three core obligations relating to abortion: a duty to respect, a duty to fulfill, and a duty to protect. In the following section, we outline how these obligations would work in our vision and offer some framework on scope.

The duty to *respect* requires states to refrain from interfering directly or indirectly with the enjoyment of reproductive rights unless that interference is justified, proportionate, and necessary to achieve a legitimate aim. Using the work of philosopher John Stuart Mill as our foundation, we argue that interference can only be justified or legitimate if it is necessary to prevent harm to others which is both morally indefensible and rights-violating.[23] Unless one subscribes to the view that the unborn entity is a rights-bearer in the first trimester, it would not be legitimate to interfere with a woman's right to terminate at that stage in order to protect the unborn entity. We do not take an explicit position on such interferences in the later stages of the pregnancy but accept that there might be other legitimate reasons to interfere, or for a state to otherwise take responsibility. For example, where the harm or potential for harm arises from related technology that has been released and managed or controlled in a public health context; or where the dignity of humanity as a whole is at stake; or to preserve/protect the essential pre-conditions for human existence or any social human existence.[24] If we take the specific example of prenatal screening, a state may be responsible for the testing technology made available in publicly-funded maternity services. The state may also have reason to intervene where private sector providers promote testing and deselection of specific non-health-related characteristics.[25] However, in these cases, the state and their agents would bear a heavy burden to justify any constraint on a woman's reproductive rights in the context of abortion.

The duty to *fulfill* requires that states adopt whatever measures are necessary—legislative, budgetary, judicial, and/or administrative—to achieve the full realization of reproductive rights. This would include the provision of appropriate forums to resolve disputes and determine or enforce appropriate remedies. We address the funding of private sector provision below. As part of their obligations, states should ensure that reproductive health information, goods, and services are *available*, *accessible*, *acceptable,* and of good *quality*: AAAQ.[26]

The duty to *protect* requires states to prevent third parties from infringing upon reproductive rights and to take steps to investigate and punish such violations when they occur. So, for example, anyone coercing or misleading a woman into an abortion or covertly inducing an abortion should be subject to some form of regulation. Similarly, any health professional acting in bad faith (for example, failing to obtain adequate consent or delivering poor standards of care) should be subject to some form of sanction. We can debate whether there should be disciplinary, civil, and/or criminal consequences in these circumstances. We should not criminalize human behavior unless absolutely necessary, and then only in a proportionate way. If we choose to direct sanctions against third parties, it may be preferable to use disciplinary or civil mechanisms before engaging the criminal law.

Under its duty to protect, the state should ensure that abortion providers do not infringe upon reproductive rights. Refusals to provide abortion care on grounds of conscience can compromise access to abortion and harm health and well-being.[27] Such refusals are not permissible in emergency situations or by institutions; they are only valid in relation to direct provision of care and, in such instances, referral must be made to an alternative willing and capable provider.[28] Objector status should be disclosed at an early stage to employers and patients so that timely alternative plans can be made; in all regions of a country there must be adequate numbers of health professionals who provide abortion care and the state must take measures to ensure that women's access to legal abortion care is not undermined.[29] Personal beliefs must not be pursued where they are in conflict with the principles of good medical practice, where they cause patients to be treated unfairly, or where they deny patients access to appropriate treatment or services or cause distress.[30]

Also, under its duty to protect, the state must ensure that members of the public with anti-choice views, while otherwise being permitted freedom of peaceful assembly, cannot infringe upon reproductive rights using intimidation and harassment close to abortion care facilities.[31] Due to the distress women have experienced as a result of protests outside facilities in many countries, safe access zones are an absolute necessity to keep any protests away from facility entrances that women and providers use.

Crisis pregnancy centers are run by non-medical organizations; they attempt to intercept those seeking abortion and persuade them to continue the pregnancy.[32] Under its duty to protect, the state must ensure that crisis pregnancy centers do not jeopardize women's health, disseminate misinformation, and target marginalized groups.[33]

The essential ingredients that facilitate a positive high-quality abortion experience

In this section, we identify the fundamental ingredients of a positive high-quality abortion experience. Some of these are not applicable to women who self-manage their abortion.

Person-centeredness

In a person-centered approach, care is individualized and tailored to women's preferences. It is acknowledged that there is no joy in the context of abortion—as with miscarriage and ectopic pregnancy and in stark contrast to childbirth.[34] Women can choose how their first-trimester abortion is carried out and their degree of presence; some prefer to be awake and experience it, some prefer to be sedated. Women can have privacy and discreet care; they may fear judgment when grouped with others undergoing abortion.[35]

The needs and rights of the pregnant woman are at the center of policymaking, information, service delivery, and one-on-one consultations. A person-centered framework and culture supports every person on their journey.[36] Person-centeredness was identified as a key dimension of quality health care by the Institute of Medicine and further developed into a framework of eight domains for maternity care by Sudhinaraset et al.; Altshuler and Whaley adapted this structure for abortion care.[37] There is inevitably some overlap between these domains. The priority rights at the heart of this framework, and our wider discussion in this section, are the rights to individual autonomy, human dignity, and privacy. Many of our points (including domains 4–8 below) are drawn from these priority rights. This overarching framework is facilitated and realized by engagement of the state duties to respect, fulfill, and protect. The eight domains are:

1. Dignity

Dignity refers to the ability of women to receive care in a respectful and caring setting. The care supports an individual's self-respect. Any perception that this will not be the case can drive women into the informal sector where the informational framework may be less reliable; or they may self-induce abortion without sufficient back-up.

2. Autonomy

Human rights considerations dictate that autonomy is the overriding determinant when choices are made in early pregnancy. This takes into account women's embodied experience of being pregnant. The two basic requirements for autonomy are agency (the capacity for intentional action) and liberty (freedom from controlling influences exerted by external sources).[38] Women should have control over their bodies and be free to make choices and decisions without external constraint in the first trimester of their pregnancies. The consent process should be valid. Providers convey to women that they are seen as moral agents, capable of making decisions about their bodies and lives.[39]

3. Privacy

Again, we are not attempting to expunge the distinction between the public and private spheres entirely, although the former is necessarily limited in our vision. Opting for an abortion is an intensely private matter. This includes physical privacy in the treatment setting and the confidentiality of sensitive medical information. Physical examinations should be carried out discreetly. Some women prefer to travel out of their area of residence in order to maintain anonymity. Some may prefer self-managed abortion, perhaps with external support, because it offers greater privacy.

4. Communication

Treatment options are fully explained and discussed; women participate actively. The woman's preferences, needs, and context are taken into account. Non-directive counseling is available, if sought, before and after the procedure or medical administration.

5. Support

This needs to be individually tailored as women differ greatly in the degree of support they desire. Some women are grateful not to be questioned too much. Others welcome some acknowledgment of the emotions they are grappling with, or possibly some discussion of them; these might be contradictory emotions (ambivalence) or existential issues that can be triggered, such as life and death, morality, and meaning.[40] While some women want to be alone, many value the support of a companion of their choice. Support should extend into the workplace, so that women are guaranteed time off work without probing into their rationale or purpose.[41]

An important resource for support is the volunteer abortion doula or pregnancy companion. Many doulas are "full spectrum," meaning they will attend a woman during any pregnancy event, including childbirth.[42] Doulas offer compassionate care and are trained to counter stigma. Women overwhelmingly recommend doula support for abortion care, despite the fact that such support is not associated with measurable effects on physical comfort or emotional responses.[43] Clinic staff believe doulas contribute to more patient-centered care.[44]

6. Compassionate care

Care is provided in a compassionate manner.[45] It is responsive to the person's specific needs. Such care protects women from distress, pain, or harm. Small gestures can make an enormous difference.[46]

7. Trust

Trust comprises how women assess the delivery of care by a specific provider in terms of their honesty and how confident service users feel about the provider's competence.

8. Health facility environment

This domain includes comfort, cleanliness, adequacy of equipment, and a pleasant environment. As well as the physical environment, this includes human aspects such as a supportive and non-judgemental atmosphere. Women sometimes have preconceived ideas about the appearance of a clinic and may be surprised by the cleanliness of their surroundings or facilities, for example.[47] In our vision, there are no Targeted Regulation of Abortion Providers laws (that is, burdensome and medically unnecessary legal requirements that target abortion providers).[48] For example, requirements suited to hospital surgical facilities may be imposed which are far in excess of those needed for the relatively 'low-tech' nature of abortion procedures.

Normalization

There are two aspects to the normalization of abortion. The first is full integration of abortion into health care as a mainstream service and, more particularly, as part of comprehensive sexual and reproductive health care.[49] This should render approved private-sector provision (that is, those not publicly funded) unnecessary, but we would not outlaw these providers unless there were consequential considerations undermining public access. In any event, approved private sector provision would not be available on more favorable terms than public services.

The second is normalization with respect to society. Abortion is mostly subject to negative framing in the media. There are associations with controversy, sensationalism, and immorality.[50] There are also associations with 'deviant' practices such as teenage pregnancy and undesirable characteristics such as promiscuity; these tend to stereotype and falsely marginalize women who have abortions.[51]

Despite a broad social narrative that abortion is by default negative, many women undergoing abortion say it is the right choice for them; some even call it a positive experience.[52] Language used to describe their experiences can be non-negative but is often intertwined with negative framings. Nevertheless, negativity can be resisted and rejected.

Normalizing representations of abortion can help destigmatize the practice.[53] For example, Australian abortion clinic websites unapologetically present "a uniformly clear set of values and practices: a woman's competency and ownership of decisions relating to her pregnancy; her entitlement to good quality non-judgmental care; and the generally positive effects of an abortion."[54] This establishes "women's position as the rightful subjects of abortion decisions and constructs abortion as a normal, positive and straightforward procedure that enables women to lead the lives they imagine for themselves."[55]

Feminist groups supporting women in self-managed abortion are driving a reduction in stigma. They share a belief "that every person who comes to them has the capacity and right to a safe and dignified abortion informed by the values and needs most important to them."[56]

Place of choice

Care closer to home as a means of contributing to the delivery of person-centered care has been in the sight of enlightened health professionals for some years, but unnecessary restrictions have got in the way.[57] Absent such restrictions, including those governing where the medicines are administered, a woman can use both mifepristone and misoprostol in the "safety and security" of her home, the home of someone of her choice, or a place of safety.[58] She can also choose who is present in that setting to support her. Those conducting their abortion at home need sufficient information that can alert them to medical conditions which would make them high-risk and therefore in need of medical advice and supervision. We would not seek to constrain the choices of the high-risk patient, but we would want to ensure that they were adequately informed and supported. Information provided would also ensure that women understand what symptoms should trigger contact with medical services. A few women request inpatient care because they do not feel safe at home, and this needs to be accommodated.

For those accessing formal health services, we envisage woman obtaining their abortions locally, without extended travel possibly entailing crossing borders.[59] Ideally, care could be accessed in a local health center, and at the nearest hospital for those who need hospital care. Special arrangements are needed for sparsely populated areas such as northern Canada and central Australia, and for remote communities with no road/rail links. In such cases, clinicians can provide medical abortion via telemedicine; this service delivery is effective, safe, and has a high satisfaction rating.[60]

Reproductive health commodity supply and security

In our vision, mifepristone is licensed in all countries. It is currently licensed in only 68 of the 193 countries in the world (35%).[61] Our vision would supplant the current situation, in which millions use the less-effective misoprostol-only regimen.

Secure systems are in place for procuring abortion pills and appropriate pregnancy tests for follow-up after abortion from reliable sources: mainly internet-based abortion services and accredited pharmacies.[62] These systems would supersede widespread circulation of substandard and counterfeit medicines and other medical products; such medicines include inactive substances, impure products, toxic substances, or other substances entirely.[63] Pharmacy supplies can be provided at a distance; an example of regulations applying to such activity is that issued by the UK General Pharmaceutical Council.[64]

In our vision, over-the-counter status for mifepristone and misoprostol is operational. Only a small amount of additional information would need to be gleaned about self-administration of mifepristone/misoprostol in order to make an application to the US Food and Drug Administration for over-the-counter approval.[65] Mechanisms for community pharmacy provision have been elaborated.[66]

Information

The motto "knowledge is power" has become a cliché but is nevertheless true. Easy access to accurate and clear information is a key element of our vision. Information is supplied in varied forms to suit different individuals. Animated films, as well as pictures and diagrams, supplement the written word.[67] Access to this information is in a variety of modes including print, audio, and electronic. Abortion hotlines providing information based on official World Health Organization protocols play an important role. They release reliable information into the public domain where people can share it.[68] It is important that relevant information is made available that speaks to all, including any marginalized/intersectional groups and individuals.

What explicit information would be made available? First, the actual choice available would be spelled out. Except where there are medical contraindications, of which there are few, women could freely choose the options of medical or surgical abortion. Early surgical abortion in the form of manual vacuum aspiration is available without delay and not necessarily in a hospital setting.[69] Manual vacuum aspiration is available from a range of providers, including nurses, midwives, and general practitioners.[70] There are many websites offering science-based information about self-managed medical abortion.

Second, information about local support would be accessible. This includes emotional, social, and financial support.

Third, there would be information about the need for Rhesus disease prophylaxis after 10 weeks' gestation for those who are Rhesus negative, when antibiotic prophylaxis is recommended, and which medical conditions require special precautions and medical input.[71]

Fourth, there is good information about what to expect when undergoing an early medical abortion and what human resources can be called upon, such as doulas.[72]

Finally, information about contraception is freely available, together with the recommended timing of initiation after abortion.[73] There is freedom of choice: no disproportionate emphasis on long-acting reversible contraception and no coercion in relation to sterilization.[74]

Clinical excellence

In our vision, clinicians are still needed to provide expertise in complex medical situations, to provide surgical services, and as a back-up for self-managed medical abortion; the number of such professionals is scaled down by adding a more varied skill mix. Policy makers and managers ensure there are sufficient trained professionals, an even geographical spread of services, hygienic facilities, and ongoing focused capacity building.[75] Careful service design ensures availability and accessibility. Waiting times operate according to specified national standards.[76] Services are operated in a variety of settings including community facilities.[77] Acceptability is continuously monitored.

Telephone advice and emergency consultation at a local medical facility would be available 24 hours a day. Women are given an idea of how much bleeding to expect. The direct experience of pain and bleeding can be distressing and often some discussion and reassurance from an adviser is all that is needed, so direct live contact by phone, video link, or web-based chat is available. Complications are inevitable and experienced staff need to be on hand to deal with these.

Task shifting or sharing optimizes the roles of health care staff.[78] Few abortions need to be provided by gynecologists.[79] General practitioners play a significant role in service delivery.[80] So-called mid-level providers (nurses, midwives, and physician assistants) can safely provide both medical and surgical abortion.[81] Pharmacists and pharmacy workers are able to safely provide medical abortion.[82]

It is envisaged that many women will practice self-care. It has been demonstrated that self-managed early medical abortion is mostly equivalent to that which is medically supervised, in terms of success rates and safety outcomes. Rates of incomplete abortion requiring surgical evacuation are somewhat higher, which may be because of care provision by clinicians with little experience in settings where abortion is legally restricted.[83]

Women obtain abortion pills through pharmacies or other reliable sources for self-managed abortion.[84] Self-care has equal status to clinician-provided care among health and regulatory systems.

Funding

Many studies report financial barriers to access to abortion.[85] In our vision, women are not expected to rely on charity for such an important component of health care. Some women will have health insurance which may cover abortion. Although women would be at liberty to pay for private services if they wished to, drugs, materials, and fees are all covered by the state for anyone, regardless of their citizenship status. Such cover is the same for any pregnancy outcome (delivery of any type, miscarriage, or ectopic pregnancy). Travel costs are paid by the state when necessary, for example, for people on state benefits or in a low-income bracket.[86]

Conclusion

We have proposed a vision where there are obligations on the state in pursuance of women's reproductive rights under the headings of duties to respect, fulfill, and protect. We recognize that this imagined world is far from current reality and might never be achieved. So, why bother to formulate such a vision? Many of us have spent considerable time addressing the existence and scope of individual rights/freedoms, and on the possible deconstruction of existing regulatory constraints in the context of abortion. We do not besmirch or seek to undermine these efforts. Rather, our central purpose in this paper is to shift attention away from discussions about the lawfulness of abortion. By starting from a world without constraints, the primary focus turns to the environment and framework of state obligations in which abortion services are accessed and delivered. It is these background factors that provide the critical foundation for the realization of individual rights and freedoms. Any reformist agenda should never lose sight of this.

Acknowledgments

We thank Dr. Fiona Bloomer, Professor Sally Sheldon, and Ms. Susan Yanow for commenting on a previous draft of this paper. Any errors remain our own.

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Health and Human Rights Journal

Operationalizing a Human Rights-Based Approach to Address Mistreatment against Women during Childbirth

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Abstract

A growing body of evidence reveals that the mistreatment of pregnant women during facility-based childbirth is occurring across the globe. As human rights bodies have increasingly recognized, numerous human rights are implicated in the context of mistreatment of women in childbirth, including the rights to be free from torture and other ill-treatment, privacy, health, non-discrimination, and equality. This paper builds on a previous paper published in this journal by Rajat Khosla, Christina Zampas, and others, and the new body of evidence describing the types of mistreatment that occur during childbirth, to unpack the drivers of the mistreatment of women during childbirth and how they are understood and addressed within human rights. Tracing recent developments, it examines how the United Nations Special Rapporteur on violence against women and the Parliamentary Assembly of the Council of Europe have addressed this issue. Understanding the drivers and human rights dimensions of the mistreatment of women during childbirth can contribute to accelerating progress toward universal health coverage, including access to reproductive health services, as mistreatment is a key barrier to women's access to such services. The article concludes by offering guidance to states on a human rights-based approach to addressing mistreatment against women during facility-based childbirth.

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Competing interests: None declared.

Disclaimer: This effort was supported by the United States Agency for International Development and the UNDP/UNFPA/UNICEF/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction, based at the World Health Organization. The contents of this article are the sole responsibility of the authors and do not necessarily reflect the views of these institutions.

Introduction

Worldwide, about 140 million women give birth every year.[1] For health care facilities, in addition to providing the high-quality clinical care specific to labor and childbirth, this means making sure that the manner in which care is delivered is woman centered and respectful and protects and promotes their rights. Ensuring a continuum of care, regular monitoring and documentation of clinical events, and clear, empathetic, and respectful communication between health care providers and clients is essential. In addition, women must be given the information, choices, and support they need to make informed decisions, and a referral plan must be in place should more advanced medical care become necessary. These are all essential elements of good-quality labor and childbirth care that every woman and newborn should receive.[2]

Within the World Health Organization's (WHO) quality of care framework for maternal and newborn health, experience of care—which includes treatment with respect and dignity, effective communication, and emotional support—is an essential component of the provision of quality care. With an increased body of evidence, there has been a growing recognition that mistreatment of pregnant women during facility-based childbirth is occurring across the globe.[3] While various terms (for example, "obstetric violence," "dehumanized care," and "disrespect and abuse") have been used to describe the phenomenon, in this paper we use the term "mistreatment of women during childbirth," which is based on a mixed-methods review capturing a range of experiences of women and health care providers, and which takes into account acts or behaviors that constitute a range of forms of abuse and violence, as well as practices that reflect health system limitations and poor quality of care.[4]

This paper builds on a previous paper by Khosla, Zampas, and others, and the new body of evidence describing the types of mistreatment that occur during childbirth, to unpack the drivers of the mistreatment of women during childbirth and how they are understood and addressed within human rights.[5] Tracing recent developments, it examines how United Nations (UN) human rights bodies, including the Special Rapporteur on violence against women, and the Parliamentary Assembly of the Council of Europe, have addressed this issue.

Understanding the drivers and human rights dimensions of the mistreatment of women during childbirth can help states meet their high-level political commitment to ensure universal access to quality health care, including reproductive health services. Under the 2030 Agenda for Sustainable Development, which is designed to "leave no one behind," states have committed to achieving the goals of healthy lives and gender equality by ensuring access to quality maternal health care and guaranteeing women's and girls' reproductive autonomy.[6] States have also committed to "end all forms of discrimination against all women and girls everywhere," including through legislative and policy reform.[7]

Universal health coverage (UHC) is the pillar of Sustainable Development Goal 3. High-level commitments and a call to action on UHC occurred at the UN General Assembly in 2019.[8] Member states agreed to accelerate progress toward UHC, including sexual and reproductive health services and reproductive rights, with a focus on poor, vulnerable, and marginalized individuals and groups. Achieving these high-level political commitments requires states to implement a human rights-based approach to addressing the mistreatment of women during childbirth.

Methods

Building on the data collected for the previous paper by Khosla and colleagues, this paper scoped relevant public health studies and WHO guidelines published since 2016. Additional references were added based on oral and written contributions made at WHO's expert group meeting with the UN Special Rapporteur on violence against women, held in Geneva, Switzerland, in April 2019. Similarly, building on the research findings of the previous paper, which covered normative developments in human rights standards between 2000 and 2015, recent human rights standards were identified by a review of reports, general comments, and decisions issued by UN and regional human rights bodies between 2016 and 2019 regarding the mistreatment of women during childbirth.

Public health evidence on the types of mistreatment of women during childbirth

There has been an evolving body of scientific research on the mistreatment of women during facility-based childbirth. Yannick Jaffre and colleagues published a paper describing this emerging phenomenon in Niger in 1994.[9] In 1998, Rachel Jewkes and colleagues published a qualitative study on why nurses abuse patients in South African obstetric wards. Jewkes highlighted the complex interplay of institutional practices, professional insecurities, coercive control, and power dynamics present during facility-based childbirth; in the meantime, in Latin America, research and advocacy efforts were informing the development of a legal framework addressing "obstetric violence."[10] In 2010, Diana Bowser and Kathleen Hill published their seminal landscape analysis on disrespect for and abuse of women during childbirth.[11] Their work informed our understanding of the definition, scope, contributors, and impact of disrespect and abuse in childbirth.

In 2014, noting that "a growing body of research on women's experiences during pregnancy, and particularly childbirth, paints a disturbing picture," WHO issued a statement on the prevention and elimination of disrespect and abuse during facility-based childbirth. In its statement, endorsed by over 90 civil society and health professional organizations, WHO highlighted that

> *[s]uch treatment not only violates the rights of women to respectful care, but can also threaten their rights to life, health, bodily integrity, and freedom from discrimination. This statement calls for greater action, dialogue, research and advocacy on this important public health and human rights issue.*[12]

This "has now sparked new empirical research across different continents, an advocacy agenda and a growing number of interventions."[13] A 2015 systematic review that synthesized the existing global qualitative and quantitative evidence on the mistreatment of women during childbirth in health facilities identified 65 studies containing research findings from 34 countries.[14] This review, as well as other studies, categorized the types of mistreatment experienced by women during facility-based childbirth.[15] They also revealed that mistreatment is more likely to occur against, for example, women from minority racial, ethnic, and religious groups; women of lower socioeconomic status; migrant women; women with disabilities; adolescents; women living with HIV; and unmarried women—women who experience intersectional discrimination on multiple grounds.

Despite the growing recognition of this issue, data collection on experiential aspects of facility-based childbirth has been limited by the lack of reliable and valid standardized tools to quantitatively measure the mistreatment of women across global settings. To address this critical gap, WHO led a multi-country mixed-methods study in four countries (Ghana, Guinea, Myanmar, and Nigeria) to develop two measurement tools (labor observation and community survey) and to measure how women are treated during facility-based childbirth across countries.[16] The evidence indicated that a little more than 30% of the study population experienced mistreatment during childbirth in health facilities. The study showed that women were at an increased risk of experiencing physical and verbal abuse between 30 minutes before birth until 15 minutes after childbirth. Moreover, younger, less educated women were most at risk, suggesting that age and lack of education compounded the discrimination faced by some subgroups of women.[17]

Additionally, it is important to note that women who experience mistreatment during childbirth may underreport these instances. A mixed-methods study in Tanzania, comparing the prevalence of mistreatment during childbirth as measured through observation and self-reporting, found a huge disparity between these two measures both during the baseline and endline measurements (baseline: 69.83% observation versus 9.91% self-reporting; endline: 32.91% observation versus 7.59%

self-reporting). This suggests that mistreatment can be internalized and normalized by users and providers alike.[18] This does not mean that the mistreatment they experienced should be ignored or is not important; rather, it highlights the need to be nuanced in the interpretation of evidence, as it appears that women have such low expectations of care that they may be satisfied with poor-quality care that includes mistreatment.[19]

Understanding the human rights dimensions of mistreatment of women during facility-based childbirth

Numerous human rights are implicated in the context of mistreatment of women in childbirth, including the right to be free from violence, the right to privacy and non-discrimination, and the right to the highest attainable standard of health.[20] Human rights organizations have published reports documenting the abuses that women and girls experience during childbirth in health care facilities around the world.[21] The impact of these rights violations on women's health, well-being, choices, and access to reproductive health services, as well as strategies for how to prevent these abuses, needs further and careful examination.[22]

A continuum of human rights violations

Childbirth and parenting are life-changing experiences for all women, regardless of their background, culture, or location, as they affect every facet of their lives, including education, employment, family life, and health. While the focus of this paper is on mistreatment against women during facility-based childbirth, it is critical to contextualize these abuses against a wider backdrop of discriminatory laws, policies, and practices faced by women and girls globally. More broadly, these abuses occur as part of a continuum of stigma and discrimination against women in society and implicate a range of human rights, including those related to housing, employment, and the exercise of freedom of expression and association. These abuses are also experienced by women and girls in the context of other sexual and reproductive health care, including abortion, fertility treatments, and contraception.[23] Human rights bodies have consistently found states in violation of numerous human rights—including the rights to be free from torture and other ill-treatment, privacy, health, and equality—when women are denied their autonomy in these contexts.[24]

Types of mistreatment

Physical and verbal abuse. Physical abuse during childbirth may entail beatings, hitting, slapping, kicking, and pinching by nurses, midwives, or doctors.[25] One woman from Ghana explained:

> *When I was due for labour and was asked to push, I couldn't push and the nurse beat me very well. She used a cane to whip me so I could push, but I told her I was tired but she insisted I should push. So she really whipped me with the cane and later used her hand to hit my thigh. There I became conscious and was able to push.*[26]

Other forms of physical abuse include providers conducting painful and medically unnecessary vaginal exams during labor.[27]

Women have also reported sexual abuse by health care providers during childbirth. One study, which focused on women's experience of mistreatment during childbirth in a hospital in Nigeria, found that 2.0% of women interviewed reported being sexually abused by a health worker.[28]

Studies and human rights reports have documented abusive, discriminatory, rude, and judgmental language by health care providers toward women in labor. Women report being mocked, scolded, insulted, and yelled at by providers.[29] A recent report on Slovakia found that medical personnel often made derogatory remarks toward Roma women about how frequently they had sexual intercourse and the number of children they had, based on the negative gender stereotype that Roma women are "promiscuous."[30] In Brazil, it has been reported that "one of the most common insults was 'Na hora de fazer não chorou' ('You didn't cry like that when making the baby')."[31]

Unmarried adolescent girls face verbal abuse during childbirth because of their age and the stigma of being unmarried.[32] Fear of such discrimination is a powerful disincentive to deliver in health facilities in Ghana, Sierra Leone, and Tanzania.[33] Women have also reported experiencing threats of treatment being withheld or "threats of beatings if the woman was noncompliant … and blame for their baby's or their own poor health outcomes."[34]

These practices violate women's right to be free from gender-based violence, as well as their rights to health and privacy. They may also constitute violations of the right to be free from torture and cruel, inhuman, or degrading treatment.[35]

Absence of informed consent, abuse of the doctrine of medical necessity, and denial of women's choices. Informed consent to medical care is fundamental in both law (including human rights law) and ethics. Patients have the right to receive information and ask questions about recommended treatments so that they can make informed and well-considered decisions about care.

The information provided by the health provider to the patient should emphasize the treatment's advantages and disadvantages, health benefits, risks, and side effects, and it should enable a comparison of various treatment options. Information should be provided in a manner and language that is understandable, accessible, and appropriate to the needs of the individual making the decision. Persons with disabilities should be provided with all the necessary support and respect for making their decisions, including by ensuring that decisions that should be made using the process of supported decision-making are not de facto substituted decisions.[36] The International Federation of Gynecology and Obstetrics (FIGO) recognizes that the implementation of informed consent is an obligation for providers, despite the fact that at times it can be challenging and time consuming.[37]

Violations of the right to informed consent occur in a number of contexts related to labor and childbirth. These include over-medicalized and unconsented-to procedures during and immediately after childbirth; coerced procedures and breaches of privacy during women's stay in health facilities; insufficient information for women to make informed decisions; and health care providers' disregard for women's preferences in the provision of care.[38]

Women have also been coerced into consenting to sterilization during childbirth.[39] For example, women living with HIV in Kenya have reported being asked to sign consent forms for sterilization while in labor, and others have been misinformed about the procedure or threatened with not being provided baby formula or antiretroviral medications if they refused to consent to sterilization.[40]

These practices deter women from seeking and using maternal health care services and erode their trust in the health care system. They also have significant health impacts on women and their newborns. Routine abuse may also mean that "both health workers and patients may have come to expect and accept the poor treatment of women as the norm."[41] In addition to violating ethical principles for providers, these practices violate numerous human rights.[42]

Denial of care, segregation, removal, and detention. In the context of facility-based maternity care, women experience discriminatory denials of care, segregation, involuntary separation from their newborns, and detention. For example, women who present at a health care facility during labor may be refused care entirely, on the grounds of lacking the economic means or due to their HIV status. Women have also reported being refused pain medication or anesthesia during childbirth because of an inability to pay. In addition to deliberate refusals to provide pain relief, structural barriers can also be responsible for the failure to provide pain management. For example, pain medication is also not always available in certain health care settings, due to stockouts.[43] Women are also subjected to deliberate delays in care, including stitching after childbirth, and serious neglect by providers, sometimes to the point of death or severe disability.[44] In some settings, migrant or refugee women are "expected to pay higher rates for services or to pay bribes" in order to receive care.[45]

Some maternity hospitals segregate women within the facility based on race, ethnicity, or medical condition, such as HIV. For example, Roma women in Slovakia are placed in "Roma-only" rooms in maternity hospitals, which are often substandard.[46] Women may also face the removal of their infants from their care against their will—with no legitimate health-related justification.[47]

The post-childbirth detention of women and their newborns in health care facilities because of their inability to pay hospital fees is another example of abuse that has been documented worldwide.[48] In Kenya, detained women and their infants have been made to sleep on the floor, denied adequate food, and watched over by guards.[49]

These practices violate the right to be free from discrimination and may also constitute violations of the right to be free from torture and cruel, inhuman, or degrading treatment.[50]

Drivers of mistreatment against women during facility-based childbirth

Efforts to prevent women from exerting full control over their bodily autonomy and decision-making are reflected in both law and practice.[51] Many states have failed to put in place a protective legal and policy framework to ensure that women receive care that is respectful of their needs and desires and that prevents and addresses mistreatment during childbirth. This has slowly begun to change. For example, in recent years, some countries have passed laws or issued policies that expressly allow a woman to be accompanied by a companion of her choice during childbirth and have developed broader legislation encouraging the "humanization" of childbirth.[52] However, other laws contribute to an environment of violence and mistreatment. These laws include spousal or third-party consent laws, and laws that deprive women with disabilities of their legal capacity, replacing women's decision-making with that of a family member or other institutional authority. They also encompass laws that recognize fetal personhood, prioritizing the fetus over the life and health of the pregnant woman.

These practices are often justified in the name of tradition, culture, and religion—grounds that human rights bodies have expressly stated may "not [be] used to justify violations of women's right to equality before the law and to equal enjoyment of all [] rights."[53] Underpinning these laws and practices are harmful gender stereotypes. In addition, the power imbalance often embedded in the provider-patient relationship further reinforces the denial of women's reproductive autonomy. Health systems conditions and constraints also play a role in fueling the mistreatment of women during facility-based childbirth.

It is important to recognize that different types of mistreatment, and even the same types, may have different causes depending on the context, even in the same facility.

Harmful gender stereotypes

Stereotypes about women's decision-making competence, women's natural role in society, and motherhood often fuel the laws and practices denying women's reproductive autonomy during childbirth. These stereotypes arise from strong religious, social, and cultural beliefs and ideas about sexuality, pregnancy, and motherhood.[54] The stereotype that women are overly emotional and vulnerable and are therefore incapable of making rational decisions about their medical care is particularly pervasive. In the reproductive health context, this stereotype is compounded by stereotypes depicting women's primary role as mother, child bearer, and caregiver.[55] These gender stereotypes create the ideal of the "self-sacrificing mother."[56]

UN human rights bodies are beginning to recognize the harms of such stereotypes.[57] The CEDAW Committee, in *L.C. v. Peru*, affirmed that this "self-sacrificing mother" stereotype "understands the exercise of a woman's reproductive capacity as a duty rather than a right."[58] As a result, any pain or suffering that accompanies the child bearing role is considered natural and expected, and health care providers may therefore not offer women the same pain management during labor and childbirth as they would offer to other patients in pain.[59]

The UN Working Group on the issue of discrimination against women in law and in practice has recognized that "unnecessary medicalization … [has] functioned as [a] form of social control exercised by patriarchal establishments to preserve the gender roles of women."[60] The Special Rapporteur on torture has also noted that in many countries, women seeking maternal health care face a high risk of ill-treatment, particularly immediately before and after childbirth, and that this "mistreatment is often motivated by stereotypes regarding women's childbearing roles and inflicts physical and psychological suffering that can amount to ill-treatment."[61] Relatedly, stereotypes can also negatively affect how women's bodies are perceived, leading to sometimes unnecessary interventions, such as episiotomies, C-sections, or symphysiotomies.[62]

All the stereotypes mentioned above interact such that health care providers in some cases do not seek women's informed consent, instead substituting their beliefs about the best course of treatment for those of the women. Such treatment is often justified on the basis of the purported interests of the fetus or the best interest of the woman, but it reinforces the stereotype that women are unable to make informed decisions and reduces them to objects of intervention without agency.[63]

Power dynamics

Interpersonal and systemic power dynamics in the provider-patient relationship are other root causes of mistreatment. As noted by Lynn Freedman, understanding power is helpful to understanding how mistreatment occurs and how to address it. Freedman classifies such power as visible (formal, observable powers such as laws and regulations), hidden (powers beyond professional standards of care, which encompass all the actors in health settings, such as guards and food service delivery personnel), or invisible (norms that operate subconsciously and are internalized by providers or women themselves).[64] Thus, power dynamics can be both interpersonal and systemic (see section below on weak health systems).

In the context of the provider-patient relationship, the provider has the power of authoritative medical knowledge and the social privilege of medical authority, while the patient is largely dependent on the provider for information and care.[65] The UN Special Rapporteur on the right to health has described the right to autonomy over decision-making as a counterweight to "the imbalance of power, experience and trust inherently present in the doctor-patient relationship."[66] This imbalance can be especially acute in childbirth, as women may experience a heightened sense of vulnerability during labor, childbirth, and the immediate post-partum period, including because women who give birth, regardless of the circumstances, are often grateful if the outcome is a healthy infant. The power dynamics between provider and patient are also a product of their specific social context: institutional maternity care "tracks lines of social disadvantage," mirroring "the inequalities of the society in which it functions."[67]

This imbalance is particularly apparent in providers' abuse of the doctrine of medical necessity to justify mistreatment and abuse during childbirth.[68] The forced sterilization of women following childbirth is one such example, with providers justifying performing the procedure without the woman's consent as somehow necessary for the best interests of the woman.[69] Providers also withhold information or mislead women into consenting to sterilization, acting, in the words of the European Court of Human Rights, with "gross disregard for her right to autonomy and choice as a patient."[70] Although providers do not necessarily have the intent to ill-treat their patients, "medical authority can foster a culture of impunity, where human rights violations do not only go unremedied, but unnoticed."[71]

Weak health systems

Health systems need to be better able to prevent and effectively respond to mistreatment against women.[72] Health system conditions and constraints play a role in driving mistreatment against women during childbirth.[73] States have an obligation to ensure the availability and quality of maternal health care facilities, goods, and services, as well as the adequate training of providers.[74] To fulfill this obligation, states "must devote the maximum available resources to sexual and reproductive health," adopt a human rights-based approach to identifying budgetary needs and allocations, and ensure accountability.[75] Human rights bodies have recognized that a state's failure to dedicate adequate resources to women's specific health needs is a violation of women's right to be free from discrimination and that it requires effective mechanisms for redress.[76]

The "entrenched gender-based discrimination within the largely female health workforce, who experience gender pay gaps, irregular salaries, lack of formal employment, sexual harassment, and inability to participate in leadership and decision-making" also plays a role in normalizing and thereby perpetuating mistreatment.[77] A 2016 WHO global survey of midwives "reveal[ed] that too often midwives report their efforts are constrained by unequal power relations within the health system. Many midwives also face cultural isolation, unsafe accommodation and low salaries."[78]

Twelve UN agencies, including WHO, have therefore urged states to pay "particular attention … to the gendered nature of the workforce" and ensure gender-sensitive facility-level policies, as well as health professional regulations operationalizing decent work and formal employment of the health work force, in order to address discrimination against women health workers in health care settings and to alleviate stressful work conditions that can foster mistreatment.[79] They have also recommended that states support health workers "in upholding their legal and ethical responsibilities, including with respect to advancing human rights, and that their role as human rights defenders [] be protected."[80]

Using global health and human rights mechanisms to address mistreatment during childbirth: The way forward

WHO and UN and regional human rights experts and bodies have called attention to the mistreatment of women during childbirth and pushed for states to take steps to ensure that women receive dignified, respectful health care during labor and childbirth.[81]

The work on the mistreatment of women during childbirth has sparked new empirical research across different continents, an advocacy agenda, and a growing number of interventions. In 2018, for example, synthesizing qualitative evidence, researchers developed domains of what constitutes respectful maternal care, expanding on the concept of mistreatment.[82] This led to WHO publishing global recommendations on intrapartum care for a positive childbirth experience that included specific recommendations on respectful maternity care.[83]

International human rights bodies have played a vital role in setting standards and monitoring human rights violations in the context of maternal health, including childbirth.[84] For example, in 2012, the Office of the United Nations High Commissioner for Human Rights issued technical guidance on the application of a human rights-based approach to the implementation of policies and programs to reduce preventable maternal morbidity and mortality.[85] And in 2011, the CEDAW Committee issued its decision in *Alyne da Silva Pimentel Teixeira v. Brazil*, considered the first decision where a government was held accountable for a preventable maternal death by an international treaty body.[86]

Although many human rights bodies have denounced the range of abusive practices as violations of human rights, their decisions and statements have often been siloed. UN mechanisms and Special Procedures mandate-holders have looked at specific sets of abuses, such as forced sterilization and the shackling of incarcerated or detained women during childbirth, leaving many types of mistreatment, many of which are often normalized, "unaddressed or inadequately analysed under international human rights law."[87] In particular, they have not necessarily articulated the rights violations in a way that acknowledges the broader backdrop of abuse and mistreatment within the context of childbirth and sexual and reproductive rights more generally.[88] In addition, courts and human rights bodies have not clearly articulated that this mistreatment is fueled by intersectional discrimination and experienced disproportionately by particular groups of women, including women with disabilities, migrants, economically disadvantaged women, adolescents, indigenous or other ethnic minorities, LGBTI persons, and women living with HIV, among others.[89]

In 2019, two important human rights mechanisms undertook the first comprehensive and robust examinations of the issue of mistreatment during childbirth. First, the UN Special Rapporteur on violence against women identified this issue as a priority and presented a thematic report on the topic to the 74th UN General Assembly on October 4, 2019.[90] WHO supported the mandate in preparation of this report by organizing an expert meeting in April 2019 and by producing a background document that included recommendations. Second, the Council of Europe Committee on Equality and Non-Discrimination prioritized this topic and prepared a report that informed the Council of Europe's Parliamentary Assembly Resolution, passed on October 3, 2019, calling on member states to address this issue.[91]

These high-level efforts underscore the global nature of this challenge and highlight the need for concerted global action to address the mistreatment of women during childbirth.

Conclusion

Women have a right to dignified, respectful health care, free from discrimination and coercion, throughout pregnancy and childbirth, as protected in international and regional human rights law and standards. States have a due diligence obligation to prevent, investigate, and punish human rights violations during childbirth, including those acts which constitute mistreatment, whether by state or non-state actors. Moving forward, it is important to ensure an enabling legal and policy environment, such that women-centered care during childbirth is part of the implementation of all relevant policies and programs. This includes efforts to implement states' 2019 commitment to accelerating the provision of universal health coverage under the Sustainable Development Goals.

Key conclusions from WHO's 2019 expert meeting provide some guidance to states and other stakeholders on how to apply a human rights framework to address mistreatment during childbirth. This expert guidance closely tracks the recommendations included in the UN Special Rapporteur on violence against women's report and the Parliamentary Assembly of the Council of Europe's resolution.[92] The WHO expert meeting called for states to do the following:

- Ensure compliance with international and regional human rights obligations and standards that protect women's rights in the context of childbirth.
- Review and strengthen laws and policies to prohibit the mistreatment of women during pregnancy and childbirth. Laws and policies must ensure autonomy in health care decision-making; guarantee free and informed consent, privacy, and confidentiality; prohibit mandatory HIV testing; prohibit screening procedures that are not of benefit to the individual or the public; ban involuntary treatment and mandatory third-party authorization and notification requirements; and explicitly guarantee women's rights to respectful maternity care and a birth companion of choice.
- Strengthen capacities to address multiple forms of discrimination that women experience during childbirth, including discrimination based on age, race, socioeconomic status, HIV status, education, disability, sexual orientation, and gender identity.
- Allocate adequate funding, staffing, and equipment for maternity care wards and facilities and ensure that the cost of health care financing "is not borne disproportionately by the poor."
- Ensure that the rights of health workers are fully protected, respected, and fulfilled and that health workers are free from discrimination and violence in the workplace.
- Ensure that policies, programs, and budgets promote health workforce educational and career development opportunities, pre-service education, and in-service training of all health workers on respectful maternal care, in accordance with WHO norms and guidelines.

- Implement evidence-based practices and guidelines, monitoring, and evaluation, including WHO's norms and standards related to respectful maternity care, intrapartum care, and violence against women.
- Ensure meaningful participation by women and civil society in all levels of legal and policy decision-making, and in monitoring.
- Strengthen mechanisms for the systematic reporting, monitoring, and evaluation of mistreatment of women during childbirth in public and private health care facilities.
- Strengthen the capacity of regulatory bodies and health professional associations, including national human rights institutions, to exercise oversight over public and private birthing facilities.
- Ensure accountability for the mistreatment of and violence against women during childbirth.
    - Create, strengthen, and fund accountability mechanisms to foster the accountability of multiple actors at various levels, both within health care settings and within the justice system.
    - Ensure that victims of rights violations are provided remedies—which may take the form of restitution, compensation, satisfaction, or guarantees of non-repetition—by both state and non-state actors.
    - Guarantee full and fair investigations into allegations of mistreatment and violence against women during childbirth, including by ensuring that the burden of proof is on the state and not the victim of the violation.
    - Raise awareness among lawyers, judges, and the public about the applicability of claims relating to women's sexual and reproductive rights in the context of childbirth to ensure the effective use of remedies in these cases.

Acknowledgments

This manuscript was developed from a background note prepared for an expert group meeting on the mistreatment of women during childbirth within the context of human rights in collaboration with Dubravka Simonovic, UN Special Rapporteur on violence against women, to support the mandate and preparation of her report. We would like to acknowledge Orlagh Mccann and Maria Roberta Serrentino at the Office of the United Nations High Commissioner for Human Rights on supporting the work on the report. We would also like to thank the participants of the expert group meeting for their contributions (in alphabetical order): Meghan Bohren, Janka Debreceniova, Catalina Devandas Aguilar, Simone Diniz, Lynn Freedman, Tamar Kabakian, Rosa Logar, Rose Mlay, Evelyne Opondo, Ivana Radacic, Gita Sen, Alessandro Stievano, Trude Thommessen, and Genoveva Tisheva.

A note on terminology

This article refers to "women" and "girls" in discussing mistreatment and violence during facility-based childbirth. Although the majority of personal experiences with these abuses relate to cisgender women and girls—who were born female and identify as female, transgender men and people who identify as neither men nor women may have the reproductive capacity to become pregnant and so may be subject to mistreatment and violence in the context of childbirth. The research did not find studies that included individuals with these gender identities, and as a result this background note does not reflect any experience they may have had with facility-based childbirth.

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HHR
Health and Human Rights Journal

The Neglect of Persons with Severe Brain Injury in the United States: An International Human Rights Analysis

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Abstract

Brain injury contributes more to death and disability globally than any other traumatic incident. While the past decade has seen significant medical advances, laws and policies remain stumbling blocks to treatment and care. The quality of life of persons with severe brain injury often declines with unnecessary institutionalization and inadequate access to rehabilitation and assistive technologies. This raises a host of rights violations that are hidden, given that persons with severe brain injury are generally invisible and marginalized. This article highlights the current neglect and experiences of persons with severe brain injury in the United States, analyzing the rights to life, health, benefit from scientific progress, education, freedom of expression, community, family, and equality.

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Competing interests: None declared.

Introduction

Brain injury contributes more to death and disability globally than any other traumatic incident.[1] Each year, there are approximately 69 million reported cases worldwide, but numbers may be even higher due to severe under-reporting.[2] In the United States, brain injury is the leading cause of death and disability among young people.[3] In fact, researchers refer to traumatic brain injury as a "silent epidemic."[4]

While medical and scientific advances mean that the lives of persons who sustain severe brain injuries can be saved, quality of life post-injury often decline because of unnecessary institutionalization in long-term care facilities and a subsequent lack of access to rehabilitation and technologies that can assist with the injured person's communication and community reintegration. Although severe brain injury seems to be solely a medical problem, many of the barriers to quality care post-injury are rights violations and can be addressed through law and policy interventions.[5]

Indeed, the care and treatment of persons with severe brain injury raises questions of fundamental rights and human dignity. Current medical practice all too often results in violations of the rights to life, health, benefit from scientific progress, education, freedom of expression, community, family, and equality. However, violations of the rights of persons with severe brain injury are often hidden since such persons are not in a position to advocate for themselves, and their family members may be burdened by grief and the demands of care.[6] Even within the disability community, the issues affecting persons with severe brain injury are largely invisible and marginalized.

This article provides an international human rights analysis of the experiences of persons with severe brain injury, highlighting their neglected rights. With severe brain injury being an overlooked topic in the human rights field, this article seeks to contribute to scholarship and advocacy in this area by providing a conceptual framework of key rights at stake through an interdisciplinary analysis of law, neuroscience, and clinical practice. While this article focuses on the United States, brain injury is a global concern, and this analysis is relevant to many other countries. The first section describes severe brain injury, outlines available medical treatments, and discusses clinical, legal, and policy barriers to care. The second section analyzes the experiences of persons with severe brain injury against the guarantees of the Convention on the Rights of Persons with Disabilities (CRPD), which sets the global standard regarding the rights of persons with disabilities, as well as the International Bill of Human Rights, consisting of the Universal Declaration of Human Rights, International Covenant on Civil and Political Rights (ICCPR), and International Covenant on Economic, Social and Cultural Rights (ICESCR).[7] Finally, the third section provides recommendations to advance the rights of persons with severe brain injury and address current gaps in treatment and care.

Severe brain injury and available treatments

Thanks to advances in medical knowledge, persons who in the recent past would have died because of severe brain injuries now often survive, many with differing degrees of disability, including disorders of consciousness (DOCs). Scientific knowledge of DOCs has evolved over the decades, and recent years have seen the development of an evidence-based practice, as well as updated terminology and standards of care published in 2018.[8] Yet much remains to be done. To date, there is no comprehensive epidemiology of patients with these conditions; instead, the prevalence is estimated to be several hundred thousand people in the United States, although these data are likely flawed methodologically.[9]

DOCs include the vegetative state and minimally conscious state (MCS). The vegetative state is "a condition of wakeful unconsciousness" in which a patient's eyes may be open but there is no evidence of consciousness.[10] The MCS, first defined in 2002, is "a condition of severely altered consciousness characterized by minimal but definite behavioral evidence of self or environmental awareness."[11] A person enters the MCS after being in a coma or vegetative state, and manifestations of consciousness are inconsistent.[12]

Scientific research has demonstrated that brain states are not static; rather, they evolve over time.[13] Indeed, with existing technology and medical knowledge, and with proper diagnosis and appropriate medical interventions, improvement and recovery are possible for persons with DOCs. Presently, two-thirds of persons with a severe brain injury regain consciousness, and just over a fifth of persons in the MCS regain functional independence when they receive the standard of rehabilitative care.[14] As the state of science advances, there is hope for persons with DOCs who have not yet regained functional independence.

There are some promising investigational neurotechnologies in development that may assist a person with a DOC in regaining consciousness and some abilities. For example, a randomized clinical trial has shown that some drugs, such as amantadine, when administered to persons with DOC accelerate the recovery of consciousness.[15] Prescribing amantadine off-label to accelerate the recovery of consciousness is now the standard of care for persons with DOCs in rehabilitation.[16] Additionally, neuromodulation is another investigational avenue being explored. This includes deep brain stimulation, vagal nerve stimulation, transcranial magnetic stimulation, hyperbaric therapy, and directed ultrasound.[17]

Despite this promise, most persons with a DOC do not have access to necessary rehabilitation, much less basic medical care. Many die of preventable illnesses such as bedsores, urinary tract infections, and pneumonia.[18] Equally critically, many are denied an accurate diagnosis. Researchers have found that over 40% of persons in the MCS in chronic care following traumatic brain injury are misdiagnosed as being in the vegetative state.[19] When improperly diagnosed as vegetative, persons fail to receive appropriate medical care and rehabilitation, and are instead housed in long-term care facilities.[20] And tragically, when patients are thought vegetative and insensate, they may also be denied pain medication.[21]

Barriers to treatment as human rights violations

Some of the issues that persons with severe brain injury and subsequent DOCs face post-injury have medical and technological solutions. If inaccurate diagnosis is because clinicians are unaware of the existence of the MCS, how to properly diagnose it, or that amantadine should be administered to try to induce consciousness, then the solution is better education and clinical training. Additionally, misdiagnosis may be because the person with severe brain injury is "covertly" conscious, unable to physically indicate their consciousness.[22] In this case, the solution is access to skilled clinicians trained to administer a neuropsychological exam known as the "coma recovery scale-revised," which is the most effective way to evaluate the presence of the MCS.[23]

What is less obvious, but perhaps more consequential, is how law and policies can negatively affect the lives of persons with severe brain injury. In the United States, for example, persons with DOCs may not be able to afford necessary rehabilitation because health insurance may not reimburse patients for the required length of rehabilitation.[24] In contrast to other wealthy countries, the United States lacks an affirmative right to health care.[25] Regulatory policies governing drugs and devices may also cause delays in getting effective treatments from bench to bedside.[26] Additionally, laws that protect persons with disabilities from discrimination and mandate accommodations, although applicable to persons with DOC, may not be applied or enforced.[27] Indeed, recent empirical scholarship has shown that physicians are often ignorant of their affirmative duties to accommodate their patients with disabilities when providing health care.[28] Furthermore, when persons with brain injury assert their legal rights under federal disability law, even when they have legal victories, there are few resulting changes in practice.[29] Finally, specific groups of persons with brain injuries may also be neglected.[30] For example, while legislators have taken action to help veterans with traumatic brain injuries gain access to necessary health care, administrative agencies have not followed through to ensure this access.[31] Thus, legal intervention is also required to improve the lives of persons with DOCs.

Clinical care, laws, and policies all need to be improved to ensure that persons with severe brain injury and subsequent DOCs are not neglected, but instead have access to appropriate medical care and thus have the opportunity to regain consciousness and be reintegrated into their communities.[32] The basic human dignity of persons with severe brain injury, as well as their legal entitlement to appropriate treatment and care, needs to be recognized.

The concepts of equality and dignity are at the heart of human rights. Indeed, the Universal Declaration of Human Rights establishes the "inherent dignity" of every person as "the foundation of freedom, justice and peace in the world."[33] Similarly, the preambles of various international human rights treaties identify dignity as the basis for other rights.[34] The CRPD, adopted in 2006, takes a significant step in affirming the dignity of persons with disabilities and their standing within the human community, asserting that "discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person."[35]

These principles and affirmations must be applied to persons with severe brain injury so that this population is no longer invisible, marginalized, or disregarded. Appropriate treatment and rehabilitation for persons with severe brain injury is not just a scientific or medical issue but a matter of respect for fundamental human dignity.[36] Framing the current subpar treatment of persons with DOCs in terms of human rights violations may provide an ethical and legal catalyst for change. This remainder of this section discusses the human rights implications for persons with DOCs.

Right to life with dignity

In some cases, health care providers may view continued medical treatment for persons with DOCs as futile. But such a lack of support for a family's desire to continue care may infringe on the right to life when patients have the potential to benefit from medical advancements.[37] As both the ICCPR and CRPD recognize, "Every human being has the inherent right to life."[38] The CRPD further calls on states to "take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis."[39]

A family's desire for ongoing treatment of a person with a DOC after a severe brain injury is often out of sync with a health care system that typically recommends that care be withheld or withdrawn upon the loss of consciousness after an injury or illness or wrongly analogizes the loss of consciousness occurring with severe brain injury to a terminal illness.[40] There is a negative bias within society and among health care providers against persons with DOCs since, in many cases, the loss of consciousness reflects the last stage of a long, drawn-out illness.[41] For example, in Alzheimer's disease, terminal cancer, and late-stage congestive heart failure, the loss of consciousness often signals the final stage of the disease.[42] However, brain injury is generally accompanied by unconsciousness at the outset, which could be the first step toward recovery.[43] Therefore, to equate the loss of consciousness from brain injury with the loss of consciousness from a degenerative or progressive disease is a flawed analogy since these illnesses have distinct trajectories.

A life with disability, even with severe brain injury, can still have great value to the person, as well as others. As the mother of a woman with severe brain injury explained, "Heather is going to be different, but I don't think that doesn't mean she won't be a wonderful daughter, friend, sister, and we won't enjoy her for the rest of her life."[44] The right to life for such persons requires respect.

Right to health

Current inadequate treatment and care of persons with severe brain injury and DOCs also violates their right to health. As set out in the ICESCR, everyone has the right "to the enjoyment of the highest attainable standard of physical and mental health."[45] The CRPD further clarifies that "persons with disabilities have the right to the enjoyment of the highest standard of health without discrimination on the basis of disability."[46] As the United Nations (UN) Committee on Economic, Social and Cultural Rights has explained, the right to the highest attainable standard of health entails quality health services that are available, acceptable, and accessible "to all, especially the most vulnerable or marginalized sections of the population."[47]

All too often, however, persons with severe brain injury receive brilliant and life-saving emergency care only to be abandoned by the health care system as they transition to the chronic care sector. Because the prevailing medical and cultural view is that the injured brain cannot recover and regain lost functionality, resources for care thus fall off after acute survival is assured, and the marginalization of persons with a DOC begins.[48] This marginalization and neglect include premature discharge, warehousing in inadequate facilities, misdiagnosis, and denial of rehabilitation.[49]

Patients with severe brain injury and subsequent DOCs are often discharged from the hospital while still unstable and transferred to long-term care facilities that are unequipped to provide appropriate care for this patient population, particularly patients in the MCS who require therapeutic engagement.[50] Further, as discussed previously, studies show that the diagnostic error rate of patients with DOCs in nursing homes is over 40%, in part because nursing homes often fail to recognize improvement in MCS patients.[51] These patients are wrongfully diagnosed as vegetative when they are, in fact, in the MCS.[52]

This misdiagnosis is often because before a patient shows overt behavioral improvements that evidence consciousness, the brain demonstrates structural changes.[53] Despite a bedside evaluation that may not show evidence of consciousness, neuroimaging may show network activation in MCS patients consistent with the ability to sustain emotion, thought, and language; progress in patients with severe brain injury may not be observable given that recovery from these injuries is particularly long and variable.[54] Measuring progress solely by motor function thus discriminates against patients who cannot yet move or speak. Patients may remain misdiagnosed for years while families struggle to obtain an accurate diagnosis. The CRPD, however, requires "early identification and intervention as appropriate."[55] Doing so is difficult, however, not only because these patients are often in long-term care facilities rather than hospitals or rehabilitative facilities where they would have neuropsychiatric health care specialists and neuroimaging equipment, but also because there is still a substantial lack of information regarding DOC prognosis, resulting from a gap in studies on patient rehabilitation and recovery.[56]

Moreover, despite the CRPD-enshrined right to "comprehensive habilitation and rehabilitation services and programmes," the denial of rehabilitation is a common problem for persons with severe brain injury and DOCs worldwide.[57] According to a 2011 report by the World Health Organization, 42% of countries surveyed adopted no rehabilitation policies, 50% had passed no rehabilitation legislation for people with disabilities, and 40% had not adequately established rehabilitation programs.[58] In the United States, the way that Medicare local coverage determination decisions are made may result in denying approval for rehabilitation for persons with DOCs, and private health insurance may differ on the scope and extent of rehabilitation coverage.[59] In sum, although the CRPD specifically "prohibit[s] discrimination against persons with disabilities in the provision of health insurance" and the "discriminatory denial of health care or health services," and the US Affordable Care Act also contains a non-discrimination section, in practice, many patients with DOCs experience discrimination in health care coverage and delivery.[60]

Right to benefit from scientific progress

Persons with severe brain injury are not adequately benefitting from scientific advances. The ICESCR recognizes the right of everyone "[t]o enjoy the benefits of scientific progress and its applications."[61] The CRPD elaborates on states' obligation "to undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communication technologies, mobility aids, devices and assistive technologies."[62] Moreover, it requires states to "promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation."[63]

Persons with severe brain injury have a right to benefit from scientific progress, including medications, rehabilitation, and neuroprosthetic technologies that may restore their ability to communicate and connect with others. Neuroprosthetics—devices that doctors implant into a patient's brain or onto their head in order to "supplement the input or output of the nervous system"—include artificial retinas, cochlear implants, and surface electromyography electrodes. Neuroprosthetics can help patients regain the ability to see and hear and re-enable the use of paralyzed limbs, and thus can be beneficial to persons with severe brain injury who acquire such disabilities.[64]

Indeed, assistive technologies are critical to the realization of a human rights of persons with severe brain injury. As the UN Special Rapporteur on the rights of persons with disabilities explains, for many persons with disabilities, access to assistive technologies and support services "constitutes a precondition for the respect of their inherent dignity and the full and equal enjoyment of all human rights and fundamental freedoms."[65] Such access is also recognized as essential to the non-discriminatory treatment of persons with disabilities under the Americans with Disabilities Act, the United States' federal disability law.[66]

However, thus far, scientific developments have had little impact on the experiences of patients with DOCs who lack access to necessary medication, rehabilitation, and neuroprosthetics.[67] This may be because in the United States, health care providers and insurers do not recognize their legal obligation under the Americans with Disabilities Act to provide existing technology and medical interventions to accommodate patients with severe brain injury in order to help them communicate with their providers to the extent they are able.[68] Further, promising neurotechnologies may never make it to the market, because of both research-related and regulatory hurdles.[69]

Indeed, we have yet to take even the first step of collecting epidemiological data and conducting studies necessary to develop assistive technologies and guide policy, a requirement under international law.[70] Under the CRPD, states must "undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies" to protect basic rights.[71] The Special Rapporteur on the rights of persons with disabilities likewise emphasizes the importance of data collection.[72] Simply put: without a count, *you don't count.*

Right to education

Persons with severe brain injury are often deprived of necessary rehabilitation and thus the ability to develop their full potential, which implicates the human right to education. The ICESCR enshrines "the right of everyone to education" for the "full development of the human personality and the sense of its dignity."[73] The CRPD mandates "an inclusive education system at all levels and lifelong learning" to enable "development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential."[74] The United States provides free public schooling for children through the age of majority in recognition of the importance of minimum education. And with regard to children with disabilities, the United States requires "a free [and] appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living."[75] Thus, both international and US domestic law recognize the need for appropriate education for people to reach their full potential.

The purpose of rehabilitation can be considered similar in key respects to the purpose of education, critical to the development of persons with severe brain injury. As noted previously, most MCS patients lack access to rehabilitative technologies and "remain sequestered in nursing homes, incompletely diagnosed … at the margins of society."[76] According to emerging scientific evidence, the brain regenerates through axonal growth, just as it does in its initial development.[77] It may thus make sense to view brain injury recovery through a developmental frame and to view rehabilitation as analogous to education.[78] Accordingly, persons with severe brain injury should have access to rehabilitation, which, like education, functions to help them reach their full potential.[79]

However, the amount of rehabilitation currently provided to patients with brain injury is meager.[80] Post-acute rehabilitation needs to be of sufficient scope, duration, and intensity for injured persons to regain lost skills and learn new compensatory strategies. Additionally, as with the education of children, this process takes months and years rather than weeks.

Right to freedom of expression

Persons with severe brain injury may not have access to tools to assist them with communication. Communicating wishes is an important element of autonomy and self-determination fundamental to personhood and human rights. Communication is also a component of the right to freedom of expression. Freedom of expression is recognized by the ICCPR and includes the "freedom to seek, receive and impart information and ideas of all kinds."[81] And under the CRPD, states must "take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion."[82] Freedom of expression also ties into the first guiding principle set out by the CRPD: "[r]espect for the inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons."[83]

For persons with severe brain injury, like all persons, the ability to communicate is critical. As one of this paper's authors has previously asserted, "If they cannot communicate, we do not know they exist."[84] Communication for many persons with severe brain injury is now possible through the use of assistive devices.[85] These devices may enable such persons to express their preferences and connect with others. When, as all too often occurs, persons with severe brain injury are not given the tools to communicate, they are denied the right to freedom of expression.[86]

Right to community

The ability to communicate is not only critical to freedom of expression but also essential to forming relationships and being part of a community, which many persons with severe brain injury and DOCs are denied.[87] The CRPD recognizes the "equal right of all persons with disabilities to life in the community."[88] States must take measures to ensure their "full inclusion and participation in the community" and "to prevent isolation or segregation." [89]

Community is not only a physical place; rather, it can also be created through communication and relationships with others. Restoring communication for persons with severe brain injury enables their reintegration into family and society, while failure to diagnose and sustain consciousness relegates such persons to continued exile.[90] As the mother of one patient with brain injury explained, "But if she can't communicate, then there is no way for her to share the life of the mind with everyone else."[91] When MCS patients are enabled to communicate, their community can be rebuilt.

Additionally, persons with severe brain injury should have access to a community of peers. Housing young patients with severe brain injury in nursing homes serving older persons with degenerative disease segregates them from their peers and deprives them of opportunities. Rather, these young patients should be cared for in facilities with patients of their generation, where the focus is not on support during decline but on facilitating rehabilitation and progress.

Right to family

Having a family is a fundamental human right, including for persons with disabilities such as severe brain injury. The ICCPR sets out the "right of men and women of marriageable age to marry and found a family," echoed by the CRPD, and the ICESCR requires the "widest possible protection and assistance … to the family, which is the natural and fundamental group unit of society."[92] The CRPD exhorts states to "take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships."[93] The UN Committee on the Rights of Persons with Disabilities has further criticized the denial of legal capacity with no provision for support in decision-making as leading to the deprivation "of many fundamental rights," including the right to marry and found a family and parental rights.[94]

The current financing mechanisms of the US health care system, however, do not protect the family relations of persons with significant disabilities but rather contribute to tearing them apart. In couples where one partner suffers from brain injury, for which the costs of care can be financially ruinous, partners may be forced into a "Medicaid divorce" to qualify for public health insurance while protecting family assets. As one spouse lamented, "This country doesn't allow a catastrophe like this to take care of someone without wiping out a family."[95] Health care regulations in the United States compound medical tragedies, severing relationships. After the divorce, the former caretaking spouse may no longer be legally entrusted with decision-making and care. Instead, this role may pass to the patient's other family members. This can be heartbreaking for the couple. One husband, eventually forced into a "Medicaid divorce," recounts comforting his wife with brain injury:

> *I hold her, tell her I love her, and tell her I'm going to find whatever help there is out there and I'll never abandon her. Because I took our marriage vows very seriously … I won't abandon you. I say, the last breath I take will be taking care of you.*[96]

This is in stark contrast with the policies of other developed countries, which provide universal health insurance with negligible out-of-pocket costs. In Canada, for instance, patients without private insurance who have sustained a traumatic brain injury enjoy free access to inpatient acute care and rehabilitation. However, care, largely financed by tax revenues from individual provinces, may entail some disparities for residents from different localities.[97] Significantly, the financing of health care in Canada does not require families to dissolve in order to receive care for significant disabilities such as severe brain injury.

In addition to the right to marry, persons with severe brain injury have the right to continuing contact and a relationship with their children. The CRPD recognizes this right and sets out that "[i]n no case shall a child be separated from parents on the basis of a disability."[98] However, in cases of separation or divorce, a person with severe brain injury may be completely cut off from any children. A woman whose adult daughter suffers from a DOC recounts the family's legal struggles to ensure contact between her daughter and her minor children, who are in the custody of an ex-spouse who refuses to allow them to see their mother because she has a DOC. She highlights that this contact with her children may be important not only to the children's well-being but also to her daughter's cognitive recovery.[99] To comply with the CRPD, states must "ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child."[100]

Right to equality

Equality is a core human rights principle that is often violated with respect to persons with severe brain injury, such as when they are legally denied the right to make their own decisions or not able to access assistive devices that would aid them in communicating with others, as discussed earlier. The first article of the Universal Declaration of Human Rights proclaims, "All human beings are born free and equal in dignity and rights."[101] The ICCPR and Universal Declaration of Human Rights further establish that all persons "are equal before the law and are entitled without any discrimination to equal protection of the law," which the CRPD echoes.[102] The equality enshrined in these international instruments is substantive rather than a formal requirement of identical treatment.[103] In fact, as the UN Human Rights Committee has recognized, equality may necessitate "affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination."[104] In this vein, the CRPD states that "[i]n order to promote equality and eliminate discrimination," states should "take all appropriate steps to ensure that reasonable accommodation is provided."[105] Moreover, "[s]pecific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination."[106]

Closely linked to equality is fundamental dignity and "the right to recognition everywhere as a person before the law" under the various international instruments.[107] As the Committee on the Rights of Persons with Disabilities has clarified, this includes the enjoyment of "legal capacity on an equal basis with others," integral to "the capacity to be both a holder of rights and an actor under the law."[108] Instead of substituting for the decisions of persons with disability, the state has the responsibility to provide the support needed for the exercise of legal capacity.[109] Moreover, a "person's mode of communication must not be a barrier to obtain support in decision-making, even where this communication is non-conventional, or understood by very few people."[110] However, as the committee has explained:

> *Support in decision-making must not be used as justification for limiting other fundamental rights of persons with disabilities, especially the right to vote, the right to marry, or establish a civil partnership, and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.*[111]

While US federal disability law (the Americans with Disabilities Act) is also meant to ensure equality and non-discrimination in employment and places of public accommodation, this law may have limited effect in assuring equality for persons with severe brain injury if actors such as health care providers do not recognize their legal duty to accommodate persons with disabilities, there is a lack of understanding about what constitutes proper accommodations, or persons with disabilities do not have the legal resources to assert their rights.[112] Significantly, many US states undermine the legal capacity and fundamental rights of persons with cognitive disabilities. While some states' laws allow for supported decision-making for a person with a cognitive impairment such as severe brain injury, where a person with a cognitive disability retains legal capacity while also receiving assistance in making decisions on the basis of their preferences and interests, most state laws necessitate the complete transfer of decision-making authority to surrogates or a guardian.[113] This often negatively affects other important rights, such as the right to benefit from scientific progress. For instance, laws that deny persons under guardianship the right to participate in clinical research may also mean that persons with severe brain injury under guardianship do not have access to cutting-edge therapies being studied in clinical trials.[114] Laws that deny legal recognition and capacity thus violate the fundamental equality and basic rights of persons with severe brain injury, requiring amendment.

A path forward

The current lack of access to treatment and rehabilitation for persons with severe brain injury violates their fundamental rights to human dignity, life, health, benefit from scientific progress, education, freedom of expression, community, marriage and family, and equality. Compliance with international human rights law requires the following:

- data collection on persons with severe brain injury
- improved diagnosis
- an end to unnecessary institutionalization in long-term care facilities
- access to rehabilitation and communication technologies, covered by health insurance
- access to a community of peers
- support for families to stay together

While full achievement of economic and social rights is subject to resource constraints, these rights bring certain immediate obligations, and governments must take steps for their progressive realization "to the maximum of available resources."[115] The right to health contains a minimum core, immediately binding, which includes non-discriminatory access to health care and the equitable distribution of health facilities, goods, and services.[116] The UN Special Rapporteur on the rights of persons with disabilities provides specific guidance on resource implications. She explains that "obligations of immediate effect," even if resources are scarce, include "the elimination of discrimination in the exercise of this right, … securing access to social protection and ensuring a minimum essential level of benefits for all persons with disabilities and their families."[117] It is important to recognize that that some technologies and rehabilitation treatments for persons with severe brain injury may be costly. Such interventions need not be provided all at once, but governments must take steps toward their provision to satisfy their obligations.

The minimum core of the right to health requires the adoption of national health strategies and plans of actions with benchmarks to measure progressive realization. These national strategies and plans must further give particular attention to vulnerable and marginalized groups, such as persons with severe brain injury.[118] Currently, with a 41% misdiagnosis rate, persons with severe brain injury do not receive a basic standard of care available to others. Indeed, many are not even receiving basic medical care or treatment at all.[119] Thus, national health strategies and plans must address this gap to protect basic rights. As the UN Special Rapporteur on the rights of persons with disabilities notes, "[t]o guarantee progressive realization of the right to social protection, States should formulate strategies and plans that include realistic, achievable and measurable indicators and time-bound targets, designed to assess progress in its implementation."[120]

Accordingly, states at the very least must eliminate discrimination in care and create strategies and action plans to meet the needs of persons with severe brain injury. Now that we understand the gravity of this situation and the vulnerability of individuals with severe brain injury and DOCs, we are ethically and legally obliged to act and advocate to address current neglect.

Acknowledgments

Tamar Ezer dedicates this piece to Johanna Fine, a talented and passionate health and human rights advocate who is currently experiencing severe brain injury. She also thanks Alisha Bjerregaard, the acting director of UN advocacy at Women Enabled International, and Joyce Fingeroth, a clinician-scientist in infectious disease immunology at the University of Massachusetts Medical School and Johanna Fine's mother, for their helpful review and feedback on a draft of this paper. Lastly, she thanks Franco Piccinini for his helpful research and support. Joseph J. Fins dedicates this piece to the memory of Javier Romañach Cabrero and to his friends and colleagues at the Instituto de Derechos Humanos Bartolomé de las Casas at Universidad Carlos III in Madrid.

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HHR Health and Human Rights Journal

Beyond the Pragmatic Definition? The Right to Non-discrimination of Persons with Disabilities in the Context of Coercive Interventions

SÁNDOR GURBAI

Abstract

According to a longstanding definition of non-discrimination, differential treatment does not constitute discrimination if the purpose or effect of the differential treatment is to achieve a legitimate aim and if the differential treatment can be objectively and reasonably justified. This characterization reflects what Wouter Vandenhole has described as the "widely-used pragmatic definition of discrimination." In mental health policy, one important application of this definition pertains to the disputed question of whether coercive psychiatric interventions constitute discrimination on the basis of disability. In this paper, I consider whether the well-established pragmatic definition of discrimination remains valid in light of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). I review evidence from the convention, from the general comment on equality and non-discrimination published by the Committee on the Rights of Persons with Disabilities, and from the committee's adjudication of individual allegations of discrimination. I conclude that the CRPD and its treaty body send mixed signals in relation to the pragmatic definition: The convention itself is silent as regards the pragmatic definition, and while the committee has in some instances invoked it, it also seems to be pointing toward a new approach that goes beyond the pragmatic definition. I survey three possible alternatives to the pragmatic definition, tracing each to suggestions in the jurisprudence of the Committee on the Rights of Persons with Disabilities, and illustrating how each can be applied in determining whether coercive psychiatry is discriminatory.

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Competing interests: None declared.

Introduction

In 2017, Dainius Pūras, the United Nations (UN) Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, gave voice to the imperative to tackle discrimination that persons with psychosocial disabilities are facing in the mental health system:

> *Discrimination, de jure and de facto, continues to influence mental health services, depriving users of a variety of rights, including the rights to refuse treatment, to legal capacity and to privacy, and other civil and political rights. The role of psychiatry and other mental health professions is particularly important and measures are needed to ensure that their professional practices do not perpetuate stigma and discrimination.*[1]

Its response to this report, the UN Human Rights Council called on states "to abandon all practices that fail to respect the rights, will and preferences of all persons, on an equal basis, and that lead to power imbalances, stigma and discrimination in mental health settings."[2]

But what exactly is meant by *discrimination*? Can people be treated *differently* in an unfavorable way? If so, can *unfavorable* treatment be justified in some circumstances? Can a *protected characteristic* ever be the basis for such treatment? If not all differential treatment constitutes discrimination, then we need a method for determining whether a particular policy or practice is *justifiable*—even if its application has an unfavorable impact on persons with one or more protected characteristics. To best of my knowledge, there is no agreed definition of "unfavorable treatment." For the purpose of the present analysis, I shall assume that "unfavorable treatment" includes any differential treatment that impairs or denies the recognition or exercise of any human rights.

Let us put these questions into the context of coercive psychiatric interventions. *Under what circumstances can people be treated against their will on the basis of their actual or perceived impairment?* This is a question to which many lawyers may think they know the answer: If a less favorable treatment on the basis of a protected ground has a *legitimate aim* and is *objectively and reasonably justified*, it cannot be viewed as discrimination. Similarly, many psychiatrists may also think they know the answer: Deprivation of liberty in a mental health care facility and coercive mental health treatment can be justified when *certain criteria* (which are either explicitly or implicitly linked to the notions of legitimate aim, objectivity, and reasonability) *are satisfied*. These criteria include that coercive measures shall be *last-resort* options and that these measures shall aim to protect the health or life of the patient and/or others.

These familiar positions are based on a longstanding principle of non-discrimination: the principle that differential treatment does not constitute discrimination if the purpose or effect of the differential treatment is to achieve a legitimate aim and if the differential treatment can be objectively and reasonably justified. Under this familiar approach, even laws and policies that would otherwise be tantamount to direct discrimination on the basis of disability can in principle be deemed compliant with human rights standards—so long as the disadvantageous differential treatment can be justified. But does this approach remain valid in light of 21st-century developments in international human rights law?

In order to answer these questions, I proceed as follows: I begin by analyzing the standard for legal defenses against allegations of discrimination in UN human rights treaties and in the interpretative instruments of their treaty bodies. I then focus on whether the text of the UN Convention on the Rights of Persons with Disabilities (CRPD) calls for rejection or acceptance of the well-established justification defense standard. In the following sections, I analyze the general comment on equality and non-discrimination published by the Committee on the Rights of Persons with Disabilities (CRPD Committee) and the committee's case law in order to identify whether the traditionally used justification defense remains valid in light of the committee's jurisprudence. Finally, I propose candidates for alternatives to the broadly used justification defense in allegations of discrimination.

Before turning to the matter at hand, it is worth reminding ourselves of the broader significance of the issues explored here. This legal analysis can have enormous consequences not only for the interpretation of fundamental international human rights standards but ultimately for determining what forms of unfavorable treatment persons with disabilities can lawfully be subject to, and what defenses are available to states when they are accused of discriminatory treatment.

The longstanding schema for defense

According to a longstanding schema for defense against allegations of discrimination, differential treatment in a comparable situation does not constitute discrimination if the purpose or effect of the differential treatment is to achieve a legitimate aim and if the differential treatment can be justified objectively and reasonably. In a synoptic 2005 review of non-discrimination as interpreted by the UN human rights treaty bodies, Wouter Vandenhole described this as the "widely-used *pragmatic definition of discrimination*."[3]

This pragmatic definition of discrimination does not come from the treaties themselves; rather, it was worked out by treaty bodies, particularly by the UN Human Rights Committee (HRC). This body—which is tasked with overseeing states' compliance with the International Covenant on Civil and Political Rights—emphasizes in its General Comment No. 18 that

> *[n]ot every differentiation of treatment will constitute discrimination, if the criteria for such differentiation are reasonable and objective and if the aim is to achieve a purpose which is legitimate under the Covenant.*[4]

The HRC has often relied on this formula in its case law and has constructed its jurisprudence on this approach to justification.[5] The UN Committee on the Elimination of Racial Discrimination (CERD) and the UN Committee on Economic, Social and Cultural Rights (CESCR) have made similar statements, endorsing the pragmatic definition.[6] Furthermore, each of these three treaty bodies has made explicit in their statements that the pragmatic definition of discrimination should apply in cases of both direct and indirect discrimination.[7]

The CESCR's General Comment No. 20 elaborates on the pragmatic definition of discrimination, clarifying that when it comes to the "objective and reasonable" justification defense,

> *[t]his will include an assessment as to whether the aim and effects of the measures or omissions are legitimate, compatible with the nature of the Covenant rights and solely for the purpose of promoting the general welfare in a democratic society. In addition, there must be a clear and reasonable relationship of proportionality between the aim sought to be realized and the measures or omissions and their effects.*[8]

Under this approach, therefore, differential treatment satisfies the "objective and reasonable" standard as long as three criteria are met: (1) the disputed policy or practice has a legitimate aim or effect; (2) the aim is compatible with international human rights and serves the purpose of promoting general welfare in a democratic society; and (3) the disputed policy represents a proportional means to achieve the intended aim.

Some hints in dissents

Up to this point, we have seen that the pragmatic definition of discrimination, together with the associated schemas for justifying differential treatment, have been explicitly endorsed by UN treaty bodies monitoring the implementation of the three oldest UN treaties. But what are the opinions of the treaty bodies that oversee the more recent UN conventions?

Surveying the various UN human rights treaty bodies in 2005, Vandenhole noted the following:

- The UN Committee on the Rights of the Child does not seem to have embraced the pragmatic definition.[9]
- The UN Committee on the Elimination of Discrimination against Women (CEDAW Committee) has not yet used the pragmatic defi-

> nition, and "[i]t is not clear whether the CEDAW Committee accepts the widely-used pragmatic definition of discrimination."[10]

Fifteen years later, the positions of these two treaty bodies remain unclear, but some relevant traces can be found, particularly in dissenting opinions of the CEDAW Committee. Although these cases are not related to coercive interventions or to persons with psychosocial disabilities, their impact on the pragmatic definition of discrimination is significant.

In 2007, the CEDAW Committee had to decide in the case of *Cristina Muñoz-Vargas y Sainz de Vicuña v. Spain*.[11] In this case, the applicant alleged that the state party had discriminated against her based on sex by denying her right, as the first-born child, to succeed her late father to the title of Count of Bulnes. The committee's decision stated that the application was inadmissible *ratione temporis*. There was a concurring opinion that also found the application inadmissible because it was incompatible with the provisions of the UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) insofar as the title of nobility in question did not have any legal effect. However, according to one member of the CEDAW Committee, Mary Shanthi Dairiam, the application was admissible. In her dissenting opinion, she argued:

> *First of all I acknowledge that the right to titles of nobility is not a fundamental human right and may not be of much material consequence to the author. However, the* **legislation and practice of States parties must in no way and in no context provide for a differential treatment of women and men in a manner that establishes the superiority of men over women and concomitantly, the inferiority of women as compared to men**. *This is what the law of 4 May 1948 and 11 October 1820 does.*[12]

Dairiam used the phrase "differential treatment," which is a neutral term in itself. By describing the avoidable situation as "establishing the superiority of men over women and concomitantly, the inferiority of women as compared to men," she clearly addressed *less favorable treatment on the basis of gender.* She talked about "States parties" and not only about Spain, by which she indicated that her statement was meant to be addressed to all states parties. Finally, by using the formulations of "no way" and "no context," she signaled that her statement was meant to be applicable under all circumstances. In other words, *if we accept that less favorable treatment on the basis of gender constitutes discrimination under all circumstances, then less favorable treatment on the basis of gender automatically amounts to gender-based discrimination.* In this regard, Dairiam's dissent is an indicator that at least one member of the CEDAW Committee harbors reservations about the adequacy of the pragmatic definition.

While Dairiam's dissent may suggest a rejection of the pragmatic definition, another committee member's dissent reflects a continued commitment to it. In 2009, the CEDAW Committee dealt with the case of *G. D. and S. F. v. France*.[13] In this case, two unmarried women without children claimed to be victims of human rights violations under CEDAW because they had been legally barred from changing their family names. They submitted that French legislation governing family names contravened the principle of equality between parents and constituted a violation of article 16(1)(g) of the convention. The CEDAW Committee found the application inadmissible because the applicants lacked the quality of victim, since article 16(1)(g) refers to "husband and wife" and the applicants were not married. Six members of the CEDAW Committee submitted a dissenting opinion on the issue of admissibility. With their statement, however, they acknowledged that less favorable treatment on the ground of sex could be justified:

> *It is a clear obligation of all States parties to the Convention to uphold the principle of equality between women and men in their legislation and to ensure practical realization of this principle (article 2) and to abolish and change stereotypes on roles of women and men (article 5).* **This means that very weighty reasons would have to be put forward before a difference of treatment on the sole ground of sex could be regarded as compatible with the Convention.**[14]

From the circumstances of the case, it is clear that the concept of *difference of treatment* is meant to be *less favorable treatment*, which means that one-third of the members of the CEDAW Committee acknowledged the possibility in principle of a justification defense when it comes to gender-based less favorable treatment. In other words, *six dissenting members of the CEDAW Committee showed a commitment to the pragmatic definition of discrimination, while the majority remained silent on it, deciding the issue on different grounds.*

In sum, in the 15 years following Vandenhole's synoptic survey, it has remained unclear whether the Committee on the Rights of the Child and the CEDAW Committee are committed to the pragmatic definition of discrimination and its associated schemas for justifying differential treatment.

UN Convention on the Rights of Persons with Disabilities

The CRPD's definition of discrimination is similar to the definitions given in the International Convention on the Elimination of All Forms of Racial Discrimination and in CEDAW.[15] According to article 2 of the CRPD:

> *"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.*

This article is of limited value in determining whether the convention adheres to the pragmatic definition. It explicitly tells us that discrimination is present if the following conditions are met: (1) the person concerned has an impairment or disability; (2) there is a less favorable treatment compared to others; (3) there is a link between the impairment and the less favorable treatment (either intentional or unintentional); and (4) the purpose or effect of the less favorable treatment is impairing or nullifying the recognition, enjoyment, or exercise of any of the human rights and fundamental freedoms.

However, the article is silent on the following aspects: (1) whether less favorable treatment on the basis of disability may have a *legitimate purpose or effect* and (2) whether there is any room for *objective and reasonable justification*.

At first sight, then, the CRPD, like the other UN human rights treaties, *neither explicitly rejects the pragmatic definition of discrimination nor explicitly relies on it.*

How should this silence be decoded? When the task is to interpret a treaty, lawyers turn to the Vienna Convention on the Law of Treaties (VCLT).[16] Can the VCLT help us determine whether the CRPD is endorsing the pragmatic definition? I suggest focusing on three provisions of the VCLT.

According to the VCLT's general rule of interpretation, "[a] treaty shall be interpreted … *in the light of its object and purpose*."[17] The stated purpose of the CRPD is to promote, protect, and ensure the *full and equal enjoyment* of *all human rights and fundamental freedoms* by *all persons with disabilities*.[18] What, if anything, does this tell us about the position of the CRPD as regards the pragmatic definition? Alas, two different answers can be offered here. On the one hand, it might be held that the convention's aim permits balancing the right to non-discrimination against other rights. Real-life situations, such as coercive interventions, are complex and generally involve conflicts of rights (for example, in the case of involuntary placement, the right to liberty of a person with disabilities versus the right to health of others or the person's own right to life or health).[19] In these situations, the usual solution is to engage in a balancing exercise of rights, which means that disability-based limitations of rights may be justified in order to achieve the protection of other rights. This approach would be tantamount to acceptance of the pragmatic definition of discrimination. On the other hand, it might be held that the aim of the CRPD precludes the pragmatic definition and its associated schemas for justifying differential treatment. Under this construction, the objective of ensuring the *full* enjoyment of *all* human rights by *all* persons with disabilities is simply incompatible with policies that restrict rights and freedoms on the basis of disability. Where circumstances arise in which the balancing of conflicting rights is required, this must never be done in a way that is tantamount to unfavorable treatment on the basis of disability.

As for the VCLT, "[a] treaty shall be interpreted … in accordance with the ordinary meaning to be given to the terms of the treaty *in their context*."[20] The principle of equality and non-discrimination is built in deliberately and systematically throughout the substantive articles of the CRPD through the formula of "on an equal basis with others." Thus, it must be recognized that the CRPD emphasizes the contextual connection between non-discrimination and the substantive rights. But this by itself does not show that the CRPD diverges from the pragmatic definition of discrimination.

According to the VCLT, "[r]ecourse may be had to supplementary means of interpretation, including the *preparatory work of the treaty*."[21] In relation to this provision of the VCLT, one might argue that there is no justification clause in the CRPD when it comes to direct and indirect discrimination. If the negotiators of the convention had wanted to include a justification provision in the definition of "discrimination on the basis of disability," they could have included one. If we accept this argument, then the absence of such a justification clause might be taken as an indication that the CRPD rejects the pragmatic definition of discrimination. However, the International Convention on the Elimination of All Forms of Racial Discrimination does not contain any justification clause either, but the interpretation of the CERD is in favor of the pragmatic definition of discrimination.

Application of the VCLT rules therefore does not provide a decisive indication as to whether the CRPD should be interpreted as conforming to the pragmatic definition or departing from it.

CRPD Committee's general comment on equality and non-discrimination

In 2017, the CRPD Committee produced an outline of its draft general comment on equality and non-discrimination and invited public comment on the document.[22] The outline did not mention justification defenses in relation to either direct or indirect forms of discrimination. One of the respondents to the call for comments was a former member of the HRC, Gerald L. Neuman. He encouraged the committee to address the issue of how differential treatment can be justified:

> *It would be useful for the Committee to clarify that the prohibition of discrimination on the basis of disability does not mean that differential treatment on the basis of disability is always a violation of the Convention per se, without any consideration of the explanation that is put forward to justify the differential treatment. Referring to disability as a "prohibited ground" does not mean that it is a ground that can never provide the basis of a lawful difference in treatment, but rather that differential treatment requires a high level of justification. The distinction between differential treatment (irrespective of justification) and "discrimination" (in the absence of sufficient justification) is fundamental in international human rights law, and should also inform the Committee's interpretation of the Convention.*[23]

Urging the committee to avoid a "rigid definition of discrimination," Neuman argued that "[a] refusal to consider whether differential treatment may be justified as reasonable, objective and proportional would not serve the goal of human rights."[24] For Neuman, a definition of discrimination is unduly "rigid" insofar as it fails to acknowledge that some disability-based differential treatment can be justified as reasonable, objective, and proportional.

Following the consultation process on its outline, the CRPD Committee defined direct discrimination in its draft general comment but did not mention explicitly any possibility for justification.[25] However, indirect discrimination was defined by explicitly allowing for objective justification of the differential treatment by a legitimate aim. The committee added that "the means achieving that aim shall be appropriate and necessary."[26] At least at the time of the *drafting* of the general comment, the committee seemed to embrace the pragmatic definition of discrimination (and its associated schemas for the justification of differential treatment) while restricting its application to allegations of indirect discrimination. But this hybrid position was not ultimately the one adopted by the committee.

The final version of General Comment No. 6 is entirely silent on justification when it comes to both direct and indirect discrimination.[27] The CRPD Committee removed the explicit mention of justification even from the definition of indirect discrimination. There is no public record of the committee's reasons for this elision. What is a matter of public record are the public comments that the committee received, both on its outline and on its draft of General Comment No. 6. Neuman, together with the Equal Rights Trust and the Danish Ministry for Children and Social Affairs, expressed support for inclusion of the pragmatic definition of discrimination.[28] However, the Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) and Inclusion International, two global networks of persons with psychosocial and intellectual disabilities, opposed it.[29] CHRUSP asked the committee to amend the draft paragraph defining direct discrimination:

> *In the examples of disability-based violence, please include forced psychiatric interventions. It would be helpful also to include … forced hospitalization … as examples of direct discrimination.*[30]

It may be that the comments of persons with disabilities and their organizations were more influential on the committee than submissions from other sources.

We should note, however, that the footnotes in the definitions of both direct and indirect discrimination take us to paragraph 10 of the CESCR's General Comment No. 20.[31] According to this paragraph, "Both direct and indirect forms of differential treatment *can* amount to discrimination under article 2, paragraph 2, of the Covenant."[32]

The word "can" suggests that in the view of the CESCR, differential treatment does not amount *automatically* to discrimination. The CESCR suggests that "[d]ifferential treatment based on prohibited grounds will be viewed as discriminatory unless the justification for differentiation is reasonable and objective."[33]

It is not entirely clear whether the CRPD Committee wanted to refer in both direct and indirect discrimination cases to the entire content of paragraph 10 of General Comment No. 20 or just specific aspects of it (such as "detrimental acts or omissions," "neutrality at face value," and "disproportionate impact") that are not related to the justification defense.

In sum, particularly when read in light of its drafting history, the CRPD Committee's general comment on equality and non-discrimination sends mixed messages in relation to the validity of the pragmatic definition in the context of the CRPD.

Jurisprudence of the CRPD Committee

The ultimate test of any definition of discrimination must concern its application to concrete cases. In order to provide the fullest possible accounting, this section expands the scope of my analysis to include all discrimination cases considered by the committee—and not just those addressing the specific topic of involuntary mental health interventions. As of October 2019, the CRPD Committee had dealt with 15 individual applications in which either direct or indirect discrimination was addressed.[34] Out of these 15 cases, there were 14 adoptions of views (decisions on the merits) and one inadmissibility decision.

Direct discrimination was addressed by the committee in three cases. In none of these cases did the committee invoke the pragmatic definition of discrimination:

- *V.F.C. v. Spain* (2019)[35]
- *Y v. United Republic of Tanzania* (2018)[36]
- *X v. United Republic of Tanzania* (2017)[37]

Direct discrimination was raised by the parties alone in two cases:

- *Marie-Louise Jüngelin v. Sweden* (2014)[38]
- *Bujdosó et al. v. Hungary* (2013)[39]

Indirect discrimination was addressed by the committee in eight cases (seven adoptions of views and one inadmissibility decision). Out of the seven adoptions of views, three cases used the pragmatic definition of discrimination and four cases did not.

- Adoptions of views where the pragmatic definition was used:
  - *Iuliia Domina and Max Bendtsen v. Denmark (2018)*[40]
  - *Marlon James Noble v. Australia (2016)*[41]
  - *H.M. v. Sweden (2012)*[42]

- Adoptions of views where the pragmatic definition was not used:
  - *J.H. v. Australia (2018)*[43]
  - *Gemma Beasley v. Australia (2016)*[44]
  - *Michael Lockrey v. Australia (2016)*[45]
  - *Liliane Gröninger et al. v. Germany (2014)*[46]

- Inadmissibility decision:
  - *S.C. v. Brazil (2014)*[47]

Indirect discrimination was raised by the parties alone in three cases:

  - *Bacher v. Austria (2018)*[48]
  - *Bujdosó et al. v. Hungary (2013)*
  - *Nyusti and Takács v. Hungary (2013)*[49]

In surveying these cases, we can distinguish three different stances taken by the CRPD Committee toward the pragmatic definition of discrimination.

Adoption of the pragmatic definition

The committee relied on the pragmatic definition of discrimination in three cases about allegations of indirect discrimination: *H.M. v. Sweden*, *Marlon James Noble v. Australia*, and *Iuliia Domina and Max Bendtsen v. Denmark*.

In *H.M. v. Sweden*, the applicant had a "chronic connective tissue disorder" due to which she could neither leave her house nor safely be transported to the hospital. The only meaningful rehabilitation was hydrotherapy in an indoor pool. The local housing committee rejected the applicant's application for permission to construct such a pool at her home, holding that it contravened land-use restrictions under the Swedish Planning and Building Act.

In the case of *Iuliia Domina and Max Bendtsen v. Denmark*, the applicants were Iuliia Domina, a national of Ukraine, and Max Bendtsen, a national of Denmark. The applicants were a married couple. Mr. Bendtsen had brain damage following a car accident in 2009 and consequently received social benefits, as he could not support himself through employment. In May 2013, the applicants applied for family reunification and a residence permit for Ms. Domina in Denmark based on their marriage, which they had celebrated in April 2013. Their application was rejected based on the Danish Alien Act, according to which a residence permit based on family reunification could not be granted if the applicant's spouse had received social benefits within a period of three years prior to the application.

In both *H.M. v. Sweden* and *Iuliia Domina and Max Bendtsen v. Denmark*, the Committee observed that "a law which is applied in a neutral manner may have a discriminatory effect when the particular circumstances of the individuals to whom it is applied are not taken into consideration."[50] When it comes to the justification defense, the committee argued in both cases that

> *[t]he right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.*[51]

In *Marlon James Noble v. Australia*, the applicant was an Aboriginal man with intellectual and psychosocial disabilities. In 2001, when he was 19 years old, he was charged with child sex abuse and was arrested. The court found that the applicant was unfit to plead and subjected him to a custody order. Because the applicant did not have the opportunity to plead not guilty, the court made no finding of guilt. The applicant was deprived of his liberty for more than 10 years, "converting his disability into the core cause of his detention."[52] In this case, the committee mentioned only the reasonableness part of the justification defense.

> *The issue before the Committee is therefore to assess whether the differential treatment provided under the Act is reasonable or whether it results in discriminatory treatment of persons with disabilities.*[53]

Thus, the CRPD Committee has explicitly adopted the pragmatic definition in indirect discrimination cases, even though the final version of General Comment No. 6 elides any explicit acknowledgement of the defenses that it affords.

Silence on the pragmatic definition

The treaty body did not address the pragmatic definition of discrimination in four cases where it dealt with the issue of indirect discrimination. For example, the cases of *Michael Lockrey v. Australia*, *Gemma Beasley v. Australia*, and *J.H. v. Australia* concerned deaf persons. While Mr. Lockrey used steno-captioning, Ms. Beasley and J.H. used Australian Sign Language (Auslan) to communicate. All three applicants were summoned to perform jury service, and while Mr. Lockrey requested steno-captioning, Ms. Beasley and J.H. requested that Auslan interpretation be provided. They were all told that under the legislation in force, Auslan service and real-time steno-captioning would not be provided, considering that the introduction of a non-jury person in the deliberations room would be incompatible with the confidentiality of jury deliberations.

In these cases, the committee did not use the pragmatic definition of discrimination even as it recalled its jurisprudence on indirect discrimination.

> *In that regard, the Committee recalls that discrimination can result from the discriminatory effect of a rule or measure that is neutral at face value or without intent to discriminate, but that disproportionately affects persons with disabilities.*[54]

In *Liliane Gröninger et al. v. Germany*, the applicant argued that her son was discriminated against in his inclusion in the labor market. She claimed that Germany's integration subsidy to assist persons with disabilities in participating in the labor market was applicable only to "persons with disabilities whose full working capacity may be restored within 36 months." Furthermore, the subsidy could be claimed only by employers, who had to go through a complicated application process whose duration and outcome were uncertain. The scheme had the effect of deterring employers from employing persons with disabilities, including the applicant's son.

In this case of allegation of indirect discrimination, the CRPD Committee indicated that there is a place for the justification defense by using the word "may," but it did not mention the content of the pragmatic definition of discrimination.

> *The already mentioned administrative complexities put applicants in a disadvantageous position and may in turn result in indirect discrimination.*[55]

Beyond the pragmatic definition?

The committee did not use the pragmatic definition of discrimination in the three cases in which it addressed explicitly the concept of direct discrimination. In the case of *V.F.C. v. Spain*, the applicant was forced to retire from his local police officer post because he was declared "permanently and totally disabled." Although the state party explicitly invoked the pragmatic definition in defense of the differential treatment, the committee saw no need to comment on that defense and found that "the facts of the present case disclose one of the forms of discrimination prohibited by the Convention, whether it is viewed as direct discrimination or as a denial of reasonable accommodation."[56]

In the cases of *X v. United Republic of Tanzania* and *Y v. United Republic of Tanzania*, which concerned allegations of direct discrimination, the state party did not submit any observation on the merits and thus did not offer any justification. Both cases concerned applications by persons with albinism, who were attacked and who lost limbs and fingers as a result. In these cases, the CRPD Committee found direct discrimination *without entering into the consideration of whether there was any legitimate aim* for the less favorable treatment based on disability.[57]

Furthermore, in *Bujdosó et al. v. Hungary*, the committee found that the assessment of individuals' capacity on the basis of disability constituted discrimination. It did not consider any justification regarding this assessment, which automatically amounted to discrimination, most probably direct discrimination. In this case, all six applicants had intellectual disabilities and were placed under guardianship, which had the effect of automatically removing their names from the electoral register pursuant to a provision of the Constitution that was in force at the time. Therefore, the applicants could not vote in either the parliamentary or municipal elections held in 2010. The committee held that since capacity assessment amounted to discrimination, it did not make any sense to assess whether there was any legitimate aim to be achieved or whether the assessment was a proportional means to achieve the objective of the state party.[58]

Before concluding this survey of the committee's jurisprudence, it is worth considering the subset of cases that have been decided since the committee's adoption of its general comment on equality and non-discrimination on March 9, 2018. In these more recent cases, the committee has only once used the pragmatic definition, and this was in a case that turned on *indirect* discrimination (*Iuliia Domina and Max Bendtsen v. Denmark*). In three other cases, the committee made no use of the pragmatic definition in its jurisprudence. These three cases involved two direct discrimination cases (*Y v. United Republic of Tanzania* and *V.F.C. v. Spain*) and one indirect discrimination case (*J.H. v. Australia*).

Alternatives to the pragmatic definition

In light of the foregoing, we need to consider the possibility that in non-discrimination law, the CRPD and the CRPD Committee are pointing toward a new approach, which is different from the pragmatic definition of discrimination. To summarize:

- The CRPD uses an inclusive language, and its definition of "discrimination on the basis of disability" is formulated very broadly. My analysis shows that the CRPD could be interpreted as rejecting the pragmatic definition of discrimination.
- Despite explicit pressure to acknowledge the pragmatic definition in its general comment on equality and non-discrimination, the committee moved in the opposite direction, eliding passages in which the pragmatic definition was endorsed and in the end acknowledging no legal framework for defenses in relation to either direct or indirect discrimination.
- The CRPD Committee did not mention or rely on the pragmatic definition of discrimination in those three cases in which it addressed allegations of *direct discrimination*, and it did not invoke the pragmatic definition in four cases out of seven in which it addressed allegations of *indirect discrimination*.

Before concluding, we need to consider what alternatives to the pragmatic definition might be available. The following proposals can be taken either as stand-alone candidates or as a package of options.

Alternative 1: No justification in direct discrimination cases

This alternative calls for zero tolerance for any reliance on disability status as the basis for treatment that limits a person's rights or freedoms. This approach would require a new definition of direct discrimination that replaces the pragmatic definition. I propose the following candidate for an alternative definition: Direct discrimination on the basis of disability means any unfavorable treatment on the basis of disability that, because of this disability, impairs or nullifies the recognition, enjoyment, or exercise of any human right or fundamental freedom. Such treatment would admit of no justification defense. Consequently, any unfavorable treatment on this basis would automatically amount to disability-based direct discrimination.

For example, if a person is subjected to unfavorable treatment by being involuntarily admitted to a psychiatric hospital and treated coercively on the grounds of an actual or perceived impairment, this would automatically be considered as disability-based discrimination, and no justification defense would be permitted.

Neuman has described this alternative as "a rigid definition of discrimination." However, if we accept that it is a sign of the inclusive approach of the CRPD and the CRPD Committee, then it would be more appropriate to describe this alternative in a positive way. My suggestion is "the progressive definition of discrimination."

Alternative 2: Justification of reasonable accommodation, support, and accessibility measures in indirect discrimination cases

Under this alternative, if there is an allegation of indirect discrimination, the state party is invited to show that the less favorable treatment of the person with disabilities happened despite the fact that all reasonable accommodations, support, and accessibility measures were provided.

If the state party shows that the less favorable treatment had a legitimate aim and the applicant with disabilities cannot exercise their rights in question even if all reasonable accommodations, support, and accessibility measures were provided for them, then there would be no discrimination. However, if the less favorable treatment did not have a legitimate aim, or even if there was a legitimate aim but the state party did not provide the applicant with disabilities with all reasonable accommodations, support, and accessibility measures in order for the person be able to exercise their rights, it would amount to indirect discrimination.

This approach is based on those four cases of the CRPD Committee in which it addressed the issue of indirect discrimination without invoking the pragmatic definition. In these cases, the committee pointed out that the applicants were denied reasonable accommodations and supports.[59] Furthermore, this alternative seems to be in line with those examples provided under the definition of "indirect discrimination" in the CRPD Committee's general comment on equality and non-discrimination.[60]

With regard to the mental health framework, if a person is involuntarily placed in a psychiatric hospital and treated coercively on a ground that is neutral at face value, but the person can show that these interventions affected them because of their disability, then the less favorable treatment can be justified by proving that the less favorable treatment had a legitimate aim and the person with disabilities was provided with all reasonable accommodations, support, and accessibility measures in order for them be able to exercise their rights.

Alternative 3: No justification in new absolute right cases.

This alternative calls for zero tolerance for specific differential-plus-disadvantageous treatment of persons with disabilities and suggests that (1) *specific absolute rights* can be closely connected to persons with disabilities, and (2) *limitations on these disability-related absolute rights* can never be justified.

The "absolute right" approach is used by the CRPD Committee, for example, when it comes to involuntary mental health interventions. Although my paper does not address the topic of absolute rights, this alternative is indeed present in the interpretative measures of the committee.[61] For example, in its *Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities*, the committee claims that there is an absolute ban on deprivation of liberty on the basis of impairments, and thus there is an *absolute right for persons with disabilities not to be deprived of liberty on the basis of disability*.[62] In connection to the absolute prohibition of torture and cruel, inhuman, or degrading treatment or punishment (article 15 of the CRPD), the committee denies the possibility of involuntary treatment on the basis of disability.[63]

Conclusion

I started my analysis by pointing to an imperative to eliminate discrimination against persons with psychosocial disabilities. I noted that according a longstanding pragmatic definition of non-discrimination, differential treatment does not constitute discrimination if the purpose or effect of the differential treatment is to achieve a legitimate aim and if the differential treatment can be objectively and reasonably justified. Then I undertook to investigate whether this approach remains valid considering recent developments in international human rights law, especially in light of the UN Convention on the Rights of Persons with Disabilities.

My findings include the following:

- Using the VCLT to interpret the CRPD offers ambiguous results on whether the pragmatic definition of discrimination remains valid under the convention.
- The drafting process of the CRPD Committee's general comment on equality and non-discrimination shows a deliberate resistance to acknowledging the "objective and reasonable" justification defense.
- The evidence that the CRPD Committee rejects the pragmatic definition is inexplicit but considerable in direct discrimination cases and in a number of indirect discrimination cases. The evidence that the committee endorses the pragmatic definition is direct and explicit in a number of indirect discrimination cases.
- In the discrimination cases adjudicated by the CRPD Committee since its adoption of General Comment No. 6, we find a trend away from reliance on the pragmatic definition in direct discrimination cases, and hesitation to rely on the pragmatic definition in indirect discrimination cases.

Taken together, these results demonstrate that with regard to the definition of non-discrimination and associated practices for justifying differential treatment, the time has come to consider alternatives to the pragmatic definition of discrimination.

The evidence that I have surveyed in this research is not itself sufficient to answer the first-order question of human rights law—namely, whether any provision of coercive psychiatric care can avoid disability-based discrimination. But in order to address that first-order question in a legally rigorous manner, it is imperative to address the issues that have been surveyed in the foregoing: whether the "pragmatic definition" of discrimination remains valid in light of developments in 21st-century international human rights standards, and what alternative approaches might be available to replace it.

I surveyed three such alternatives above, tracing each to suggestions in the jurisprudence of the CRPD Committee and illustrating how each can be applied in determining whether coercive psychiatry is discriminatory. Under Alternative 1, coercive psychiatric interventions constitute discrimination on the basis of disability if these interventions are directly based on the disability or impairment of the person concerned. Under Alternative 2, there is scope in principle for defenses against the charge that coercive psychiatric interventions constitute indirect discrimination. Under Alternative 3, such interventions are discriminatory in nature and can never be justified.

It is not yet entirely clear in which direction the CRPD Committee's interpretation of the principle and the right to equality and non-discrimination will evolve. The committee may decide to continue using the pragmatic definition but can also replace the "objective and reasonable" justification defense with alternatives presented in this analysis or with other schemata.

I hope that this exploration of existing and potential schemata for defenses can strengthen the human rights of persons with disabilities.

Acknowledgments

Support for the research presented here was provided by the Wellcome Trust as part of its Mental Health and Justice initiative (grant number 203376/Z/16/Z). An earlier draft of this paper was presented to the Human Rights and Mental Health International Spring School at the Institute for Medical Ethics and History of Medicine, Ruhr University Bochum. I am grateful for the feedback from that audience and for comments provided by Polona Curk, Wayne Martin, Sabine Michalowski, Alex Ruck Keene, Lucy Series, and two anonymous referees for this journal.

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17. Ibid., art. 31(1) (emphasis added).

18. Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (2006), art. 1 (emphasis added).

19. See W. Martin and S. Gurbai, "Surveying the Geneva impasse: Coercive care and human rights," *International Journal of Law and Psychiatry* 64 (2019), pp. 120–121.

20. Vienna Convention on the Law of Treaties (see note 16), art. 31(1) (emphasis added).

21. Ibid., art. 32 (emphasis added).

22. Committee on the Rights of Persons with Disabilities (CRPD Committee), *Outline of the draft general comment on article 5: 12 April 2017*. Available at https://www.ohchr.org/Documents/HRBodies/CRPD/EqualityNonDiscrimination/FinalOutlineGCArticle5andNonDiscrimination.doc.

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24. Ibid., p. 4.

25. CRPD Committee, *General Comment on Equality and Non-discrimination (Article 5): First draft as at 31 August 2017*, para. 20(a). Available at https://www.ohchr.org/Documents/HRBodies/CRPD/GCArt5.docx.

26. Ibid., para. 20(b).

27. CRPD Committee (2018, see note 15).

28. Equal Rights Trust, *Written submission to the Committee on the Rights of Persons with Disabilities relating to the outline of the draft general comment on article 5* (2017), p. 4; Danish Ministry for Children and Social Affairs, *Response from the government of Denmark with regards to draft general comment on article 5 of the convention: Equality and non-discrimination* (2017), p. 2.

29. Center for the Human Rights of Users and Survivors of Psychiatry, *Comments on draft General Comment 6 on article 5, equality and non-discrimination* (2017), pp. 2–3; Inclusion Europe, *Equality and non-discrimination: Submission to the UN Committee on the Convention on the Rights of Persons with Disabilities: Draft general comment no. 6 on article 5* (2017), pp. 2, 11.

30. Center for the Human Rights of Users and Survivors of Psychiatry (see note 29), p. 3.

31. CRPD Committee (2018, see note 15), footnotes 2, 3.

32. Committee on Economic, Social and Cultural Rights (see note 7), para. 10 (emphasis added).

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34. See Office of the United Nations High Commissioner for Human Rights, *Jurisprudence*. Available at https://juris.ohchr.org/Search/Documents.

35. *V.F.C. v. Spain*, CRPD Committee, Communication No. 34/2015, UN Doc. CRPD/C/21/D/34/2015 (2019).

36. *Y v. United Republic of Tanzania*, CRPD Committee, Communication No. 23/2014, UN Doc. CRPD/C/20/D/23/2014 (2018).

37. *X v. United Republic of Tanzania*, CRPD Committee, Communication No. 022/2014, UN Doc. CRPD/C/18/D/22/2014 (2017).

38. *Marie-Louise Jüngelin v. Sweden*, CRPD Committee, Communication No. 5/2011, UN Doc. CRPD/C/12/D/5/2011 (2014), para. 8.4.

39. *Bujdosó et al. v. Hungary*, CRPD Committee, Communication No. 004/2011, UN Doc. CRPD/C/10/D/4/2011 (2013).

40. *Iuliia Domina and Max Bendtsen v. Denmark*, CRPD Committee, Communication No. 39/2017, UN Doc. CRPD/C/20/D/39/2017 (2018).

41. *Marlon James Noble v. Australia*, CRPD Committee, Communication No. 007/2012, UN Doc. CRPD/C/16/D/7/2012 (2016).

42. *H.M. v. Sweden*, CRPD Committee, Communication No. 003/2011, UN Doc. CRPD/C/7/D/3/2011 (2012).

43. *J.H. v. Australia*, CRPD Committee, Communication No. 35/2016, UN Doc. CRPD/C/20/D/35/2016 (2018).

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45. *Michael Lockrey v. Australia*, CRPD Committee, Communication No. 013/2013, UN Doc. CRPD/C/15/D/13/2013 (2016).

46. *Liliane Gröninger et al. v. Germany*, CRPD Committee, Communication No. 002/2010, UN Doc. CRPD/C/D/2/2010 (2014).

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48. *Bacher v. Austria*, CRPD Committee, Communication No. 026/2014, UN Doc. CRPD/C/19/D/26/2014 (2018).

49. *Nyusti and Takács v. Hungary*, CRPD Committee, Communication No. 1/2010, UN Doc. CRPD/C/9/D/1/2010 (2013).

50. *H.M. v. Sweden* (see note 42), para. 8.3; *Iuliia Domina and Max Bendtsen v. Denmark* (see note 40), para. 8.3.

51. *H.M. v. Sweden* (see note 42), para. 8.3; *Iuliia Domina and Max Bendtsen v. Denmark* (see note 40), para. 8.3.

52. *Marlon James Noble v. Australia* (see note 41), para. 8.7.

53. Ibid., para. 8.3.

54. *J.H. v. Australia* (see note 43), para. 7.3; *Michael Lockrey v. Australia* (see note 45), para. 8.3; *Gemma Beasley v. Australia* (see note 44), para. 8.3.

55. *Liliane Gröninger et al. v. Germany* (see note 46), para. 6.2 (emphasis added).

56. *V.F.C. v. Spain* (see note 35), paras 6.3, 8.10.

57. *X v. United Republic of Tanzania* (see note 37), para. 8.4; *Y v. United Republic of Tanzania* (see note 36), para. 8.4.

58. *Bujdosó et al. v. Hungary* (see note 39), paras 9.4, 9.6.

59. *J.H. v. Australia* (see note 43) para. 7.5; *Gemma Beasley v. Australia* (see note 44), para. 8.5.; *Michael Lockrey v. Australia* (see note 45), para. 8.5; *Liliane Gröninger et al. v. Germany* (see note 46), para. 6.3.

60. CRPD Committee (2018, see note 15), para. 18(b).

61. For an analysis of absolute rights, especially in the context of coercive care, see Martin and Gurbai (see note 19), pp. 121–124.

62. *Cf.* CRPD Committee, *Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities* (2015), para. 10.

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HHR
Health and Human Rights Journal

Safer Viewing: A Study of Secondary Trauma Mitigation Techniques in Open Source Investigations

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Abstract

Human rights investigators often review graphic imagery of potential war crimes and human rights abuses while conducting open source investigations. As a result, they are at risk of developing secondary trauma, a condition that can produce a range of cognitive and behavioral consequences, including elevated anxiety and distress, depression, and post-traumatic stress disorder. Human rights organizations have traditionally been slow to recognize the risk of secondary trauma. However, in recent years, several university programs offering students practical experience in open source human rights investigations have implemented training on secondary trauma mitigation. We administered a survey to students in these programs to determine whether they are implementing recommended mitigation techniques and to document what techniques they find helpful. From 33 responses, we identified six general practices as helping mitigate secondary trauma: processing graphic content, limiting exposure to graphic content, drawing boundaries between personal life and investigations, bringing positivity into investigations, learning from more experienced investigators, and employing a combination of techniques. We also identified recommendations for institutions to protect the right to health of investigators and to support secondary trauma mitigation, both through frequent training and through practices such as labeling graphic content and emphasizing self-care. The article concludes with areas for future research.

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Competing interests: None declared.

Introduction

As technology improves and social media platforms grow, people living in conflict zones are increasingly posting video and photographic documentation of human rights violations online. This audio and visual documentation allows investigators to view events they were never physically present for and to study footage of these events from multiple viewpoints. With audio-visual documentation, investigators can independently verify suspected human rights violations or war crimes by geolocating footage, ascertaining approximate time and date, identifying perpetrators and weapons, and confirming casualties and physical destruction. This process of identifying, collecting, and analyzing open source information—information that is publicly available and attainable by anyone—is known as "open source investigation."[1]

In recent years, international tribunals, United Nations bodies, and nongovernmental human rights organizations—ranging from large groups such as Amnesty International (Amnesty) to smaller groups such as the Syrian Archive—have assigned individual staff members or entire teams to conduct digital open source investigations.[2] Today, Amnesty maintains one of the largest open source investigation programs, known as the Digital Verification Corps (DVC). Established in 2016, the DVC comprises more than 100 student volunteers from the University of California, Berkeley (UC Berkeley); University of Cambridge; University of Essex; University of Hong Kong; University of Pretoria; and University of Toronto. Students receive training in open source investigation and verification methods and assist Amnesty researchers in monitoring and documenting human rights violations.[3]

Digital open source investigators scour the internet for information relevant to their investigations. They source information from blogs and websites; reports and other digital documents; user-generated content; digital photographs, videos, and audio recordings; satellite imagery, maps, and geospatial data; and information contained in internet archives and databases. While this audio-visual documentation may be a goldmine of information, it can also serve as a trigger for secondary trauma. Witnessing traumatic events on screens poses mental health risks, as the American Psychiatric Association has recognized.[4] Digital open source human rights investigators are only beginning to recognize the scope of these risks and how to mitigate them.

Background

Secondary trauma refers to a range of trauma-related stress reactions and symptoms that may result from exposure to graphic details of another individual's traumatic experience. There is no single, agreed-on definition of secondary trauma, and the Diagnostic and Statistical Manual of Mental Disorders does not define or discuss secondary trauma, vicarious traumatization, compassion fatigue, or other related terms. The term "secondary trauma" is used broadly in this paper to encompass a range of cognitive and behavioral changes one may experience from indirect trauma exposure.[5]

The cognitive and behavioral changes that can result from secondary trauma include elevated levels of anxiety and distress, depression, post-traumatic stress disorder (PTSD), sub-threshold PTSD (multiple symptoms of PTSD that do not rise to levels sufficient for a PTSD diagnosis), and fundamental changes to world views.[6] According to Sam Dubberley, the head of Amnesty's DVC, secondary trauma can lead to "changes in social and occupational functioning or to thoughts of harming oneself or others. All of these changes are cause for concern, and thoughts of harm should prompt an investigator to seek immediate support."[7]

Studies have found high rates of secondary trauma in psychologists and other helping professions, such as police, emergency medical workers, crisis workers, and religious leaders.[8] While there is comparatively less literature on secondary trauma in the human rights field, this area of study has grown in the past five years. In 2015, two studies on mental health and well-being in the human rights field were published. An online survey-based study examined rates of depression, PTSD, and sub-threshold PTSD among human rights workers and found that 19.4% of respondents met PTSD criteria, 18.8% met criteria for subthreshold PTSD, and 14.7% indicated probable major depression.[9] An interview-based study examining mental health effects of traumatic content on human rights workers and journalists found that 44% of human rights and humanitarian respondents reported high or very high "personal adverse effects"—feelings of isolation, flashbacks, nightmares, and other stress-related symptoms—as a result of their work, while 25% reported high or very high "professional adverse effects."[10] Three recent studies have also examined occupational and personal factors that affect one's ability to mitigate the negative mental health impacts of traumatic content, as well as human rights organizations' responses to mental health and well-being needs.[11]

These studies have identified potential risk factors for secondary trauma and recommended a range of techniques to help mitigate these risks. Recommendations include strategies for reviewing content, such as working in groups or next to colleagues, taking breaks, not working late at night, prohibiting work from bleeding into personal life, and limiting exposure to graphic images and sounds.[12] Recommended community support techniques include talking about work with colleagues, supervisors, family, friends, and counselors; bonding with colleagues outside of work; and reflecting on the impact and positive aspects of work.[13] Recommended self-care practices include meditation and mindfulness, regular exercise, adequate sleep, and limited exposure to graphic or disturbing materials outside of work.[14]

However, until now, no study has assessed whether these mitigation techniques are effective in preventing the onset of secondary trauma. To fill this gap, we designed this study to identify what mitigation techniques open source investigators self-report as useful or unproductive, and why. Our hope is that this study can contribute to improving health outcomes for human rights researchers who put their health at risk to carry out their work.

Methodology

We developed a survey to examine the perceived efficacy of secondary trauma mitigation techniques recommended by previous studies. The primary goal of this study was to see whether investigators were implementing the training they had received on secondary trauma, and to understand what they found helpful, what they found unproductive, and why. The broader purpose of this research is to improve and ensure the protection of human rights researchers' own health and human rights. The study was designed to be a preliminary study on perceived efficacy, which could pave the way for future empirical research on the efficacy of mitigation techniques. The study did not seek to identify rates of secondary trauma among respondents.

The survey was sent to students who had participated for at least one semester in a digital open source human rights investigation program at UC Berkeley, University of Cambridge, University of Essex, University of Hong Kong, University of Pretoria, or University of Toronto. These university programs provide students with an opportunity to work on open source human rights investigations with Amnesty's DVC and other clients.[15] The programs all also instruct students on mitigation techniques to reduce the risk of developing secondary trauma, teach students to recognize signs of secondary trauma, and provide resources on how to cope with traumatic content.[16]

Between August and October 2019, we used an online tool to conduct our survey. Students were asked 46 questions covering the training they had received on secondary trauma mitigation and whether they found certain techniques helpful. Questions were based on mitigation techniques identified in literature on secondary trauma in the human rights field, discussed above, and recommended in trainings students received. The survey produced quantitative data from yes/no responses to questions about whether students employed a certain technique. It also produced qualitative data from open-ended questions about why students found a certain migration technique useful or unproductive. The authors can provide the survey upon request.

Quantitative survey data were analyzed in Excel to provide demographic statistics. Qualitative survey data were analyzed using a conceptual content analysis approach. Concepts to code for were identified based on quantitative survey results and through an iterative process of reading open-ended survey responses. Concepts were coded for frequency and for both explicit and implicit references.

The Committee for the Protection of Human Subjects at UC Berkeley approved this study on June 28, 2019, under protocol number 2019-03-12007.

Results

Out of approximately 160 students who received the survey link, 33 responded. Twenty-six respondents were from UC Berkeley, three from University of Toronto, two from University of Pretoria, one from University of Cambridge, one from University of Essex, and none from University of Hong Kong. Twenty-two respondents identified as female, 10 as male, and one as non-binary. The average age of respondents was 23.4 years, with the youngest being 19 and the oldest being 48. Respondents had spent between one and seven semesters with their university's open source investigation program, while the average number of semesters was 2.7.

The study examined three categories of secondary trauma mitigation techniques: (1) strategies for reviewing content, (2) community support techniques, and (3) self-care practices. In general, respondents said they were more inclined to implement strategies for reviewing content than to seek community support or implement self-care practices. Quantitative and qualitative data on each of the three categories are discussed in detail below.

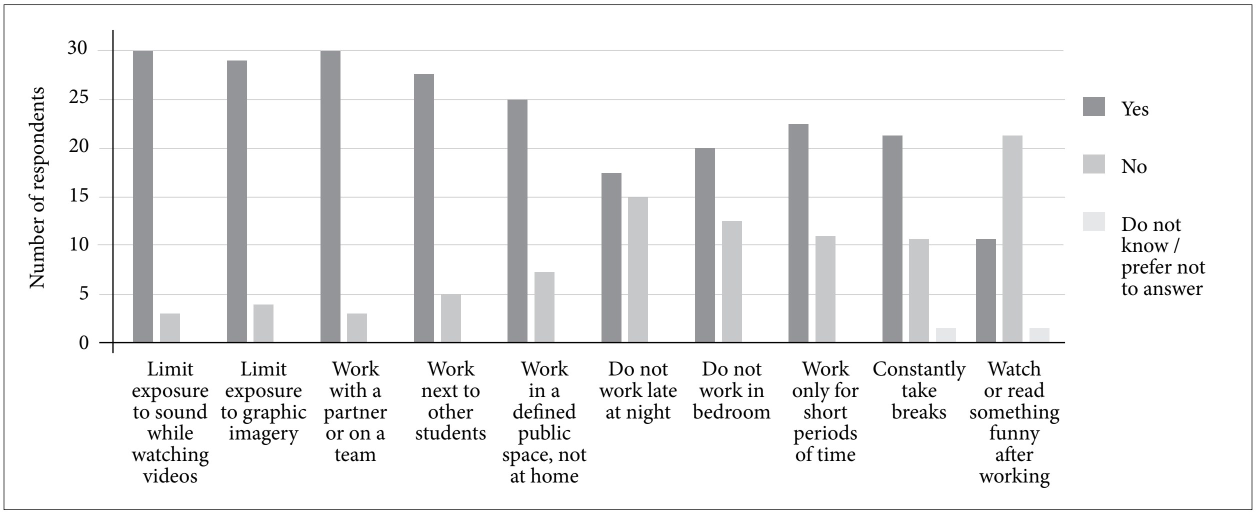
Strategies for reviewing content

The survey asked students about 10 strategies for reviewing graphic or potentially traumatic content. Nine of the strategies were implemented by a majority of respondents, while one strategy was less frequently implemented. Figure 1 illustrates responses for all 10 strategies.

Two questions focused on limiting exposure to potentially traumatic content. The majority of respondents (n=30, or 90.9%) said they followed the recommendation of limiting exposure to sound while watching graphic videos. Many respondents explained that turning off sound helped reduce the emotive impact of graphic content and that they muted videos unless they were actively listening to audio for verification purposes. One respondent added that sound was more "stimulating" than visual content, as it had the effect of making it "seem like you're there at the moment of the video." Some respondents added that they listened to music while they worked, rather than listening to the audio content.

The majority of respondents (n=29, or 87.9%) also said they followed the recommendation of limiting exposure to graphic imagery, such as by avoiding unnecessary exposure, minimizing win-

FIGURE 1. Strategies for reviewing content



dows with graphic imagery, and reducing the size of graphic images on screens. Many respondents said that reducing the display size of graphic content helped limit its impact, as did focusing on the corner of an image and using peripheral vision to assess content. Some respondents also said they reduced overall exposure to graphic content by stopping videos before graphic content appeared or by watching graphic content only when "absolutely necessary." One respondent said that limiting overall exposure to graphic content helped keep her in the right "frame of mind." Another respondent stressed the importance of labeling graphic content in advance, as it would limit surprise and allow investigators to "steer clear" of extremely graphic material. Similarly, one respondent said she clicked through individual frames before watching a video so as to prepare herself in advance of viewing disturbing images.

However, some respondents said they did not limit exposure to sound (n=3, or 9.1%) or graphic imagery (n=4, or 12.1%) because doing so was not always possible. Audio content can have valuable information that contextualizes images and can thus be important to listen to. Oftentimes it is also necessary to view images in full resolution in order to identify landmarks for geolocation and obtain other "vital information" for verification. One respondent said it was particularly difficult to avoid graphic content while doing discovery (searching for documentation online) but that he would prepare himself in advance to reduce the surprise of encountering graphic content.

Three questions asked respondents about techniques relating to where and with whom they conducted human rights investigations. The majority of respondents said they implemented recommendations of working with a partner or team (n=30, or 90.9%), working next to other students (n=28, or 84.8%), and working in public spaces around other people (n=25, or 75.8%). Respondents explained that working in groups or next to others created a sense of community and offered opportunities to discuss material, which helped with processing content. Others explained that having someone next to them was helpful, even if they were not collaborating, as it made them realize they were not alone. Working with a partner also helped "distance" themselves from the "immediacy" and "shock" of graphic content. Others stressed the importance of having a designated physical space to work in with others, with one stating, "when we leave, we leave the work in the room."

However, some respondents said they did not work with a partner or team (n=3, or 9.1%), work next to other students (n=5, or 15.2%), or work in public spaces around other people (n=8, or 24.2%). Some explained that they did not find these recommendations helpful, as working next to others could be counter-productive or distracting. Others said that practical challenges, such as scheduling conflicts, prevented them from implementing these recommendations. Some respondents discussed strategies they employed to mitigate the risks of working alone, when forced to do so. For example, one respondent would set a timer and announce, "Ok, I'm starting to work on [project name] now, I'll stop in X hours." The respondent explained that the verbal and auditory signals helped set boundaries—when the timer went off, the work was over. One respondent also expressed concern over the risks associated with working in public—public internet connections may be insecure, and working in public can unnecessarily expose others to graphic content.

Two survey questions focused on recommendations to not let work bleed into personal lives. The majority of respondents said they followed recommendations of not working late at night (n=18, or 54.5%) and not doing work in their bedroom (n=20, or 60.6%). In explaining why they found these recommendations useful, respondents emphasized the need to separate their "investigative life" from their "private life." Respondents stressed the importance of dissociating their work from their home life, as they did not want to associate it with traumatic material that could potentially consume their lives. One respondent said that while the separation of work and home was important when working on graphic content, it was less important when looking at non-graphic content such as corporate documents.

However, a significant minority of respondents said they did work late at night (n=15, or 45.5%) and in their bedroom (n=13, or 39.4%), largely because of practical considerations. Deadlines could force people to work late into the night, especially students, whose daytime hours are often filled with classes and other obligations. The lack of a defined workspace for students also posed challenges. One respondent explained that she worked in her bedroom because she lived far from campus. Another respondent lived in a one-room apartment and had no choice but to work in the bedroom. Four respondents said they worked late at night only if they took additional precautions such as making sure they were not particularly tired, leaving time to unwind before going to bed, and working with someone else.

Regarding the length of time students worked on investigations, the majority of respondents said they worked only for short periods of time (n=22, or 66.7%) and regularly took breaks (n=21, or 63.6%). Several respondents said these practices helped them avoid getting "bogged down" watching graphic content and helped reduce stress. However, a significant minority of respondents said they did not follow recommendations to work only for short periods of time (n=11, or 33.3%) or to regularly take breaks (n=11, or 33.3%). Some respondents explained that they got "caught up in" or "lost in" the work and simply forgot to take breaks. Others explained that working for short periods of time or taking breaks was less productive, as it made them less engaged and caused them to lose their train of thought.

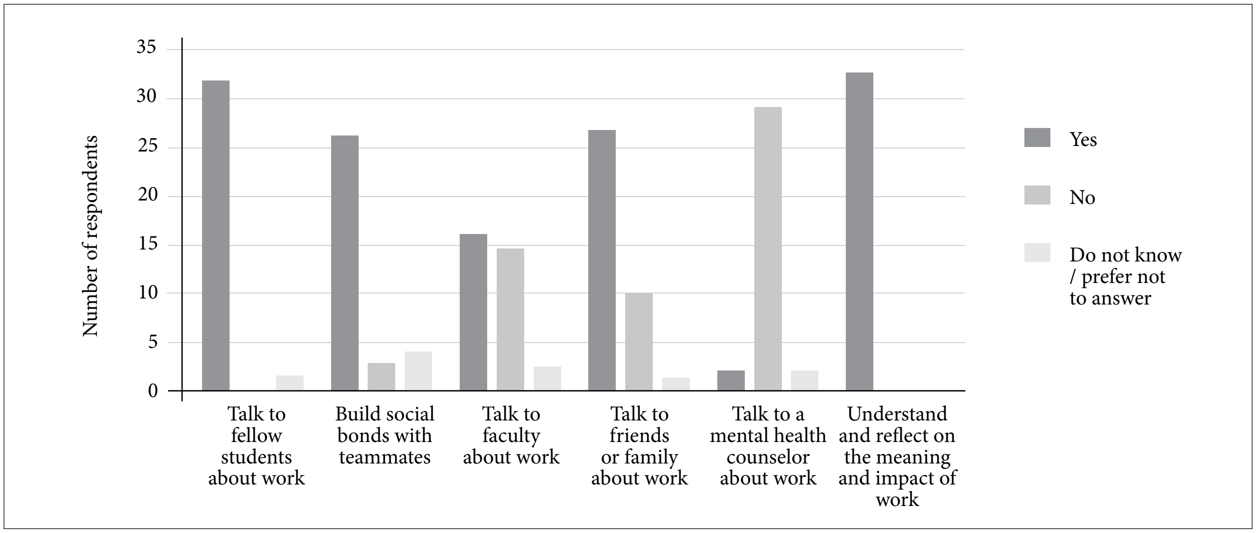
A majority of respondents (n=21, or 63.6%) said they did not use distraction techniques, such as reading or watching something funny after working or during breaks. Two respondents explained why. One said that interrupting investigations with social media or funny content risked collapsing leisure activities with "hard or mundane" investigations work; scrolling through Facebook for fun, after scrolling through Facebook for investigative content, risked emotionally conflating the two activities and rendering Facebook unenjoyable in personal life. Another respondent explained she did not want to use mindless content to dissociate from the work, as she did not want to trivialize the people who had suffered from a terrible event.

Community support techniques

The survey asked students about six community support techniques for mitigating the risk of secondary trauma. Three techniques were reported as popularly implemented, while two had mixed implementation, and one had rare implementation. Figure 2 illustrates responses for all six techniques.

Two survey questions focused on team-building and social bonds among teams. The vast

Figure 2. Community support techniques



majority of respondents (n=32, or 97.0%) said they followed recommendations of talking to fellow students about their work. Many explained that this helped them process information, provided relief, and reassured them of the importance of their work. Many respondents further explained that talking to teammates helped create a sense of understanding, trust, and empathy. Some respondents said that talking with teammates brought positivity and humor to their work, which helped create a more lighthearted work atmosphere. This was particularly true when speaking with team leaders or more experienced students who could provide additional insight and new perspectives. Some respondents noted that discussing graphic content and mental well-being with team members was useful, as it reduced feelings of being alone. Some respondents recommended having structured resiliency check-ins within teams. One respondent said that bringing snacks to team meetings helped facilitate bonds, as it became a collaborative effort and helped make meetings "fun," even if the work was hard.

The majority of respondents (n=26, or 78.8%) said they followed the recommendation of building social bonds with teammates outside of work. This practice helped facilitate better collaboration, improved team support, fostered a collective sense of progress, and prompted reflection on the purpose of their work. Some respondents said that building friendships with teammates helped them look forward to team meetings, as they were like "getting together with friends to work on something important." This made graphic content "easier to bear" and reduced feelings of being alone.

About half of respondents (n=16, or 48.5%) said they implemented the recommendation of talking to faculty about their work. Two respondents said they found it particularly helpful to talk to professionals about resiliency, as hearing about real-world experiences helped drive home the importance of self-care. However, half of respondents (n=15, or 45.5%) said they did not talk to faculty. One respondent explained that while they would have liked to talk to faculty more, it was difficult finding time to connect.

A majority of respondents (n=22, or 66.7%) said they talked to friends or family about their work, while a significant minority (n=10, or 30.3%) said they avoided doing so as they believed their family and friends would not understand their work. One respondent added that discussing traumatic content with family and friends was not useful, as their displays of shock, horror, and dismay were more "performative" than empathetic. Some respondents explained they could not talk to family and friends about their work because of its confidential nature.

The vast majority of respondents (n=29, or 87.9%) said they did not talk to a professional mental health counselor about their work. In explaining why, many respondents said they remained resilient using other mitigation techniques and did not need professional help. Some respondents viewed counseling as a last resort, saying they had not sought mental health care because they had not experienced any "serious traumatic episodes." One respondent added that wait times for accessing mental health care posed an additional barrier. Only two respondents (n=2, or 6.1%) said they spoke to a professional counselor about their work. Two respondents explained they previously did not feel a need to talk to a professional but had recently changed their minds.

All respondents (n=33, or 100%) said they followed the recommendation of reflecting on the meaning of their work. Many respondents explained that reflection helped motivate them to continue, even when work was difficult. One respondent added that reflection helped reduce feelings of being overwhelmed by the large amount of content she had to work though. One respondent explained that reflection was an important ethical practice, while another said she found it helpful to receive explicit thanks or congratulations for her work.

Self-care practices

The last category of mitigation techniques was self-care practices to reduce the risk of secondary trauma. Although implemented by many respondents, this set of mitigation techniques was the least popular. Figure 3 illustrates responses for the four self-care practices that students were asked about.

Three survey questions focused on self-care practices that students would engage in when working with graphic content. Roughly half of respondents said they meditated or practiced mindfulness (n=15, or 45.5%), exercised (n=18, or 54.5%), and slept more (n=19, or 57.6%). Some respondents explained that meditation helped center them, cleared their minds, and reduced anxiety. Respondents also said that sleep and exercise helped increase energy levels. However, roughly half of respondents said they did not meditate or practice mindfulness (n=18, or 54.5%), exercise (n=14, or 42.4%), or sleep more (n=14, or 42.4%), explaining that they did not have enough time or did not find these practices useful. On meditation in particular, some respondents remarked that they had not found it useful, as it stressed them out or they could not stop their mind from wandering. One respondent said that sleeping more felt unproductive, while another found exercise too stressful.

The final survey question asked if respondents limited exposure to sad or graphic content outside of work. Roughly half (n=17, or 51.5%) said they implemented this recommendation. Some respondents explained that continuous exposure to graphic content outside of work could increase the risk of secondary trauma during work, and they consciously limited exposure to graphic media, films, and other content outside work. One respondent noted that after starting to work on human rights investigations, media coverage of war or violence evoked stronger emotions than it had previously.

However, roughly half of respondents (n=16, or 48.5%) said they did not limit exposure to sad or graphic content outside of work. Many respondents explained that they conducted human rights investigations because they cared about current events and human rights issues, and they did not want to limit consumption of this information and feel less connected to these issues. Some respondents said they found it important to read the news and remain aware of events happening outside their work. Some respondents also explained that it was not practical to limit exposure to sad or graphic content, as they studied that content in their coursework. However, many respondents said they watched sad or graphic content cautiously and only when "necessary."

When asked whether they took other personal actions to mitigate the risk of secondary trauma, respondents provided a list of activities they found useful. This list included cooking, spending time in nature, playing music, and watching positive and inspiring content. One respondent said she took time to study the culture of the region their team was working on, so as to view those affected by violence as a "whole" rather than reducing them to their "oppression and suffering."

Discussion

Open source human rights investigations, especially those involving graphic content, can be difficult for investigators. However, the survey results demonstrate that investigators are employing

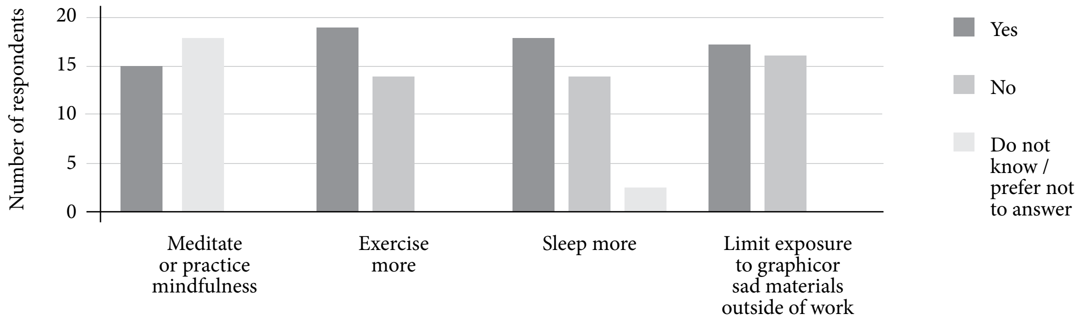


Figure 3. Self-care practices

techniques to reduce the impact of graphic content and mitigate the risk of secondary trauma. Overall findings on mitigation techniques are discussed below, focusing on which techniques appear to be most effective and what institutions can do to support investigators.

Successful mitigation techniques

Six general takeaways on mitigation techniques emerged from the study. First, investigators need to process graphic materials and information with individuals who understand the work they do. It is also important that they develop ways of reflecting on the meaning of their work, which, in turn, will help them process graphic material and stay motivated. Working in teams is also critical. Teamwork offers opportunities to discuss challenges that will undoubtedly emerge in an investigation and reduce feelings of isolation. When possible, investigators should also strive to build community with teammates by spending time together on activities separate from their investigations. Many respondents explained that they preferred to process their work with people who shared a common understanding—teammates, faculty, or professionals in the same field—rather than processing with family, friends, or counselors outside of work.

Second, limiting exposure to graphic content is important and can be practiced in numerous ways. Setting limits includes taking breaks, working for shorter periods of time, muting audio, reducing the size of graphic imagery, focusing on the corner of a graphic video, or clicking through video frames to prevent surprisingly graphic content. Many respondents noted that reviewing audio and visual content was more emotionally impactful than reviewing written content, suggesting that exposure to these mediums in particular should be limited. Some respondents also noted the importance of reducing exposure to graphic content in their personal lives.

Third, investigators need to draw boundaries between human rights investigations and their personal lives. Investigators should have access to a distinct physical space for working (for example, a common space or office) to prevent work from bleeding into their personal lives. They should also avoid mixing too much of their personal lives into work and maintain a life outside of their investigations work.

Fourth, it is important to bring positivity into human rights investigations. While investigators need to set boundaries between their private lives and investigative work and respect the dignity of those affected by the violations they are investigating, establishing such a boundary does not mean they should avoid creating a lighthearted working atmosphere with their teammates. Supervisors, in particular, should be aware of the importance of giving positive feedback to investigators by thanking and congratulating them for work completed. Supervisors and investigators alike should learn about the political, social, and cultural lives of the communities affected by the human rights abuses or war crimes they are investigating. This can include inviting individuals from affected communities to speak to a team or having team members give presentations on a community's cultural practices, such as food, musical traditions, or sports activities.

Fifth, investigators need to receive guidance from more experienced human rights investigators and other professionals to gain insight and perspective. Respondents said they found talking with faculty and area experts useful. Equally important was hearing about resiliency from human rights professionals who have conducted investigations in war zones or other extreme situations.

Sixth, not every mitigation technique will work for everyone and every type of work. Investigators have different work styles, process graphic content differently, and have different relaxation needs. In addition, different projects may also call for different mitigation techniques. Investigators should explore a variety of mitigation techniques to determine what works best for them. Investigators should also implement a range of mitigation techniques and continue to adjust techniques throughout their careers, being mindful of how personal changes or particular investigations may demand different techniques.

Institutional support for implementing mitigation techniques

The survey findings discussed above also suggest ways institutions can support investigators—whether students or staff—to mitigate secondary trauma, through both training and the implementation of techniques. Institutions that employ or train individuals to conduct human rights research—including universities, nonprofit organizations, courts, and tribunals—have both practical and ethical responsibilities to protect the health of those engaged in such activities. If institutions ask individuals to put their health at risk by conducting this type of work, they must help mitigate the negative health impacts of that work.[17]

Institutions should train investigators on a variety of mitigation techniques, as not all will be adopted by or work for every person or project. During training, instructors should identify practical challenges that may impede implementation of a mitigation technique and train investigators on how to overcome those challenges. Universities should consider practical challenges that students may face because of their class schedules, living and working arrangements, and financial situations. Institutions should also consider and inform investigators of possible risk factors associated with implementing mitigation techniques, such as the risks of insecure internet connections and exposing others to graphic content when working in public. Most importantly, training on mitigation techniques should not be a one-off activity but should take place during the breadth of an investigation. Consistent attention to resiliency strategies will help ensure that investigators remain well-versed in mitigation techniques throughout their work.

In addition to training, institutions should support investigators in implementing secondary trauma mitigation techniques in a variety of ways. Institutions should establish procedures for flagging graphic content—labeling images and videos as "graphic" or "very graphic," and providing some indication of the type of content (for example, sexual violence or murder)—so that investigators can prepare themselves before viewing such material. Institutions should also enable investigators to separate their work and personal lives. This can be done by ensuring that investigators have the time and physical space to do their work in a way that will not infringe on their personal lives. Institutions should also ensure that investigators can access mental health professionals familiar with human rights investigations, to ensure that access is not a barrier to needed mental health care. Finally, institutions should underscore the importance of self-care and of taking time off from investigative work. This may include providing ample opportunities for breaks, allowing for flexible work schedules and locations, and offering opportunities for staff to engage in entertaining activities that may help build a sense of mutual support and community.

Limitations

The survey was designed to reduce potential bias and other threats to its viability. Nevertheless, possible limitations must be acknowledged. First, the data set is limited to 33 responses. This sample size is not large enough to draw statistically significant conclusions. Second, the study does not have equal representation from all universities included in the study; more than three-quarters of respondents were from UC Berkeley. Third, the responses are not from a representative sample of students participating in each university's program. The sample was not randomized; respondents were a self-selecting group that may be more attuned to issues of secondary trauma than other students or may vary from norms in other ways. Fourth, the survey does not account for differences in secondary trauma training among respondents, which results from variation in training practices between universities, variation in the number of semesters that respondents have participated in programs, and the degree to which respondents paid attention to trainings. Fifth, the study does not consider prior trauma exposure, prior exposure to or use of mitigation techniques, or preexisting mental health issues, which are potential confounding factors. Finally, the study does not account for intensity, duration, or recency of exposure to traumatic content, all of which are additional potential confounding factors.

Given these limitations, this study cannot conclusively identify which mitigation techniques do and do not work. However, the study is helpful for viewing recommended mitigation techniques in a practical light, formulating hypotheses on what works, and identifying areas for further research.

Future research

This study provides the first systematic glimpse into the adoption and potential efficacy of secondary trauma mitigation techniques in student-led open source human rights investigations. But it provides only a glimpse. We have much more to learn, and it is our hope that additional studies and research will follow with the aim of making online human rights and war crimes investigations as safe and effective as possible.

Future research should explore specific findings from this survey, which mitigation techniques are most useful for different types of investigations, and changes in the implementation and success of mitigation techniques over time. Studies should examine why and in what contexts investigators favor community support techniques over self-care practices such as meditation and exercise. Research should also explore why reflecting on the impact and meaning of work is helpful, as all respondents indicated its usefulness but few explained why. Future research should also explore which specific audio and visual techniques work best for reducing exposure to graphic content, and which other self-care practices might be helpful.

Future studies should include deployment of a survey similar to the one used in this study but should administer the survey to a larger and more representative sample of human rights investigators, so as to determine in a statistically significant manner which mitigation techniques are most often used and most helpful. Additional interviews with survey respondents could explore open-ended answers provided in survey responses, to better understand the reasons why certain mitigation techniques are more or less useful. Future research could also include longitudinal studies to explore changes in secondary trauma mitigation techniques over time and to determine the extent to which these techniques are successful in improving well-being in the medium to long term. Longitudinal studies could be deployed through repeat surveys and interviews, or by conducting an ethnographic study within an institution, following select investigators over a period of months or years. Longitudinal studies could include psychometric tools to measure PTSD, depression, and self-efficacy before and after the implementation of mitigation techniques, to more objectively test efficacy of techniques.

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Health and Human Rights Journal

Tuberculosis Care in Mexico's Chiapas Highlands Region: A Right to Health Analysis

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Abstract

This article analyzes the fulfillment of the four essential and interrelated elements of availability, accessibility, acceptability, and quality (AAAQ) presented in General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights. We examined the ways that AAAQ criteria are met in tuberculosis (TB) care by evaluating a sample of 33 primary health care units (PHCUs) in 10 municipalities of the Chiapas Highlands region of Mexico. We collected information about 56 people with TB who were treated in those PHCUs, the structural conditions of the health facilities, and data about all health care workers in the PHCUs (n=423). Our results show that there is great variability in how AAAQ criteria are met among the PHCUs and in the way that TB care programs are delivered. Resource shortages and infrastructure characteristics hinder the fulfillment of AAAQ elements despite the commitment made by Mexico to guarantee the right to health as outlined in General Comment 14.

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Competing interest: None declared.

Introduction

The high incidence and prevalence of tuberculosis (TB) in a population can reveal a long history of poverty, exploitation, exclusion, and the obstruction of human rights.[1] In Chiapas, Mexico, as in many other places in the world where TB is persistent, a common characteristic among TB patients is their disempowerment and failure to recognize and demand their rights. Medical care is focused on tackling the biological aspects of the disease, with poor practical consideration of its social determinants. This, together with frequent shortcomings in diagnosis and treatment, hinders rights fulfillment for patients and their families, an essential element of full recovery.

The Mexican state is constitutionally bound to recognize and guarantee all human rights contained in the international treaties that it has ratified, including the International Covenant on Economic, Social and Cultural Rights.[2] Even though General Comment 14 of the United Nations Committee on Economic, Social and Cultural Rights is not legally binding, it provides an authoritative interpretation of the scope and meaning of the right to health.[3] In particular, it identifies the availability, accessibility, acceptability, and quality (AAAQ) of health services as essential elements of the right to health and provides guidelines for duty bearers to follow in their efforts to realize the right to the highest attainable standard of health.[4]

This paper analyzes the ways that AAAQ criteria are met in Mexican TB care efforts by evaluating primary health care facilities and services in the Chiapas Highlands region. The Mexican Secretariat of Health's 2013–2018 Specific Action Program for TB Prevention and Control assists health services in providing practical and consistent TB care throughout the country. It is based on Official Mexican Standard NOM-006-SSA2-2013 (NOM-006) for the prevention and control of TB. Both of these standards must be followed in all public, social, and private health care establishments.[5]

Two fundamental features of a human rights-based approach in a study are its intention and purpose—that is, the use to which the information yielded by the study will be put. Structure, process, and outcome indicators can provide useful information about specific populations, territories, and periods of time to measure a state's compliance with its human rights obligations.[6]

In this research project, we sought to identify the merits and shortcomings of Mexican health care institutions and health workforce in the fulfillment of the right to health. In order to address human rights accountability and transparency, we also used information that is routinely gathered by the national TB program.

Methods and instruments

In Chiapas, a mainly rural state with a population of 5,217,908 people, 77.1% of residents live in poverty, the highest rate among Mexico's 32 states.[7] Chiapas is also home to 12 of Mexico's 58 recognized indigenous groups.[8] These social determinants possibly contribute to Chiapas's higher TB incidence rate (24.7/100,000 in 2016) compared to the national incidence rate (17.3/100,000).[9]

Our study focused on primary health care units (PHCUs) within Sanitary Jurisdiction No. 2 of San Cristóbal de Las Casas, Chiapas, which oversees public health care services in the 18 municipalities of the Chiapas Highlands, 13 of which are categorized as very highly marginalized and 4 as highly marginalized.[10] Sanitary Jurisdiction No. 2 has the second-highest prevalence of TB of the 10 jurisdictions in Chiapas. However, official figures on TB incidence and prevalence are likely underestimates, as there have been reports of high numbers of subnotification and underdiagnosis in Chiapas, especially in the highlands.[11] Given the socioeconomic and health conditions in the region, it is probable that the pulmonary TB incidence rate is as high as 276/100,000 in the Chiapas Highlands, as found in other regions of Chiapas.[12]

We chose PHCUs as the study unit because the achievement of health program goals depends both on the performance of the health workforce and the infrastructure and resources in each PHCU.[13] Of the 119 PHCUs in the studied region, we used a randomized technique to select 33 units with sociopolitically secure conditions and a capacity to respond to our study questions. Of these, 10 PHCUs were in municipal capitals and 23 were in rural communities.

We used four instruments to collect data: (1) a structured questionnaire that examined the functioning and structure of each PHCU; (2) a checklist concerning TB care supplies and materials; (3) a health care personnel survey that gathered information pertaining to job position, sex and gender, ethnic group, and training in the topics of TB, interculturality, and gender; and (4) a TB patient information form that gathered clinical and socioeconomic data for patients diagnosed between January 2017 and June 2018 in each PHCU. These instruments were examined and validated by a group of experts on human rights and experts on TB prevention and control programs. Our indicators on AAAQ criteria were developed using NOM-006 and the 2013–2018 Specific Action Program for TB Prevention and Control as guidelines. Our indicator on physician and nursing personnel per 1,000 people in each PHCU was calculated by dividing the number of physicians and nursing staff in each PHCU by the total population targeted by each PHCU.

We used the health secretariat's public electronic registries to locate the total target population of each PHCU.[14] We carried out our fieldwork between July and November 2018. For data capture and analysis, we used IBM SPSS Statistics version 21.

Our study was approved by the Research Ethics Committee of El Colegio de la Frontera Sur in San Cristóbal de Las Casas, Chiapas.

Results

Our study collected information from 30 PHCUs and 423 health care workers in these facilities. Three PHCUs were closed on four different attempts to gather information and were considered nonrespondent. Thirteen PHCUs that had provided services to people with TB between January 2017 and June 2018 were regarded as "treating PHCUs." There were 56 people diagnosed with and registered as having TB by the treating PHCUs during the study's time frame.

Availability

Realization of the right to health requires that health care facilities, goods, services, and programs be available in sufficient quantity.[15] We assessed availability by verifying the existence of specific medical supplies, infrastructure, and resources to provide proper care for TB patients.

In the case of pulmonary TB, the diagnostic protocol begins with sputum collection. All sputum samples collected at the PHCUs undergo a smear test at the Sanitary Jurisdiction No. 2 TB laboratory in San Cristóbal de Las Casas, Chiapas. Table 1 summarizes the availability of supplies and infrastructure required to obtain sputum samples and transport them to the Sanitary Jurisdiction No. 2 TB laboratory.

Although 83.3% of PHCUs had at least one available jar for sputum collection, only 36.7% of PHCUs had ten or more jars. Considering that three samples are needed for smear tests for each person tested, when PHCUs have fewer than ten jars, only three people with respiratory symptoms can be tested until more jars are available.

The storage temperature of sputum samples may not affect positivity in smear tests, but mycobacteria growth in cultures may be lower when samples are stored at room temperature.[16] PHCUs with coolers, ice packs, and a thermometer are more likely to get sputum samples to the TB laboratory in optimal conditions.

Supply shortage or unavailability, inadequate infrastructure, and lack of transportation may delay TB diagnosis and the initiation of treatment, which is a major problem for TB control and prevention programs in low- and middle-income countries.[17]

In addition, we analyzed the availability of resources in each PHCU for the clinical assessment, treatment, and follow-up of people with TB (Table 2).

Adequate infrastructure and safe water are necessary components in health care facilities. The availability of potable water is identified in General Comment 14 as an underlying determinant of health that must be present in functioning public health-care facilities, and it is important for the administration of directly observed therapy short-course (DOTS).[18] However, only 46.7% of PHCUs had it. Furthermore, in pulmonary TB care, the consultation office must be adequately illuminated and ventilated to prevent contagion of other patients and health personnel.[19] In 30% of the PHCUs, consultation offices did not have adequate ventilation.

The use of surgical masks by respiratory symptomatic people in waiting areas is a preventive action to avoid the spread of infection within PHCUs. Such masks were routinely provided in only 60.6% of PHCUs, even though they were available in 93.3% of them.[20]

Guidelines and manuals are necessary so that health personnel in primary and rural settings can manage and comply with all protocols and programs. The NOM-006 was available in 83.3% of PHCUs and the TB procedures manual for nursing personnel in 50%.

Any person suspected of having TB, as well as people already diagnosed with it, should be tested for HIV and diabetes.[21] All of the PHCUs had the necessary material for diabetes detection and glucose level assessment; however, 50% of the units did not have rapid HIV-testing methods available for TB patients.

A monthly clinical evaluation is also required for every person with TB who is undergoing treatment.[22] All of the PHCUs had a functioning scale to weigh patients, and all but one had a stethoscope.

Five treating PHCUs had completed treatment for TB patients included in this study before the fieldwork was carried out. In eight PHCUs, at least one person was undergoing DOTS at the time of the study, but only two of these PHCUs had all of the medications needed to complete the treatment for each patient. Five PHCUs had no more than a one-week medication supply because they obtained medications on a weekly basis from the Sanitary Jurisdiction No. 2 TB Program, when health workers reported on patient follow-up. One treating PHCU did not have any TB medication because the medical intern assigned to that unit was on leave for two weeks and had not left collection instructions.

Our assessment of health worker availability was based on indicators published by Mexico's National Council for the Evaluation of Social Development Policy in 2018. In 2014, there were 0.88 general and family physicians per 1,000 population.[23] Of the 27 PHCUs that provided us with data, two-thirds had fewer physicians than this. The mean of general and family physicians per 1,000 population in the 27 PHCUs was 0.68 (CI 95%: 0.41–0.96).

In 2015, there were an estimated 2.8 nurses per 1,000 people at the national level.[24] In our study, 92.6% of the 27 PHCUs that responded to this question had fewer nurses than this, with a mean of 1.5 nurses per 1,000 people (CI 95%: 0.80–2.2).

The DOTS nursing network in Mexico was created in 2003 with the purpose of improving detection coverage, treatment follow-up, and quality

TABLE 1. Availability of supplies for sputum collection for TB diagnosis

Materials and infrastructure	Availability in PHCUs (%) (n=30)*
Specimen jars	83.3
Labels for specimen jars	96.7
Markers for the labeling of specimen jars	80
Laboratory request form	96.7
Complete materials for initial sputum collection: jars, labels, markers, and request form	66.7
Portable cooler, ice packs, and thermometer	46.7
Refrigerator for the storage of sputum samples	36.7
Transportation to Sanitary Jurisdiction No. 2	26.7
N-95 respirators	6.7
Well-ventilated, illuminated, and roofless open space for the gathering of sputum samples	70
PHCUs with all of the elements	0
PHCUs with none of the elements	0

*Three PHCUs did not provide information of care.[25] It aims to have at least one nurse participating in network activities in every PHCU in the country.[26] In our study, only 15 PHCUs had a nurse in the DOTS network.

In Mexico, medical and nursing students must complete a year of social service in PHCUs.[27] When medical and nursing interns were excluded from health workforce calculations, the means lowered from 0.88 to 0.45 (CI 95%: 0.22–0.67) and from 1.5 to 0.93 (CI 95%: 0.53–1.3), respectively. This suggests that PHCUs are dependent on health workers in training to provide essential primary health services, even though they may not have the expertise to diagnose and treat patients with TB.

Accessibility

Accessibility refers to people's ability to seek and obtain health care.[28] There are four overlapping and complementary dimensions of accessibility: physical access, financial access (affordability), access to information, and non-discrimination.[29]

Physical accessibility. Physical accessibility means that everyone must be able to safely reach health facilities, goods, and services. This includes adequate access to buildings for people with disabilities and those who are vulnerable or marginalized.[30]

Geographic accessibility is estimated by the distance, measured by the time taken using the usual means of transport, between the attendant population and the health facility.[31] The mean time-distance between each PHCU and the furthest communities they serve was 70.38 minutes (CI 95%: 37.4–103.3), based on data from 26 (78%) of the PHCUs. In two other units, health workers knew the distance in kilometers (2 and 12 kilometers) but could not give a time-distance estimate. One PHCU provided health care services directly in each of the five locations it served, and one PHCU functioned as an open service unit and did not have a target population or geographic limits. The other three PHCUs had no available information.

There was adequate access to buildings in 16 units (53.5%), assessed by the presence of a functional ramp or the absence of steps or ladders.

Economic accessibility. Payments for health care should be based on the principle of equity, ensuring that they are within economic reach of the entire population and that poorer households are not dis-

TABLE 2. Availability of supplies for TB care, treatment, and follow-up

Materials and infrastructure	Availability in PHCUs (%) (n=30)*
Consultation office with adequate illumination and ventilation	70.0
Physical or electronic copy of the Official Mexican Standard NOM-006-SSA2-2013 for TB control and prevention	83.3
Physical or electronic copy of the TB procedures manual for nursing personnel	50.0
Surgical masks for respiratory symptomatic subjects	93.3
Stethoscope	96.7
Glucometer, lancets, and glucose test strips	100.0
Weighing scale	100.0
Rapid HIV tests	50.0
TB diagnostic and follow-up registry notebook	45.5
Potable water	46.7
PHCUs with all of the elements	6.1
PHCUs with none of the elements	0.0
Treating PHCUs with complete TB treatments (in the eight units that were administering directly observed therapy short-course at the time of the study)	25

*Three PHCUs did not provide information proportionately burdened with health expenses.[32]

In Mexico, people with TB are entitled to free care in the public health system, including all medications under the DOTS strategy, medical consultations, X-rays, and other diagnostic tests. If the person with TB is not affiliated with a public health program, they are enrolled in "popular insurance," which covers all costs within public health units. None of the 33 PHCUs solicited payment for medical consultations, and none of the people with TB was charged for medication, treatment of adverse effects of DOTS, medical consultations, or follow-up. Free lab tests and X-rays are performed in the Jurisdictional Laboratory and in the Ministry of Health public hospital San Cristóbal de Las Casas. When these services are unavailable in these institutions, patients must obtain them in the private health sector (our study did not inquire if these services were available at the time of the study). According to the information provided by health personnel, none of the PHCUs gives aid to cover the costs of private lab tests or X-rays, and even though health personnel recalled that some patients had used private services, we were unable to gather the exact details, as such information was not registered in patients' clinical records.

Costs related to transportation, lodging, or meals that patients incur when seeking TB care are not covered by Mexico's public health services. Of the 13 treating PHCUs, only 5 had given some form of assistance to cover transportation expenses: 4 PHCUs had ambulances and had helped with free transportation to San Cristóbal de Las Casas for patients; another PHCU delivered DOTS directly to a patient at their home. There was no financial support for lodging near the PHCU where DOTS was administered for people who had to stay overnight. Three PHCUs gave advice to people to use the shelters in San Cristóbal de Las Casas if they required accommodation there, five PHCUs gave patients food supplies, and three provided vitamin B supplements.

Even if there are no direct costs for medications and clinical examinations, a health service cannot be considered fully financially accessible if patients cannot afford the indirect costs.[33] In resource-poor settings, illness imposes high direct and indirect cost burdens on patients and their families; equipment shortages for TB diagnosis, follow-up, and treatment, a low number of health facilities, and the understaffing of PHCUs all contribute to such cost burdens.[34] In Mexico, TB programs do not consider the economic burden that TB imposes on patients, and public health services have no financial assistance program aimed at covering indirect costs for TB patients, such as transportation, lodging, and nourishment.

Information accessibility. Adequate access to information refers to the capacity to seek, obtain, and divulge information and ideas related to health issues.[35] Health workers are responsible for providing appropriate information to people with TB to help them understand the disease, the importance of compliance with treatment, and preventive measures.[36] In the Chiapas Highlands, information is needed in the indigenous languages of Tsotsil and Tseltal, as well as in Spanish.

Physicians or nurses who could convey health information in Tsotsil or Tseltal were categorized as bilingual health professionals in our study. In total, 28 PHCUs (93.3%) had a bilingual health professional; these bilingual professionals were general physicians (licensed or interns) in 3 (10%) of the PHCUs, and licensed or intern nurses in 25 of the PHCUs. Two PHCUs reported that they did not have any health workers who spoke Tsotsil or Tseltal. Ten people with TB in our study (17.9%) did not speak Spanish; nine of them had information translated to them by nurses, and one received care in a PHCU without any bilingual health professionals.

Within the Sanitary Jurisdiction No. 2 coverage area, each community has at least one health promoter, appointed by that community's assembly, who serves as a liaison between the PHCU and the community. The health promoter receives a symbolic monthly payment of 250 Mexican pesos (about US$11) by the public health system as an incentive to undertake the role. Their duties include the translation of health information to people who do not speak or read Spanish.

Our health care worker survey found that only seven PHCUs referred to these community health promoters as part of the workforce. The two PHCUs mentioned above that had no health workers who spoke Tsotsil or Tseltal also had no health promoters in their workforce. Further research into the role of health promoters and their interactions with both health workers and TB patients would be helpful to assess their contribution to the fulfilment of the right to health.

Our health care worker survey found that 73 (17.3%) of the 423 workers surveyed could translate health information. Of these, 5 (6.8%) were licensed medical physicians, 25 (34.2%) were licensed nurses, 12 (16.4%) were nursing interns, 3 (4.1%) were primary health care technicians, 24 (32.8 %) were health technician assistants (people with basic level education who have received a two-month training in rural hospitals to be certified for this position), and 4 (5.5%) were either administration, maintenance, social work, dentistry, or psychology professionals.

People with TB who do not speak Spanish may receive a different standard of TB care and treatment than those who do speak the language, depending on whether there are health personnel in the PHCU who speak Tsotsil or Tseltal and on the level of education and training among those health workers. Language is a known barrier in health care and in TB prevention and control in intercultural contexts.[37]

Breaches of the right to access to information in TB care may lead to misunderstanding of the disease, which in turn results in poorer control and prevention efforts, social discrimination, and stigma. It can also lead patients to delay their search for care, diagnosis, and treatment, which further perpetuates disease transmission and increases the likelihood of treatment failure or death.[38] The consequences of stigma can be greater among women than among men because women are more likely to live in poverty and to be worse off in terms of the social determinants of health. In this sense, stigma exacerbates the loss of spousal, family, social, and economic support.[39]

Non-discrimination. Non-discrimination is a core human rights principle. Health services, goods, and facilities must be accessible to all, especially the most vulnerable or marginalized groups, without any form of discrimination.[40]

Our study found that services were denied to specific people or groups in 10 PHCUs. In five (16.7%) of these, people who were not affiliated with any form of public insurance ("popular insurance" or the Prospera Program) were not admitted for consultations; in four, complying with the PHCU management guidelines, service was denied to people who were not part of that PHCU's target population, or to people who had been drinking alcohol. One PHCU, acting on instruction of the authorities of the host community, denied care to a group of families who had settled near the unit after having been displaced from their territory due to social conflicts.

The PHCUs' consultation times also represented barriers to care: only 19 PHCUs (57.6%) received patients throughout the entire workday; 11 (33.3%) limited their consultation hours or set a maximum number of consultations that could be conducted in a day. As a result, some patients are turned away from the PHCUs and are rescheduled or asked to arrive earlier another day. This makes access difficult for people who live far away from the PHCU or who need to be attended to promptly.

The absence of ramps in 46.5% of the PHCUs impedes physical accessibility and discriminates against people with physical disabilities.[41]

Regulations in public or private organizations that prevent the equal exercise of rights to all groups in society are a form of institutionalized discrimination.[42] This, in turn, results in health inequities between social groups, further impeding fulfilment of their right to health.[43]

Acceptability

Health facilities, goods, and services must be respectful of medical ethics and provide culturally acceptable services for all people, all genders and ages.[44]

Twenty PHCUs (66.7%) stated that certain population groups did not attend the unit. The non-attending groups included members of the Zapatista National Liberation Army (EZLN) (seven

PHCUs), members of other autonomous organizations (two PHCUs), families whose customs and religions allow healing only through prayer or rituals (five PHCUs), people who are not affiliated with any public health program (three PHCUs), families who do not cooperate in the organization of the community's health services (one PHCU), families of traditional authorities (one PHCU), families who oppose vaccination (one PHCU), and men (two PHCUs). The health personnel we interviewed listed a number of reasons for this lack of attendance:

- *rejection of state-provided health services as a form of civil resistance*
- *poor perception of health care services*
- *long travel distance to the PHCU*
- *cultural factors, such as beliefs in supernatural causes and treatments of diseases, as well as gender roles, such as women not being allowed out of their homes without a male companion*
- *conflicts between communities*

Among these 20 PHCUs, 7 carried out open workshops or distributed information about TB to the groups who did not attend their facilities. This was an indicator of the PHCUs' efforts to increase acceptability. However, according to the health personnel we interviewed, the groups at whom these actions were directed remained unwilling to seek the facilities' health care services.

The 2013–2018 Specific Action Program for TB Prevention and Control acknowledges the importance of culturally appropriate and gender-sensitive service delivery, as well as the need for all health workers to undergo relevant training in the context of TB care.[45] In the year preceding our study, 22% (92/423) of health workers had undertaken gender training and 42.6% (180/423) had attended trainings on interculturalism. Further research into the content and impact of training would be helpful to assess whether it enhances the acceptability of TB care.

People may describe health services as acceptable if the services satisfy their culturally determined priorities.[46] In Chiapas, many people self-medicate using traditional remedies, which may delay the diagnosis and treatment of TB and promote its spread.[47] This makes the need to identify culturally appropriate ways of providing effective clinical care ever more important.

Quality

We evaluated the provision of TB care through process and result indicators.[48] Active case seeking must be performed among all respiratory symptomatic, vulnerable, and high-risk populations (such as people in prisons, asylums, or shelters; migrants; people who use drugs; alcoholics; people with diabetes; immune-compromised people; and indigenous groups).[49] All PHCUs provided services to at least one high-risk group; 7 PHCUs (21.2%) identified these groups and undertook systematic screening, 14 PHCUs (42.4%) did not, and 9 PHCUs (27.3%) did not identify any risk groups among whom to do systematic screening. Pulmonary TB case identification in all respiratory symptomatic people was fulfilled in only 15 PHCUs (50%).

TB diagnosis among respiratory symptomatic people requires the analysis of three seriated sputum samples.[50] In 22 PHCUs (73.3%), health personnel requested, but did not always obtain, three sputum samples from each person with suspected pulmonary TB.

Between January 2017 and June 2018, 56 people were diagnosed with TB and registered in the surveyed PHCUs. Table 3 summarizes their classification upon admission. Two of these individuals are not included, as both died before starting treatment.

In Mexico, people undergoing TB care must have a complete medical record that complies with NOM-004-SSA3-2012.[51] We reviewed the records of the 54 TB patients outlined in Table 3 to verify whether their age, sex, ethnic group, and HIV and diabetes type 2 status were registered (Table 4).

Not all people with TB had their HIV or diabetes status recorded. Even if each patient's co-morbidities are known by health workers, information may be lost if it is not recorded. The loss of information makes it difficult to guarantee continuity in treatment and follow-up; this is particularly important in light of the frequent health personnel turnover in the studied PHCUs.

Complete clinical records are necessary for health systems to analyze morbidity and mortality, the quality of care, patients' socioeconomic status, and risks, as well as to conduct follow-up and contact studies. Such information is also necessary for health promotion and planning, as well as accountability.[52]

Of the 54 patients who began TB treatment, 20 had finished their treatment and were registered as cured with laboratory confirmation (11 women and 9 men); 6 finished treatment with clinical recovery but no laboratory confirmation (1 woman and 5 men); 5 patients died during treatment (1 woman and 2 men without a registered cause; 1 woman from TB; 1 woman from another cause); 1 man had a failed treatment; 1 woman was transferred to another PHCU during treatment; 1 man discontinued treatment, and 1 man had finished treatment but had no final classification. These numbers place treatment success at 74.3%, which is lower than the goal of 86% set in the Specific Action Program for TB.[53] The remaining 19 patients were still undergoing treatment when our study ended.

People classified as cured by clinical or laboratory findings must undergo sputum sample screening every six months for the following two years.[54] Fifteen TB patients were classified as cured at least six months prior to the gathering of information (6 women and 9 men). Of these, 8 had undergone at least one sputum smear test as follow-up to a finished treatment (4 men and 4 women); the other 7 cases lacked registered follow-up information.

Discussion

Insufficient supplies for collecting sputum samples, personnel shortages, and the lack of systematic screening hinder the timely detection of TB and, as a result, epidemiologic surveillance. Newer, more accurate methods of diagnosis (such as GeneXpert MTB/RIF) are more expensive and require more sophisticated equipment, infrastructure, and health worker training than sputum smear tests, which means that they are not available in regions such as Chiapas. Cheaper sputum smear tests remain the routine method of TB diagnosis, despite their known limitations. In addition, the difficulty of recruiting trained health workers to remote regions limits TB case follow-up, contact studies, and active case seeking in areas of high incidence. These challenges help explain the underreporting of TB in remote states such as Chiapas.[55]

The failings in the fulfillment of the right to health in Chiapas highlight the challenges faced in

TABLE 3. Patients with TB: Classification upon admission to treatment

Classification	Pulmonary		Extrapulmonary		Total
	Female	Male	Female	Male	
New case	19	22	4	4	49
Re-entry	0	2	0	0	2
Relapse	0	1	0	0	1
Transferred from another facility	0	1	0	0	1
Incomplete data	0	1	0	0	1
Total	19	27	4	4	54

TABLE 4. Registration of TB patients' age, sex, ethnic group, and HIV and diabetes status

	Total patients registered (n=54)	Registered males (n=30)	Registered females (n=24)
Age	54 (100%)	30 (100%)	24 (100%)
Sex*	42 (79.2%)	23 (82.6%)	19 (76.7%)
Ethnic group	32 (59.3%)	15 (50.0%)	17 (70.8%)
HIV status	46 (85.2%)	24 (80.0%)	22 (91.7%)
Diabetes type 2 status	43 (79.6%)	22 (73.3%)	21 (87.5%)
All five indicators registered	27 (50%)	12 (40%)	15 (62.5%)

*In the 12 cases where the sex was not registered, health personnel reported it verbally.

achieving the goals outlined in the global End TB Strategy.[56] The first and foremost challenge is the explicit incorporation of the strategy's principles into Mexico's TB program and the way it is implemented in Chiapas. In Chiapas, government accountability, monitoring, and evaluation are based on reports that do not reflect the real epidemic (principle one). There are also few coalitions between organizations and communities centered around TB prevention and care (principle two). Further, the protection and promotion of human rights, ethics, and equity is mentioned only marginally in the 2013–2018 Specific Action Program for TB Prevention and Control and is not explicitly incorporated into the program's activities. In practice, human rights—specifically the right to health—are being neither guaranteed nor protected by the different duty bearers that provide TB care (principle three). It would thus seem that the global strategy and targets are not being observed in Chiapas.

Accountability calls for duty bearers to have dynamic and meaningful dialogues with rights holders and public servants about their actions or omissions to fulfill their rights obligations.[57] Mexico's health sector has lacked accountability due to two main factors. First, public health reports and information are not presented to the general population, meaning that citizens are unable to monitor or evaluate duty bearers' actions. Second, in the best-case scenario, bodies such as the Secretariat of the Civil Service base their evaluations on the use of resources and not on the impact of health programs and activities of the health sector.

Under international law, states have legal obligations to realize human rights. One function of national human rights institutions is to monitor the acts of commission or omission by the state regarding its duty to respect, protect, and fulfill economic, social, and cultural rights, and its specific obligations to not discriminate and to adopt measures to progressively realize these rights. Periodic monitoring of the indicators used in our study could provide a useful tool for this purpose. The information shared by health workers, patients, and users of the services could become a relevant contribution to the improvement of services and to the enhancement of platforms to increase the enforceability of the right to health.

Study limitations

Our study had several limitations. Insecure conditions resulted in a reduction of the number of PHCUs that could be included. In addition, clinical files and registries were often unavailable or incomplete. Further, there was a lack of knowledge in some PHCUs about the way that TB care was provided, and in some PHCUs, the personnel we interviewed were unaware of their facility's structure and availability of supplies, which resulted in multiple visits to several PHCUs, limiting our time and research funds.

Conclusion

Our evaluation of AAAQ in Chiapas's PHCUs found that these four criteria are not fully achieved in TB care, despite the commitment made by Mexico to guarantee the right to health as described in General Comment 14.

Even though TB care varied across the PHCUs we studied, in general, TB programs were inadequately implemented due to a scarcity of supplies (such as materials for sputum sample collection, rapid HIV tests, and complete TB treatments), personnel shortages, patients' inability to assume the indirect costs of care, discrimination, and a lack of systematic screening among high-risk groups. These aspects may be considered violations of the right to health because they impede the adequate prevention, diagnosis, and treatment of the TB patients.[58] The low treatment success rate (74.3%) reflects the poor quality of TB care.

TB programs require more explicit and specific integration of AAAQ indicators, because even if they had been completely and correctly implemented in all PHCUs, there would still have been shortcomings in the AAAQ elements for two main reasons. First, TB programs do not consider the indirect economic burdens that patients face when obtaining TB care. Second, relevant guidelines do not consider the needs of specific populations, such as rural, indigenous, or isolated communities, which, in Chiapas's multicultural context, hinders the fulfillment of acceptability.

Finally, inadequate access to information, along with physical inaccessibility, discrimination, stigmatization, and lack of consideration of social, cultural, and economic factors that affect the care-seeking behavior of people with TB form combined barriers whereby the unfulfillment of one AAAQ element relates to shortcomings in the others.[59]

Acknowledgments

We thank the health care personnel of the Sanitary Jurisdiction No. 2 in San Cristóbal de Las Casas, Chiapas, for their participation in our study.

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HHR Health and Human Rights Journal

PERSPECTIVE

Sleep Deprivation of Detained Children: Another Reason to End Child Detention

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Introduction

The US administration's "zero tolerance" policy has ushered in an escalation of mass detention of immigrants in the United States. In its present iteration, this system processes children without sufficient numbers of personnel with pediatric medical training or who can recognize life-threatening conditions. This same system also detains increasing numbers of children for longer periods of time without trauma-informed pediatric physical and mental health oversight. Since September 2018, at least seven children have died in US government custody or immediately after being released.[1] This provoked nationwide concern that led to the exposure of unsanitary and dangerous conditions in border patrol facilities holding hundreds of migrant children in Texas.[2] In *Flores v. Barr*, attorneys representing detained migrant children successfully argued that the government violated the "safe and sanitary" standard of the 1997 *Flores* settlement agreement based on recent evidence of horrific conditions in US Customs and Border Protection holding cells.[3] Conditions cited included lack of facilities for bathing, sleep surfaces of concrete floors instead of beds, overcrowding, cold temperatures, aluminum blankets as the only source of warmth, and constant illumination.

We wish to call attention to a specific inevitable and inhumane consequence of child detention—sleep deprivation—as yet another reason to end child detention altogether. As part of the ruling in *Flores v. Barr*, the 9th Circuit Court of Appeals upheld a district court ruling that inadequate conditions for sleep are included in the violation of the definition of "safe and sanitary" conditions. Such violations are ram-

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Competing interests: None declared.

Funding source: There was no specific support for this project. Dr. Ijadi-Maghsoodi is supported by funding from the National Institute on Drug Abuse of the National Institutes of Health under Award Number K12DA000357 and the UCLA Pritzker Center for Strengthening Children and Families.

pant. Border Patrol holding cells are illuminated 24 hours per day and do not have beds. They are referred to as *hieleras* (iceboxes) given their frigid temperatures. Sleeping mats and actual blankets are only inconsistently provided. As a result, children frequently attempt sleep in freezing rooms with constant illumination on concrete floors with aluminum blankets as the only coverage for warmth. Family detention centers are no better. There, children stay in rooms with non-related adults and are routinely woken up for head counts at night and in the early morning. In one family detention center, the Berks County Family Residential Center in Pennsylvania, an official bed check policy occurs every 15 minutes throughout the night. Findings from interviews with families and staff at the Berks facility, as detailed in an amicus brief filed in support of the Pennsylvania Department of Human Services, revealed grave concern about the effects of this practice of sleep deprivation.[4] Families detailed how children at Berks exhibited mental health and behavioral problems associated with sleep deprivation, such as withdrawal from family members, self-injurious behaviors, and suicidal ideation.[5]

As physicians, public health professionals, and human rights advocates who care for children, we call for all practices that cause sleep deprivation within detention facilities to stop immediately. Sleep deprivation, whether resulting from intentional practices or as the unintentional consequence of inappropriate environments, is inhumane. It is associated with long-term physical and mental health morbidity, which we argue compounds the harms and trauma of detention. While halting such practices is the appropriate first step, the Department of Homeland Security must urgently prioritize alternatives to detention to minimize or eliminate entirely the detention time of any one child. In this perspectives piece, we expand on the negative health effects of sleep deprivation, explore how such practices in other contexts are considered a form of cruel, inhumane and degrading treatment, and offer recommendations for action by child and adolescent health providers and policy makers.

Mental and physical health effects of sleep deprivation and the compounding effects of detention

Quality sleep is integral to the health and development of infants and children.[6] Mental health markers generally known to correlate positively with appropriate sleep include improved attention, behavior, learning, memory, and emotional regulation. As would follow, insufficient or poor quality sleep has negative impacts on normal cognitive and neurobehavioral function, such that children with sleep disruption commonly experience problems with memory recall, behavioral regulation, and attention-related disorders.[7] Furthermore, while sleep deprivation has a known reciprocal association with depression and anxiety, sleep deprivation independently predicts an increased risk of suicidal behavior.[8] One study of 779 Palestinian adults found that sleep disturbances were associated with worsening post-traumatic stress disorder symptoms and intensified severity of anxiety-related disorders.[9] This worsening of symptoms is especially harmful for detainees who have a high likelihood of experiencing trauma in detention, thus compounding the trauma that forced them to flee their home countries in the first place.

Chronic sleep deprivation also has significant physical health consequences. Observed associations between sleep disruptions and negative cardiometabolic health outcomes include the development of diabetes and obesity in children and adults, suggesting sleep's important role in modulating insulin and hunger-related hormones.[10] Sleep deprivation is additionally associated with endothothelial dysfunction, hypertension, inflammatory states, changes in autonomic tone, and hormonal dysregulation, all known risk factors for the development of cardiovascular disease.[11]

While the potential harms caused specifically by sleep deprivation are worrying in their own right, they further compound other harms inherent in the practice of detaining children. In an American Academy of Pediatrics policy statement, cited studies noted that detained immigrant children experienced developmental regression, poor psychological adjustment, high rates of post-traumatic stress disorder, anxiety, depression, suicidal ideation, and other behavioral problems.[12]

Inhumane treatment of children

Intentional sleep deprivation is internationally denounced as a form of torture or cruel, inhumane, and degrading treatment, including as a form of prisoner abuse practiced by the US government in Guantanamo Bay.[13] Several US federal courts characterize sleep deprivation as torture when inflicted by *other* countries. The *Flores* settlement agreement requires children to stay in the least restrictive settings possible, but mandatory bed checks, lack of access to normal diurnal patterns of light and darkness, shared sleeping facilities, and inhospitable temperature regulation are all characteristic of highly secured facilities, rather than "least restrictive" settings.[14]

The detention of children and its direct association with sleep deprivation conflicts with child rights standards, which state that the best interests of the child must be the primary consideration in all actions involving children.[15] Intentionally holding children for prolonged periods in conditions where they will be unable to obtain the recommended amount of healthy sleep is unnecessary, harmful, and violates the right of children to be treated humanely.

Recommendations

As clinicians and asylum experts who conduct and organize physical and psychological evaluations for youth asylum seekers, we call for the cessation of all practices—intentional or otherwise—that lead to sleep deprivation of detained immigrant children. We ask policy makers, regulators, and detention facility managers to cease all unnecessary bed checks, provide reasonable darkness or dimmed lighting in sleep areas, and ensure full access to warm blankets, beds, or sleeping mats, and pillows. The trauma caused by detention itself, the structural limits of family detention centers whereby multiple families are forced to share rooms, and the procedures in place—such as the night-time "bed checks"—make the adequate and high-quality sleep necessary for normal child development impossible. Furthermore, beyond the lack of quality sleep, these very practices of bed checks, inhospitable temperatures, and constant lighting can be severely re-traumatizing for youth who have fled situations of abuse, neglect, and risk to their life.

The inhumane conditions of pre-detention holding facilities and detention centers and the lack of comprehensive pediatric care cause significant health risks. Unfortunately, the last year has borne witness to the most extreme form of such risk—the death of detained children from preventable causes. Thus, the most appropriate step is to stop detaining immigrant children altogether. The appropriate alternative to detention is to transfer children and families to community settings through proven case-management approaches. Such approaches ensure compliance with immigration proceedings and facilitate expanded access to health care, legal assistance, education, housing, and other essential services.[16] With the transfer of children and families to community settings, trained pediatric medical providers can play an integral role in caring for these children and families, including coordinating care across multiple service sectors. Experts in child development, pediatricians, child mental health clinicians, and family physicians will be instrumental in calling for such alternatives to detention and creating appropriate child-centered programs and resources as part of these models.

Lastly, those interacting closely with previously detained children and families in the community—clinicians, child welfare and social service workers, attorneys, teachers, and school staff—should be aware not only of the harmful effects of detention but also of the lesser known effects of sleep deprivation. Such awareness is critical to be able to appropriately care for these families in the community. Ongoing effects of detention and sleep deprivation—such as insomnia and fear at night, worsening of post-traumatic stress disorder symptoms, poor concentration and performance in school, and irritability and depression—may continue to plague youth and affect functioning long after detention. Future studies should assess the mental and physical health consequences of the combination of sleep deprivation and detention in children.

Conclusion

During this time of mass detention, it is increasingly important for all clinicians, policy makers, and advocates who work with children to understand the trauma and health risks that children and families face through pre-detention and detention, including experiences such as sleep deprivation, to mitigate the acute and chronic effects of trauma experienced by these youth and families. Clinicians have a crucial role in bringing attention to these cruel practices and their health and mental health effects in order to stem the long-lasting damage being inflicted on this generation of children. Detention of a child inflicts profound short- and long-term harm, and its use for thousands of children as standard policy of the US government should end. In the short term, practices in detention centers that deprive children of sleep should cease immediately. Detainees must have access to warmth and to a safe sleep environment.

The content and views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the US Department of Veterans Affairs, the National Institutes of Health, or the United States Government.

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BOOK REVIEW

Why Prosecution Is Not the Go-To Tool to Secure Human Rights

MARGE BERER

Beyond Virtue and Vice: Rethinking Human Rights and Criminal Law, edited by Alice M. Miller and Mindy Jane Roseman, University of Pennsylvania Press, 2019.

This multi-authored book, edited by Alice M. Miller and Mindy Jane Roseman, raises questions about when and why human rights defenders promoting sexuality, reproductive, and gender-based rights as human rights are increasingly calling for the use of criminal law as an enforcement mechanism. Its aim is to explore the silence surrounding what they see as a fraught relationship between human rights and criminal law, arising out of a profound distrust of state power and its misuse, while at the same time hoping that greater use of the criminal law can and will reduce human rights abuses. The title of the second chapter succinctly expresses the main conundrum explored in the book: "How prosecution became the go-to tool to vindicate rights."

It is above all a book that challenges and questions some of the ways human rights are being pursued today—and deserves to be known widely. The introduction and 14 chapters address prostitution, sex laws, violence against women, relations of gender and sexuality, illegal abortion, sex selection, and, unexpectedly, clothes. There are reflections on the definition and role of harm reduction, offenses against morality, and unequal treatment under the law, and on how to achieve justice. The toughest issue the book raises is how to achieve human rights in practice. It concludes that given how many abuses arise from the application of criminal law, criminal law will not deliver human rights, but nor can we do without criminal law.

The book is dense politically and linguistically. The authors (from all world regions) hail from the academic disciplines of history, law, public health and anthropology, and from activist roles in women's rights, gay rights, sex workers' rights, HIV, and constitutional law—with connections to the human rights movement. The chapters include legal analysis, essays, interviews, first-person accounts and self-reflective critiques.

The introduction goes into depth on the primary conflict between two pursuits: (1) constraining the abuse of human rights and critiquing the administration of criminal justice, and (2) calling on state power in the fields of health, housing, and education to fulfill their social, economic, and political duties in order to remedy and reduce harm arising from human rights abuses and denial.

Part I covers specific aspects of transnational theory and practice. While the use of criminal law to regulate sex, gender expression, and reproduction is nothing new, the involvement of human rights in responding to these *is* new, arriving in the past 20 or so years, via social movements. Calls to liberalize and decriminalize (for example, sex outside marriage, the consensual sale of sex for money and goods, and abortion) occur alongside calls for greater criminalization and more prosecution (for example, of gender-based violence, sexual violence, rape and rape in marriage, sexual abuse of children, and sex trafficking).

The purpose of criminal law is to punish for doing harm, which itself is intended to inflict pain through the loss of freedom and even the death penalty. Thus, criminals are also harmed through punishment. This calls for caution and an awareness of the contradictions involved in hurting those who have hurt others.

The book aims to identify (1) the "guiding conditions and rules of engagement for human rights advocacy and practice in expanding or limiting recourse to criminal law"; (2) the perils of both over- and under-regulation in efforts to promote decriminalization; and (3) the effects of criminal law and regulations on diverse groups of people, especially "marginalized populations who are often unrecognized as victims of crimes."

The range of issues covered is impressive, and the whole is worth reading. I will focus here on the chapters and examples that made the biggest impression on me.

In the chapter featuring an interview by Janet Halley with Aziza Ahmed, Ahmed argues that feminists have turned to the international criminal justice system in large numbers because it promises to use force to eliminate serious wrongs. Yet prosecution, conviction, incarceration, and the death penalty hand the state and the international criminal justice system "a monopoly over legitimate force." Yet, in fact, "the criminal law doesn't end much of anything"—certainly not violence or sexual violence against women, for example. It has at times also created new problems, such as courts wrongly equating non-consensual sex trafficking with the consensual sale of sex, which is highly controversial. This is the first of several chapters that stresses the lofty goals of criminal law versus its flawed and often discriminatory application.

Alice Miller with Tara Zivkovic look at this from another angle. It was hoped that if implemented from a rights basis, criminal law would stop being used for the repression of rights and the morality-based regulation of behavior, instead turning toward harm reduction and rights protections. In the spheres of gender, sexuality, and reproduction, this has led to some definite successes—that is, progressive law reforms and judicial decisions and greater public understanding of the issues. It has also motivated recent generations of activists to support and demand bodily autonomy in its many forms.

On the other hand, Miller and Zivkovic provide examples of how the reliance on criminal law to right wrongs has had negative consequences. For example, in the late 1980s, sexual violence became a subject of primary focus for many women's rights advocates, culminating in wide-ranging demands for justice at the 1993 World Conference on Human Rights in Vienna. Prosecution became the primary tool recommended—both for prevention and to end the impunity of violations. Increased prosecutions were seen as key evidence of a commitment by states to equality. Expanding the state's obligations in this way, however, also leads to expanding the power of the penal state—a two-edged sword.

Alli Jernow's chapter opens by describing the important role played by John Stuart Mills' *On Liberty* (1859) in the United States and the Wolfenden Report (1957) in the United Kingdom as seminal statements on the sovereignty of the individual over their own mind and body when it does no harm to others. *On Liberty*, Jernow says, carried the "harm principle" from philosophy into legislative guidance and later into the courts, most famously in cases decriminalizing sodomy and other criminalized forms of sexual relations. The Wolfenden Report argued that society should not use the law to equate the sphere of crime with the sphere of sin. Instead, there must remain a realm of private morality and immorality that is not the law's business, if there is an absence of harm.

Jernow analyzes what happened in courts in the USA, UK, South Africa and India, and in the European Court of Human Rights, when "the harm principle met morality offenses" in relation to privacy, personal autonomy, and the regulation of sex and gender. These courts all reacted differently. No human rights body has as yet declared that safe, legal abortion is a human right. Why? Because instead of focusing entirely on the harms of unsafe abortion to women, for example in *A, B and C v. Ireland* in 2010, the European Court of Human Rights focused on the harm to the "life" of the embryo or fetus *as balanced against* the pregnant woman's health, bodily integrity, and privacy.[1] However, the Convention on the Rights of the Child makes it clear that the "right to life" begins at birth, and points up the way in which morality, conservative religion, and the failure to fully recognize women's rights still support ongoing restrictions on abortion when this issue should have been resolved as a rights issue decades ago.[2]

Jernow is at her strongest discussing how consent to sexual relations is treated. For example, the United Nations Human Rights Committee found it "undisputed that adult consensual sexual activity in private is covered by the concept of 'privacy.'" The European Court of Human Rights (ECHR), on the other hand, "disavowed any broad notion of sexual autonomy in cases involving sadomasochistic sex and adult consensual incest." In a case of incest the ECHR examined between a brother and sister, it expressed concern that the girl's sexual self-determination over a long period of time was in question, and imposed a criminal sentence on the brother. Central to such decisions, the court argued, is preventing harm by protecting the right to withdraw consent, even if it was given at an earlier moment.

Jernow also examines several South African courts' decisions to reject the legal enforcement of private moral views when they are based on prejudice and hostility, such as toward gay men. She quotes Justice Albie Sachs, who similarly insisted on using the "harm principle" to proscribe what is unacceptable in relation to sexual expression, even in the sanctum of the home. He argued that it remains important to "penalize what is harmful and regulate what is offensive," thus overriding in some cases the privacy principle.[3] In contrast, in a more recent South African case, a sex worker sought compensation for unfair dismissal from a brothel on the grounds that she still had constitutional rights, even though prostitution was illegal.[4]

Lastly, Jernow covers the 2009 ruling in *Naz Foundation v. Union Government of India* in which—in spite of the absence of protection of privacy in the Indian Constitution—the Delhi High Court read down Section 377 of the Indian Penal Code, ending the ban on gay sex. The judgment was overturned in 2013, however, by the Supreme Court of India in an opinion that Jernow describes as "notable both for the thinness of its reasoning and its deference to majority [moral] opinion." She thus concludes that while the "harm principle" is accepted everywhere as a reason to proscribe harmful behavior, its interpretation is so "plastic as to be without any real power to challenge state regulation of private behavior" if a state wishes to do so.

Which takes us to Widney Brown, who offers a swingeing critique of how the criminal justice system in many countries fails most victims of crime, from women who have been raped in New York City to women migrants working as housemaids in Saudi Arabia. She describes how women migrants working as housemaids in Saudi Arabia are imprisoned for "becoming pregnant illegally" due to sexual exploitation by men in the households where they were employed, and then deported penniless upon their release. She also describes the well-known phenomenon whereby victims of rape may or may not be re-victimized by the criminal justice system, depending on their race and class, while perpetrators may be assumed to be guilty or innocent, depending on *their* race and class. Thus, in the United States, if a rape victim is a white, educated woman and the defendant is an African American man, he is presumed to be guilty, but the opposite is true if the woman is African American and the accused man is white. Hence, no one is surprised that most men in prison for rape in the United States are African American.

In Saudi Arabia, apparently, according to one minister of the interior that Brown spoke to, people confess if they are guilty. However, if they refuse to confess, this is also evidence of their guilt, so they are tortured until they confess their guilt. The "torture simply helps those who are guilty to come to terms with their guilt." Moreover, in "refusing to confess initially, they were responsible for the torture." I may be naïve to be shocked by this, but I am shocked. Yet this is only an extreme example of the deeper point Widney Brown, and indeed all the authors in this book, are making—that the justice system is not our salvation. She asks, "How can human rights activists demand that the state bring those who perpetrate crimes to justice" when the justice system itself is so often systemically unjust?

In assessing a given country's "scorecard" on these issues, she recommends asking the following:

> *What is defined as a crime? What are the patterns and practices of the police? How is prosecutorial discretion exercised? Are all defendants ensured legal representation? Are there disparities in sentencing for comparable crimes?*

And perhaps most importantly: Who is in the country's prisons, because the answer to this last question is indicative of who is denied their rights in that country.

She asks equally critical questions about procedural issues: whether rules of evidence or procedure undermine due process or fair trials protections, or discount the testimony of victims or witnesses; whether the presumption of innocence is reflected in all parts of the system; and whether there is judicial independence (and, I would add, judicial expertise) on the law itself.

She concludes that it is not possible to ignore the failures of the criminal justice system—which themselves cause great harm—nor is it possible to give up on the system. She therefore urges the human rights movement to campaign to strictly limit the scope of criminal law and to demand that states provide for an independent, civilian oversight mechanism that represents the diversity of the community and ensures that the communities most scrutinized by the police have the strongest representation. The goals of equity and equality of treatment, fairness, and transparency, she says, require tackling the criminal justice system and not allowing the privileged and the marginalized to be treated differently by it.

Part II of the book has chapters on national historical perspectives, including prostitution and sex trafficking in South Korea since the 1990s and the law; the trajectory of criminal law in relation to sex in Brazil from 1830 onwards; and abortion treated as treason by the Germans in France in 1942, when the Vichy government made obtaining and providing an abortion punishable by death.

These studies explore how the content and role of the law changes over long periods of time, going back as much as 100 years. The value of such research in contextualizing current law and policy and when trying to make change happen is important—knowledge of the past may make the difference between success and failure in seeking to reform national law and policy.

Part III of the book has six chapters on the following contemporary national concerns:

- the impact of criminal laws on sexual and gender non-conforming people in East Africa;
- criminal law, activism, and sexual and reproductive justice in regard to sex selection in India;
- whether old moralities are only wearing new clothes—and whether modern laws on sex crimes protect neutral moral values or not, which concludes that this is, at best, a work in progress;
- "sex panics," a vividly descriptive term, in relation to pornographic films, gay bars, unnatural sex, marital rape, and sexual relations among migrants and refugees;
- a reflection on sexual rights advocacy and the legal recognition of same-sex marriages, what counts as a family, how families are formed, who is included, what legal protections are extended, and how this all relates to family law versus criminal law; and
- a closing argument on the decriminalization of what produces harm, asking whether the harm caused by, for example, restrictive abortion laws, laws against prostitution, and laws criminalizing the non-disclosure of HIV infection provide a compelling enough rationale for decriminalization on its own.

I've left one chapter, from part II, for last, because it was so unexpected. After 40 years of publishing on reproductive and sexual health and rights, it isn't often that something new comes along for me. This chapter, by Oliver Phillips, is called "The Reach of a Skirt"—a provocative enough title—which opens with an even more provocative question: "What's in a skirt?" You may well ask!

The chapter opens with a story from 1992:

> *A woman walking alone on campus at the University of Zimbabwe was pursued and stripped naked by a mob of approximately 100 male students. She was rescued … by being bundled into the car of two female deans who happened to be passing, thus saving her from further violence.*

The male students claimed that their actions were justified because she was wearing a miniskirt and it was too short. A few days later, a second such attack took place at a nearby shopping center. A few days after that, women students began mobilizing on campus, and about 40 women dressed in miniskirts held a protest march to which supporters came, of whom six were men, including the author of this chapter. The march was surrounded by more than 500 male students who threatened the women with gang rape and threw stones and sticks at them. Four of the six supportive men were big and well known. They intimidated the mob just enough to restrain them. When the author talked to some of the men afterwards, they said they were "defending traditional values" and that women should wear decent skirts and "discipline themselves" (or it would be done for them).

There have apparently been other such attacks over the years too. In 2014, a young woman wearing a short skirt was attacked in central Harare near a taxi rank. This incident was filmed on a smartphone and posted on YouTube, where it went viral. The attackers were shouting "Whore!" at her as they tore at her skirt and underwear. She and the young man who was with her tried to get into a taxi, but the drivers closed their doors against them. Finally, another taxi came to their rescue and drove them away. Women with a significant public profile, including a member of Parliament who was previously a deputy minister of justice and legal affairs, spoke out against the attack, as did many others. The video led to police involvement, and two men were eventually arrested and convicted of assault and imprisoned for eight months. But it had taken from 1992 to 2014 for an intervention supporting the rights of the women to take place.

The rest of this chapter discusses the complex role of clothing and gender, and the conflicting interpretations of culture and tradition in relation to women believing they have the right to wear clothes of their choice. The author found occurrences of disputes about miniskirts not only in Zimbabwe but also in Nigeria, Botswana, Namibia, and Zambia, and proposals to ban miniskirts in Uganda, Nigeria, Swaziland, Chile, Indonesia, South Korea, and Italy.

Thus, the "dressed body" has social import, signifying conformity in some cases and transgression in others, but always serving as a visible "representation of the relationships between power, gender, class, race, and sexuality." It was sexual repression that led to the young men's reactions in 1992 and has continued to do so. For the young women, the miniskirt was their challenge to what the author called "gender hierarchies." Because the young men were "disturbed, excited and confused" (and felt taunted with sexual arousal), they blamed the young women for provoking them.

When women insist on their right to dress as they wish and choose dress that is considered transgressive, conservative men demand they be regulated by "decency," prohibition, or even criminalization, and all sides want the law on their side. Thus, appeals to "law" (whether social, moral, or legal) may be associated with social control and claims to liberty and equality at the same time. This challenging thought is, I think, a good place to end this review.

I hope this book will inspire many other papers, as there is so much more to delve into along these lines. *Beyond Virtue and Vice* should be high on the reading list of anyone who wants an international perspective alongside national examples of the contradictions and inter-connectedness of struggles for human rights and the role of criminal law. It's a major contribution.

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VIEWPOINT

Reflections on 25 Years of Health and Human Rights: History, Context, and the Need for Strategic Action

SOFIA GRUSKIN

When we launched the Health & Human Rights Journal 25 years ago it was a heady time for health and human rights conceptually, empirically, and politically. I had just moved to Boston to begin working with Jonathan Mann and Daniel Tarantola at the newly created FXB Center for Health and Human Rights. In those early years, we hosted two international conferences on health and human rights and began to put together education and training materials, but our primary concern was establishment of the Journal. In our internal meetings, we all agreed the thing most crucial to development and establishment of this new field was the launching of a credible peer reviewed and accessible journal. Sandwiched between the Vienna Conference on Human Rights and the Cairo International Conference on Population and Development, its creation occurred in the years where not only was there programmatic work establishing and documenting the linkages between health and rights, but most importantly, from all corners of the globe, it seemed there was general political willingness to "do the right thing." Perhaps naively, the big issue as we saw it then was the lack of a home where relevant work could be published.

It was HIV that had initially brought us all together and helped us to illuminate the links between health and human rights. What was immediately clear, however, was that if the Journal was to succeed it needed to bring into play other health topics and areas of focus. In many ways, the conferences we held were critical to this effort, highlighting work being done, and that needed to be done, not only in HIV but in other areas such as reproductive health, tobacco control, and humanitarian crises. We worked internally to draw parallels between the concepts and issues we were seeing. Out of that came the famous (at least to us) language of inextricable linkages and three relationships. Under Jonathan's guidance the first issue of the journal laid out the three relationships as we saw them then: the positive and negative impacts of health policies and programs on human rights; the impacts of human rights violation or promotion on health; and "the inextricable linkages" between the two.

I served as associate editor for the first two years of the Journal's existence and as its editor until 2006. Throughout that time for each issue we produced, whatever the theme, we strove to ensure we were fostering a coherent body of work, and we worked with authors to ensure all of the articles accepted helped in some way to further clarify these relationships. Those years helped us to move from the conceptual meaning of these linkages across different domains of health, to what these links mean in practice.

In the decade or so that followed, we saw UN agencies and small grassroots organizations alike taking on the ubiquitous "rights-based approach" (whether in rhetoric or reality) as a framework for doing their

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This Viewpoint was originally published on the Journal website on 10 December 2020 and can be viewed here:
https://www.hhrjournal.org/2019/12/reflections-on-25-years-of-health-and-human-rights-history-context-and-the-need-for-strategic-action/.

health-related work. A focus on process, more than simply outcomes, was understood to be crucial. It was increasingly recognized that paying attention to rights concerns prior to implementation could not only help to ensure violations did not occur but might actually result, ultimately, in better outcomes and lived experience for the communities most affected. This period also saw the growth of courses and academic institutions around the world engaged in health and human rights training, increased documentation of successes and failures in bringing human rights into health work, and importantly a significant growth in journals open to publishing work at this intersection.

Until recently, it seemed as though the original ideas at the heart of the creation of the Journal and the FXB Center were flourishing. Health and human rights had become an established field, with trainings, publications, new generations of researchers and activists, and even significant differences in methodologies and approach amongst many who see themselves/ourselves as part of what was once called the health and human rights movement. A field was established.

And that takes me to the present moment. Within the larger world within which we live, it is no exaggeration to say that we are all fighting to address increased conservatism, nationalism, populism, and related violence. Outright resistance and ideological attacks against gender equality, sexuality, reproductive freedom, and self-determination increasingly go unchecked, not only in the words of some politicians, but in the words of some media, and even some colleagues and students. Within the health field, there is a visible decline in the willingness to take on these issues once considered acceptable or even crucial. One can only posit this is because they are now considered too controversial or even radical. All of which threaten the very foundations of the health and human rights movement established 25 years ago with the launch of the Journal. National spaces are becoming increasingly constrained, with immediate and direct impacts also on the larger geopolitical space. As I have noted elsewhere, this is leading, in some cases deliberately, but also in some cases inadvertently, towards our agreement with—or complicity in—reductionist approaches to the health and human rights project. Important issues are being dropped, or de-emphasized, often with technocratic justifications, but with the same ultimate outcome: a decrease in visibility, attention, funding, and action.

At a global level, the Sustainable Development Goals, the most positive blueprint we have for our future, are limited in what they can explicitly offer health and human rights concerns. There are, of course, continuing efforts underway to tease out these dimensions. It is, nonetheless, ironic that 1994's Cairo International Conference on Population and Development (perhaps because it is ostensibly endorsed by a majority of the governments of the world) to this day remains the touchstone undergirding much of health and rights in all spheres, and not only with respect to sexuality and reproduction. It is nothing short of depressing that in the current political moment we are seeking to hold the line on something that happened 25 years ago, and that was recognized even at the time to be inadequate.

The crisis of the moment calls for us to be strategic, not just reactive, and to be able to count on one another whatever our past and present differences. Taking a long view, the stakes are just too high. As a first step we need to support publication of efforts in all domains—research, programming, service delivery, and activism—that can help to ensure the health and human rights of all people. And, however "sensitive" the issue, do not slide off the table simply because it's a complicated political moment. We risk losing not only the gains made so far, but attention and support for the very many tough issues at the crux of health and human rights work. We need more than ever to draw attention to all that is happening to undermine health and rights, and collectively and directly take this on wherever we work. This is not simply a matter of academic concern. It tangibly matters for the health and lives of people around the globe. Twenty-five years since its inception, the importance of the Journal, and the space it provides to keep critical issues on the table in academic, policy, and programmatic discussions, has never been greater.

VIEWPOINT

The Right to Health: Then, Now and a Call to Arms

Audrey R. Chapman

I first became involved with right to health issues around the time of the launching of the *Health and Human Rights Journal* when I became director of a human rights program at the American Association for the Advancement of Science. Having spent nearly 10 years in Africa, I gravitated toward economic and social rights and then the right to health naively believing the human rights rhetoric that all rights are considered interdependent and equal in status and respect. When I became aware that it was not the case, particularly in the United States, where economic and social rights were, and still often are, relegated to the status of aspirational goals, I thought that better conceptualizing the scope and content of states' obligations would confer more respect. To that end, I organized several projects and worked with members of the United Nations Committee on Economic, Social and Cultural Rights who were engaged in developing a general comment on the right to health. The general comment, which was adopted in 2000, contributed toward the goal of better understanding the conceptual scope of the right to health and related state obligations. But obviously, it was not the magic wand encouraging governments to take the right to health more seriously that I had assumed it would be. Nor have been the many significant articles published in the *Health and Human Rights Journal.* Yet both have contributed toward a better understanding of health and human rights issues.

I now see the challenges to implementing the right to health quite differently. I understand far better that the political, social, and economic environment in which we live, more specifically the neoliberal policies that have dominated many countries and international agencies during the past 35 years, present significant obstacles to the realization of economic and social rights. I wrote in Global Health, Human Rights, and the Challenges of Neoliberal Policies, that ironically, as the right to health has evolved and become more widely recognized as an appropriate normative foundation and ethical requirement for health policy development, there has been a global paradigm shift engendered by the increasing hegemony of neoliberal ideology and policies.[1] Neoliberalism contends that markets are the appropriate basis for organizing all areas of economic and social life regardless of their deleterious effects on human welfare and dignity. In contrast with a human rights approach, which conceptualizes health to be a social good contributing to human welfare, neoliberal policies consider health service to be an economic commodity. As such, the availability of health services depends on having the resources to pay for them. Human rights vest fundamental responsibility for realizing human rights obligations in the state and thereby requires a strong and effective state apparatus able to realize human rights obligations. In contrast, neoliberalism promotes political policies minimizing the role of the state and advocates transferring the provision of health and other social services to the private sector on a for-profit basis. All of this makes the realization of human

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This Viewpoint was originally published on the Journal website on 10 December 2020 and can be viewed here:
https://www.hhrjournal.org/2019/12/the-right-to-health-then-now-and-a-call-to-arms/.

rights goals far more difficult to achieve.

Today there is an apparent consensus on the importance of achieving universal health coverage, which is a major right to health commitment. This goal has been affirmed in a 2011 WHO resolution, serves as the central target in the comprehensive health goal in the Sustainable Development Goals and most recently was the subject of the political declaration signed by all countries participating in the September 2019 High Level Meeting on Universal Health Coverage.[2] However, according to recent WHO statistics, in 2017 only between one third and half of world's population was covered by essential health services, and many more did not have access to clean water, sanitation, or education, all of which are important social determinants of health. Moreover, globally and in many countries the pace of progress toward universal health coverage has slowed since 2010. Troublingly, financial protection, a key component of universal health coverage, as well as the right to health, is going in the wrong direction. Impoverishment related to healthcare expenses is increasing. The incidence of catastrophic health expenditures increased between 2000 and 2015. WHO's Universal Coverage Monitoring Report states that nearly one billion people spent more than 10 percent of household income on basic healthcare in 2015 and 210 million spent more than 25 percent.[3]

So how can right to health advocates counter these trends? I believe that directly challenging the assumptions and key ideological premises of neoliberalism that have contributed to these outcomes is key to doing so. To that extent, I agree with some of the critics of human rights like Samuel Moyn who have taken the human rights community to task for not opposing neoliberalism more forthrightly, although I would disagree with him on many other of his claims.[4] Currently, the human rights literature critiquing neoliberalism and its impact on achieving human rights goals is relatively sparse. Paul O'Connell and Ted Schrecker early sounded the alarm in their publications.[5] Alicia Yamin has published a number of important articles, some in this journal.[6] Gillian MacNaughton and Diane Frey have recently published an edited volume, Economic and Social Rights in a Neoliberal World that has essays documenting the impact of neoliberalism on a wide range of countries and international agencies.[7] There needs to be many more.

I intend this reflection to be a call to arms to the human rights community, particularly those committed to improving health access and outcomes, to more vigorously oppose neoliberalism and its deleterious impacts on health and the human welfare. Research and writing of course is one way. But I think that we need individually and as a community, to the extent there still is a human rights community, to also become more involved in the formulation of policy priorities and policy implementation to counter neoliberalism.

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HHR
Health and Human Rights Journal

VIEWPOINT

Health and Human Rights at a Crossroads

RAJAT KHOSLA

Reflecting on the 25th anniversary of *Health and Human Rights* (HHRJ) is in a way a reflection on the history of health and human rights. It is an opportunity to pause and reflect on past and present challenges. On the one hand, human rights in health have become institutionalized with an array of norms and standards and professionalised with senior roles in key global institutions, and on the other, the global paradigms seem to have become increasingly dislodged from the movements that inspired the global reckoning of health as a human right.

As a lecturer in human rights and health, I used to talk about three moments when human rights in health started to be taken "seriously" at the global level. The first moment was in 1993 when Professor Jonathan Mann, the founding editor, together with his colleagues set up the François-Xavier Bagnoud Centre on Health and Human Rights at the Harvard School of Public Health and HHRJ was launched. Since then, the journal has played a critical role in educating and raising awareness about health and human rights and situating health and human rights squarely within the movements that demand global recognition of health as a human right. Mann and colleagues, in the *Health and Human Rights: A reader*, explain that "Modern human rights is a civilizational achievement, a historic effort to identify and agree upon what governments should not do to people and what they should assure to all."[1]

The second moment, also in 1993, was the World Conference on Human Rights, held in Vienna which sent out a call for the universality, indivisibility, and interdependence of all human rights and fostered a global deepening of the discourse on economic and social rights. This was followed by then UN Secretary General Kofi Annan's plea, to integrate human rights across the UN system. Together, these two developments fostered a global recognition and institutionalization of economic and social rights, and the right to health in particular. Since then, desk officers on human rights have been appointed at WHO, UNFPA and other entities, and normative unpacking of these issues has been undertaken by UN Treaty Monitoring Bodies (for instance the UN CESCR General Comment 14 (2000)) and at the national level.

The third moment was the appointment of the first UN Special Rapporteur on Right to Health in 2002, which spurred advances in the normative development of health as a human right. Similar trends can be seen outside the multilateral system with the establishment of the People's Health Movement in 2000, numerous national level litigations on claims based on the right to health (e.g. *Minister of Health v. Treatment Action Campaign* (2002), *Paschim Banga Khet Mazdoor Samity and Ors v State of West Bengal* (1996), *K.L. v Peru* (2003) and others) and the mainstream human rights organisations, such as Amnesty International and Human Rights Watch, who expanded their mandates to include health and human rights.

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This Viewpoint was originally published on the Journal website on 11 December 2019 and can be viewed here: https://www.hhrjournal.org/2019/12/health-and-human-rights-at-a-crossroads/

The Health and Human Rights "movement" has been and remains many movements covering a variety of health areas, working in different arenas and with distinct and occasionally overlapping trajectories. Regardless of what is happening at the global level, local actors around the world are mobilizing and struggling to claim their rights in the most challenging contexts. Their efforts are often unrecognized and failed by the human rights mechanisms that have been put in place.[2]

In the past 25 years there have been significant, though uneven, advances in health and human rights. Understanding of discrimination and inequality have been recognized as critical for people to attain and maintain their human right to health.[3] There is a general acceptance, at least discursively, that an individual's ability to manifest their human rights has a direct bearing on their health and vice versa.[4] Major strides have been made in the development of normative aspects, for instance in access to medicines, sexual and reproductive health, mental health and also in terms of the development of tools for monitoring health and human rights through indicators, impact assessments and in other areas.[5]

These advances, however, have been paralleled by regressive tendencies. The operationalization of health as a human right within countries has been undermined by arguments that the specificities of national contexts justify the abdication of human rights responsibilities, resulting in policy incoherence and an uneven implementation of international norms and standards. Furthermore, macro-level politics and ruling ideologies have been demonstrated to have a profound impact both on an individual's realization of their health and human rights and on the provision of services. Patterns of financing and funding for global health have also had a significant bearing on both the normative developments as well as the implementation of interventions on the ground.

This uneven evolution of health and human rights is visible in a number of different ways, for instance:

- It is clear that some human rights are more acceptable and palatable than others, with social and political forces affecting the normative and operational aspects of health and human rights.
- *Ad hoc* and variable transnational conversations on human rights and how national ideologies play into these geopolitical conversations have consequences on our ability to assert human rights in health and health in human rights.
- Much global health work is couched in the discourse of human rights, appearing to address global and national development priorities, but it does not embrace health and human rights as intrinsic to the capability of individuals to achieve a life they value.[6]

Reflections for the future

Firstly, Ruth Levine wrote that "The identification of what's wrong must come from those who are experiencing those wrongs. People working on the "evidence agenda"—academics, think tank researchers, experts in official statistics—should do work that is informed by and complementary to social movements."[7] We in the health and human rights "movement" have failed on this point. Our work, that is, those working on health and human rights within global arenas, has increasingly become top down and any meaningful connections with social movements, have tapered. This is our biggest challenge and our ability to reconnect with the social movements will determine our future collective success. As Levine concludes, "the fastest and longest-lasting progress will come from connecting organized outrage about the infringement of rights—work done by social movements that authentically represent and give voice to people whom the system is failing—to people who understand and influence the levers for change within the system."

Secondly, we need to actively safeguard against regression and retrogression. The internal and external pressures against health and human rights are enormous and unprecedented. Today's world sees new pandemics threatening global health combined with a rise in regressive policies that are eroding the gains made in global health norms over the last three decades.[8] As David Sanders et al summarized recently, it is one step forward and two steps backward.[9] As we move forward with implementing the UHC agenda, Sanders reminded us that we must not compromise the progress made on global health standards; we need to focus on efforts to reform public health and address the social determinants of health whilst keeping community and social participation at the heart of human rights work. I agree there is a need for a bolder and more honest model to inspire those working in the field of human rights and health to make health equity a reality.

Thirdly, social justice is inherent to health as a human right. Paul Farmer, reflecting on how a social justice approach can be used to address disease and suffering, emphasized that "A truly committed quest for high-quality care for destitute sick starts from the perspective that health is a fundamental human right."[10] Our pathway for the future indeed needs to build on this idea of social justice and as Amartya Sen argued, "In seeing health as a human right, there is a call to action now to advance people's health in the same way that the 18th-century activists fought for freedom and liberty."[11] He elaborated, this requires, "…political, social, economic, scientific, and cultural actions that we can take for advancing the cause of good health for all." Seen through this lens, health and human rights becomes the nucleus of social justice, both as the means to an end and also as an end in itself.

Finally, there is a need to foster a collective voice to demand recognition that health is a human right. One of the biggest challenges today is the absence of a collective moral outrage and a deafening silence on massive violations of health and human rights. From climate change to sexual and reproductive health and rights, the litany of violations is too long and the response is often far from adequate. We lean on the underfunded, under-resourced human rights defenders, local movements, and civil society organizations to fight these battles while global institutions stand in silence. Romila Thappar famously asked: "Are we all being co-opted too easily by the comforts of conforming? Are we fearful of the retribution that questioning may and often does bring? Do we need an independent space that would encourage us to think and act, and to think and act together?"[12] The answers to these questions are central to our reflections for our collective future. It is certainly possible to generate a global common cause. Indeed, the success of our present and future endeavours may depend on such a collective call for health as a human right.

Rights alone are not panacea for global health and never will be. But they are a reflection of our collective common conscience. The time is now to rebuild a health and human rights movement that exercises not just our collective conscience, but also our collective responsibility. To conclude with the words of Jonathan Mann, the time is now for us to come together as "equal partners in the belief that the world can change."[13]

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Health and Human Rights Journal

VIEWPOINT

War, Political Conflict, and the Right to Health

Leonard Rubenstein

The Universal Declaration of Human Rights makes no reference to war except to assert that respect for human rights is a means of preventing it. The lack of attention is not surprising given that in the post-World War II period the conduct of war was the subject of the 1945 Nuremberg Declaration about war crimes and crimes against humanity, and intense debate in the lead-up to the re-drafting of the Geneva Conventions of 1949. Indeed, part of the push for addressing human rights in the UN Charter was the belief that respect for human dignity in peacetime was being neglected.[1] The consequence of that peacetime focus, though, led to almost 60 years of neglect of the right to health in armed conflict.

Over time, human rights ideas made their way into the law of armed conflict. Traditionally, the responsibilities of belligerents not to harm people not engaged in combat were grounded in the principle of humanity, to avoid unnecessary suffering. It a far more limited concept than ideas of human dignity that ground the UDHR and the conventions that followed. In the two decades leading up to the 1949 conference on new Geneva Conventions, some international humanitarian law experts sought to introduce human rights concepts, especially human dignity, into the Conventions. For political and institutional reasons, though, the drafters of the 1949 Conventions rejected that approach.[2] The new conventions only recognized a handful of rights, such as freedoms of religion and not to be tortured or be subjected to human experimentation.

While this initial effort to ground international humanitarian law in human rights was largely squelched, as David Luban has shown, human rights ideas came to influence interpretations of the laws of armed conflict.[3] Moreover, as the global human rights movement grew in the last quarter of the 20th century, so did its embrace of documentation and advocacy to end impunity for violations of international humanitarian law. Human rights organizations also fought for its expansion, for example in treaties to ban anti-personnel landmines and cluster munitions, and to establish international tribunals for prosecution of war crimes and crimes against humanity. UN human rights mechanisms began to address violations of international humanitarian law.

Yet even as the human rights community employed international humanitarian law in its work, it largely ignored the right to health in situations of political and armed conflict. This neglect extended beyond war, to situations of political volatility and violence, where international humanitarian law does not apply. In part, this neglect was a product of the general lack of attention to the power of the right to health to advance human well-being. After all, the seminal article on health and human rights by Jonathan Mann and colleagues that launched this journal makes only passing mention of the right to health.[4] Many

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This Viewpoint was originally published on the Journal website on 11 December 2019 and can be viewed here: https://www.hhrjournal.org/2019/12/war-political-conflict-and-the-right-to-health/.

human rights organizations expressed skepticism about the power and even the relevance of the right, adopted cramped interpretations of it, or ignored it altogether.

I was at Physicians for Human Rights in the 1990s when we issued a report on attacks on health care in the war in former Yugoslavia. Aside from its documentation of atrocities, the report proposed a classification of the nature of the violations of what we called medical neutrality (something of a misnomer, as immunity from attack does not depend on neutrality). The classification was supported by 30 citations to treaties, court decisions, declarations and the like, but only a single reference to the right to health, and that was in connection with torture.[5] Even when the right to health began gaining traction in the human rights community, its application in armed conflict found no place. Except for references to humanitarian aid, the seminal General Comment 14 of the Committee on Social, Economic and Cultural Rights, released in 2000, ignored armed conflict altogether except to refer back to international humanitarian law and call for humanitarian assistance in war.

The omission had serious consequences. First, major gaps in Geneva Conventions regarding health in armed conflict are properly filled by the right to health. The Conventions require parties to the conflict to refrain from attacking the wounded and sick and the health workers that offer them care, to collect and care for the wounded and sick in war, and to provide care impartially. But they are silent on ongoing obligations by states engaged in war to offer available, accessible, acceptable and quality health services to the civilian population. Even during military occupation, the Conventions only obligate occupying military forces to preserve existing services and lack human rights criteria for their content and administration, much less any requirements for participation of the local population or accountability to it. The right to health fills this major gap in critical ways by requiring continuity of health services and mitigating the effects of war on the civilian populations such as through prevention and treatment of infectious diseases that so often accompany armed conflict.[6] Especially in this time of protracted and chronic armed conflict, governments cannot be left off the hook by ignoring the right to health.

The right to health is also a central tool to protect those in need of care and health workers and facilities in times of political violence short of war, where all too frequently protestors are denied access to health care because of their political activities and health workers are arrested and prosecuted for providing the care. Yet as late as the Arab Spring in 2011, a major human rights organization expressed uncertainty about states' obligations to refrain from interference with health workers who attend to wounded protesters beyond prohibitions on arbitrary arrests and curbing of free expression. Similarly, while the menace of applying ever-expanding counter-terrorism law to restrict medical and humanitarian action in war is clearly contrary to international humanitarian law, without the right to health the tools to counter the criminalization of health care by states only indirectly involved in conflict are weak.

Only in recent years has the importance of the right to health in war and other situations of political violence begun to develop. The first breakthrough likely came in a 2013 report by the Special Rapporteur on the Right to Health, Anand Grover. The report recognized that insecurity often limited states' ability to ensure the resources needed to maintain access to health but explained that the requirement of progressive realization remained in place, requiring "concrete steps towards the full realization of the right to health to all, without discrimination and regardless of the status of persons as combatants or civilians."[7] His report was soon followed by another by the Office of the High Commissioner of Human Rights on economic, social and cultural rights in armed conflict.[8] Then in 2018, Agnes Callamard, Special Rapporteur on summary, arbitrary and extra-judicial executions, wrote a powerful analysis entitled "Saving Lives is not a Crime" that showed how the criminalization of humanitarian aid and medical care under counter-terrorism law violates the rights to life and health.[9]

This recognition of the role of the right to health in armed conflict has been too long in coming. Some soul-searching is warranted to ask why it was so marginalized in circumstances where infringements are so common and health needs are so great. Going forward, the right to health needs to be employed as a tool to seek to advance the well-being of people whose health is most in jeopardy. There is now some movement in that that direction. In Afghanistan, ongoing insecurity and violence against civilians and health facilities has resulted in enormous strains in the country's effort to construct a functioning health system. Threats and violence have led to closure of large numbers of clinics and hospitals. Nevertheless, the government's national health plan is premised on the right to health, using its criteria to develop its governance and programs.[10] The right to health is also being used to contest the criminalization of health care and discriminatory and inequitable health care under occupation.

These are just the first steps. We know how devastating war is to health. Foregoing the use of the tool of human rights to try to lessen its harms can no longer be acceptable.

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VIEWPOINT

The Maturing Right to Health: Deeper, Broader and More Complex but Still Unequal

Gillian MacNaughton

Looking back over the past 25 years, the right to health has matured in healthy ways. It is deeper, broader and considerably more complex. From a narrow focus on freedoms, such as nondiscrimination and privacy, the right to health has grown to encompass a broad range of entitlements, including universal health care and the underlying or social determinants of health.[1] From a siloed right of interest to a few lawyers, the right to health has come to be understood as requiring an interdisciplinary approach, involving experts in many disciplines—most notably health professionals—to fully realize the right for all.[2] This broad and complex understanding of the right to health is also reflected in the United Nations Sustainable Development Agenda 2030 as Goal 3: "Ensure healthy lives and promote well-being for all at all ages."[3] All of these advancements are worthy of celebration.

This maturing is reflected in *Health and Human Rights*. In the first issue of the journal, Lawrence Gostin and Jonathan Mann published an article proposing human rights impact assessment as a tool to evaluate the potential effects of proposed health policies on human rights.[4] Interestingly, their article invokes the right to health only twice, once in the introduction and once in the conclusion, but does not use the right to health in the proposed human rights impact assessment process. As the authors state in their introduction, at that time, the right to health had "not been operationally defined, and no organized body of jurisprudence exist[ed] to describe the parameters of that right."[5] Further, at that time, economic and social rights in general were extremely marginalized, despite the 1993 World Conference on Human Rights, which reinforced the indivisibility and interdependency of all human rights.[6] As a result, Gostin and Mann's proposed human rights impact assessment tool relies on civil and political rights—the rights to security of the person, nondiscrimination, privacy, and informed consent, as well as the rights to information and participation.

In contrast, today, there is a large body of jurisprudence on the right to health, and many dimensions of the right to health have been elaborated in the work of the Committee on Economic, Social and Cultural Rights, as well as other treaty bodies, and in the reports of the UN Special Rapporteur on the right to health. Further, numerous scholarly books have been published on the right to health.[7] Moreover, the International Covenant on Economic, Social and Cultural Rights has been ratified by 170 countries (compared to 135 in 1994). These rights are appearing in the agendas of mainstream human rights organizations, like Amnesty International; are the core mission of more recently established organizations, such as the

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This Viewpoint was originally published on the Journal website on 16 December 2019 and can be viewed here: https://www.hhrjournal.org/2019/12/the-maturing-right-to-health-deeper-broader-and-more-complex-but-still-unequal/.

Center for Economic and Social Rights, ESCR-Net, and the Global Initiative for Economic, Social and Cultural Rights; and are the inspiration for social justice movements around the world, such as the Treatment Action Campaign in South Africa and the Healthcare is a Human Right campaigns in Vermont and Massachusetts, USA.[8] The American Public Health Association has recently recognized a new interest section, the Human Rights Forum. Public health programs in universities now teach about the right to health.[9] The Office of the High Commissioner for Human Rights has signed a Framework of Cooperation with the World Health Organization to deepen their collaboration to (1) advance norms and standards for realization of the right to health, (2) advance national implementation of human rights standards, (3) advance national-level capacity to monitor health and human rights, and (4) cooperate in research and development on health and human rights. And notably, health and human rights impact assessment (1) is now grounded in the complex right to health, including availability, accessibility, acceptability and quality (AAAQ) and the tripartite obligations (respect, protect and fulfill), (2) is the subject of many scholarly publications, and (3) has been put into practice in many locales from the clinical to the national policy level.[10]

Health and Human Rights has published articles on all these topics and many more. Nonetheless, one issue that is both alarming and yet still largely ignored is the relationship between economic inequality and the right to health. In his 2005 book "The Impact of Inequality: How to Make Sick Societies Healthier," Richard Wilkinson provides considerable evidence to show that (1) health, as measured by life expectancy, correlates directly to one's economic status in a society, and (2) more unequal societies have lower life expectancy (and other poor social outcomes) for all economic groups in comparison to more equal societies.[11] Wilkinson presents these large disparities in life expectancy as social injustices and human rights violations.[12] Since 2005, researchers have also documented numerous other negative impacts of gross economic inequality, such as heightened violence, lower levels of voter participation, and political and economic instability, which all negatively impact on the right to health.[13]

And economic inequality continues to grow every year in almost every country in the world. Yet, few human rights scholars and practitioners have addressed the issue, and fewer still have examined the relationship of economic inequality to the right to health specifically.[14] The human rights bodies have, with few exceptions, largely avoided the topic as well, preferring to focus on well-accepted human rights norms such as nondiscrimination and the minimum core of economic and social rights.[15] The issue of economic inequality and human rights, particularly economic inequality and the right to health, however, requires urgent attention from the human rights community, just as it has gained attention from economists, politicians, and voters. Despite amazing advances in conceptualizing and implementing the right to health over the past 25 years, economic inequality remains a crucial barrier to the full realization of the right to health.

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Health and Human Rights Journal

VIEWPOINT

A Letter to Young and Future Leaders in Struggles for Health Rights and Social Justice

ALICIA ELY YAMIN

Dear young and future leaders in struggles for health rights and social justice:

The world has changed tremendously in the almost 25 years since I had the privilege of studying under the late Dr. Jonathan Mann at what is now the Harvard TH Chan School of Public Health, and to witness the birth of a movement for health and human rights. You may be inclined to dismiss this collection of anniversary reminiscences as largely irrelevant to the issues faced around the globe today, but please resist that urge. We can only understand where we need to go and what to do in deploying human rights for health justice, if we understand how we got here. And, when the very idea of human rights is under such widespread attack—not just from self-serving authoritarians but also from progressives who argue that human rights has been ineffectual or worse with respect to stemming the rise of neoliberalism—it is imperative that you, and we all, try our best to understand how we got here.[1]

By "here" I mean a context of growing distrust of democratic institutions and multilateralism; hyper-globalization and concentration of private wealth; ravaging inequalities within and between nations; impending climate cataclysm; mass migration and displacement; toxic synergies between ethno-nationalism, racism, and misogyny—and all of the ensuing impacts on the distribution of population health and human dignity. There is important "evidence for hope," but it is clearly "not enough".[2] This is not a time for self-congratulation; nor can we afford "business as usual" in efforts to apply human rights to advance health and social equality. It is a time for critical reflection in order to permit reconstruction of our aspirations, creative adaptation of our strategies—and disruption of some of our cherished certainties.

In When Misfortune Becomes Injustice: Evolving Human Rights Struggles for Health and Social Equality, I engage in that critical (self) reflection.[3] Based on experiences living in multiple regions and bridging academia and advocacy over the last few decades, I offer my own subjective and invariably partial account of efforts to change a narrative of health deprivations as misfortunes to be endured into one of injustices to be remedied.[4] I argue that over these years, advocates for health and other economic, social, and cultural (ESC) rights have faced three principal challenges: (1) subverting entrenched ideas that these were not real rights, but mere programmatic aspirations; (2) articulating a vision for taking health-related rights seriously in laws, policies, and practices; and (3) demonstrating that doing so could achieve meaningful progress toward social justice in national and global orders, which was particularly essential in global

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This Viewpoint was originally published on the Journal website on 16 December 2019 and can be viewed here: https://www.hhrjournal.org/2019/12/a-letter-to-young-and-future-leaders-in-struggles-for-health-rights-and-social-justice/.

health. While much has been achieved in terms of the first two challenges, as the contributions to this journal over the years attest, we who have been engaged in these struggles since the beginning need to collectively acknowledge that we have failed with respect to the third.

Why have we failed in this regard? And what does that mean for moving forward?

Answering the why question, in my view, requires examining how an array of opportunity structures evolved and were perceived by different sets of actors as the law changed, public health evidence was built, global economic and political configurations shifted, and technologies advanced over the last decades. In When Misfortune Becomes Injustice, I argue that the duality of the historical narrative becomes easier to understand in this way. That is, over these years we have theorized health-related rights and what they implied in terms of social contracts, institutional arrangements, and the conditions necessary for diverse groups facing intersectional disadvantages to effectively enjoy them. And arguably nowhere has evolution in normative frameworks been more dramatic than in relation to sexual and reproductive rights (and nowhere has the backlash been more brutal). Yet, just as health-related and other ESC rights were being articulated, increasingly intrusive global economic governance, often in synergy with anti-democratic centralization of power at national levels, was limiting the political possibilities to realize them.

Nonetheless, there is no cause for fatalism and no room for despair; this unpacking of the temporal sequence allows us to see that alternative socio-legal narratives and social mobilization strategies might have led us down other paths—and they can open new possibilities for advancing health and social equality today. Without conceding the extraordinary achievements and critical ground gained in so many respects, we can and urgently must re-energize the original human rights aspirations of a social and international order based upon equal dignity of diverse human beings, which includes economic justice.[5]

What does this mean for you young advocates and future leaders?

There is of course no single response, and even as I suggest some points of departure in When Misfortune Becomes Injustice, I argue we should eschew facile formulas. Advancing rights with respect to any particular health issue in our deeply interconnected, but simultaneously fragmented, world demands collective deliberation, and collective efforts. And that in turn calls for broadening the circle to include cross-disciplinary dialogue with progressive economists, among others, and forging alliances with varied social movements.

When Jonathan Mann, together with colleagues, founded this journal and held initial conferences on health and human rights at Harvard in the 1990s, he envisioned fostering a broad movement that would bridge the fields of health and human rights through both scholarship and advocacy, in order to challenge the status quo in public health. And arguably no single person has done more than Paul Farmer, through Partners in Health and across many other spaces, to inspire people around the globe to challenge orthodoxies not just in medicine and public health, but also in human rights.

I was privileged to be part of the team that Farmer assembled when he initially became Editor-in-Chief of this journal over a decade ago. In that 2007-2010 re-envisioning, we understood that learnings in relation to applying rights to health needed to be far more accessible, and so the journal not only went online, but was an early adopter of completely open access. Recognizing the barriers language presented, we included articles in other languages, together with translations. We also thought it imperative for such a forum to include the voices of those on the front lines, and dedicated one of two principal sections to writing "from practice." The other principal section highlighted critical concepts, as well as contestations, in the multiple intersecting fields related to health and health and human rights in order to inform reflective and innovative practice.

Needless to say, that sweepingly ambitious endeavor faced enormous practical obstacles, including funding, and the fact that meaningful social impacts are rarely measurable in algorithmic "factors." Nonetheless, it was an experiment worth undertaking; under Farmer's leadership, as reflected in the mission statement that remains on the website to this day, we were committed to developing a platform for human rights praxis that would be relevant to the health and related struggles of those whose lives are shadowed by structural injustice.[6] The journal's entry into another exciting phase provides an invitation to once again consider the possibilities this forum might offer. At this critical inflection point, we should all challenge ourselves to enlarge our imaginations beyond the aim of sustaining a professionalized "health and human rights field," which can all too easily reproduce the very global, institutional, and epistemic hierarchies that we claim to challenge.

But it will be up to you young advocates and future leaders to hold those of us who have been at this for a while to account. Consider whether we are asking the right questions, deploying effective strategies and using metrics that are fit-for-purpose in our current age of neoliberalism. And please don't hesitate to raise "difficult" issues, dissent from majority views, and surface contestation. We all need to reflect on how political and epistemic colonialism in global health and international human rights shape the politics of agenda-setting, the production of social meanings, and the dynamics of privilege and power within which we all operate. Likewise, all of us need to grapple with the complexities of promoting a universal understanding of human being in a world, and within representations of that world in both law and biomedicine, constructed by (and for) men. And we all—in global governance as well as at national level, in academic institutions as well as in advocacy organizations—need to confront how the control and uses of funding are (mis) aligned with progressively reshaping the political economy of global health.

Further, while lawyers and development economists, physicians and biomedical researchers, and other professional disciplines play critical roles, please don't be cowed by labels of technical expertise. Be skeptical of technologies of knowledge that enable governance at a distance, disconnected from the contexts in which institutional actors need to be mapped, relations need to be (re)shaped, and politics need to be contested in order to produce social change. Beware of the "technical" policy-making exercises that exclude or diminish the lived realities of activists or abuse survivors, of health system users or community health workers, or of any other variant of ordinary human being.

If health is largely socially constructed, it can be reconstructed and democratized. But the only way to democratize health is to actually democratize health. And democracy depends upon "ordinary" political energy, when diverse people whose lives are affected come together to participate meaningfully in identifying ways forward and mobilizing for change. "Ordinary" people have always been, and will always be, the drivers of extraordinary social transformations in relation to health and more broadly—from movements for labor rights and social protection to sexual and reproductive health and rights, from movements for the rights of persons living with HIV/AIDS to movements for climate justice and planetary health.

Using human rights for social change in health and beyond is a relentless and often anguishing struggle, so choose your mentors and companions on this journey well. The exuberance of victories will often be short-lived because the goal posts, and indeed the fields of play themselves, are constantly shifting. There will be times when you sink into despondency at the vastness of needless suffering that is so normalized, and the hopeless inadequacy of our efforts to remedy it. But, in the end, it is the struggles we most passionately pursue that define our lives. And what is at stake here is nothing less than what we owe to one another and to future generations, as diverse but equal human beings sharing one irreplaceable planet.

So, please: learn from our many hard-won achievements—and from where we have fallen short. Be bold, be creative, be disruptive. The future that you will leave to the young advocates who are emerging in 25 years depends upon it.

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VIEWPOINT

Challenges in Promoting the Interdependence of all Human Rights

DAINIUS PŪRAS

I am taking the opportunity presented by this series of reflections on the right to health to comment on my experiences as the UN Special Rapporteur on the right to health, especially as I am now entering the final year of this mandate.

Our understanding of the meaning of the right to health was greatly helped in the year 2000 by General Comment 14, and its resulting analytical framework. This has assisted States to understand their legal obligations regarding the right to health, and accordingly, over the past five years I have seen a lot of progress, globally, and in certain countries as states have invested in healthcare services and attempted to make these services available, accessible, acceptable, and of good quality. During my 11 official country missions to date, covering all geographical regions, I have observed many good efforts to balance an investment in primary care with hospital care. But I have also had to remind many other states, even when they are enthusiastic about reaching universal health coverage, that primary healthcare is of crucial importance. Furthermore, primary healthcare extends considerably further than simply ensuring, for example, that essential medicines and vaccines are available; it also demands that there are adequate standards of sexual and reproductive healthcare, mental healthcare, and palliative care.

Health-related policies need to ensure that costly diagnostic and therapeutic biomedical interventions are not prioritized at the expense of strengthening primary healthcare which is the key to reaching everyone and leaving no one behind. Users and providers of healthcare services, especially medical doctors, as well as politicians and the general public, need to understand that money spent addressing the determinants of health is the most effective investment in health and healthcare.

Various incentives from those with vested interests have influenced medical education, as well as decision makers and the general public, to see healthcare predominantly as a field of biomedicine. I respond to this very limited perspective of healthcare by reminding all stakeholders that:

- medicine is a social science
- "do no harm" is a primary principle
- primary care, community health, and preventive medicine should be prioritized over specialized medicine.

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This Viewpoint was originally published on the Journal website on 19 December 2019 and can be viewed here: https://www.hhrjournal.org/2019/12/challenges-in-promoting-the-interdependence-of-all-human-rights/

The right to health cannot be exercised effectively if other human rights are undermined. During my numerous debates with stakeholders I have often observed their reluctance to accept this broad approach in health. Instead, they prefer to narrowly focus only on healthcare itself. For example, during my country missions I have expressed my wish to visit not only hospitals and other healthcare facilities, but also migrant detention centers, prisons, long-term social care institutions, and other places where people are deprived of liberty. I have also visited places where people live, grow, work, including in disadvantaged communities, schools, and workplaces. This reflects my view that the right to health is not just about entitlements, but it is also about freedoms. Even though the right to health is an economic, social and cultural right, it is very important to acknowledge that people's right to health entitlements cannot be exercised effectively if their civil and political rights are undermined, and if space for civil society is shrinking.

In the current political economy, human rights are often used selectively. It is crucial to counteract this by stressing the indivisibility and interconnectedness of all human rights. We are witnessing rising populism and nationalism in many countries. This can result in a combination of some improvement in social and economic rights (addressing poverty, providing better healthcare), and at the same time shrinking space for civil society, and restricting civil and political rights and freedoms. In my missions to countries and in reports, I have warned that such a selective approach to human rights will not be helpful in achieving the Sustainable Development Goals (SDGs), including Goal 3 (ensure healthy lives and promote wellbeing for all at all stages). To fully achieve this goal, people need to be empowered to take control and ownership of their lives and their health, which also requires democracy and space for civil society. Realization of the right to physical and mental health is absolutely dependent on realization of all human rights.

I can illustrate this interdependence of rights with two important issues: the right to health in childhood, and the right to mental health.

Illustration of child health and development

There has been a high level of political commitment over the past few decades to reduce the mortality of infants and children under five years of age. The question I have raised frequently, including in thematic reports and in country missions, is why the global community still often considers that the rights of children to holistic development, including emotional and social development, is not as important as the right to life and survival. Article 6 of the Convention of the Rights of the Child is about the right to life, survival, and development. It is not wise to limit investment to just the prevention of child mortality and not support development. If the global community ignores the need to support the healthy development of children, it should not be surprised to witness subsequent high levels of all forms of violence, which will further threaten the attainment of the SDGs.

The best way to prevent threats to peace and security and to achieve sustainable development is to protect children, starting in early childhood, from adverse childhood experiences including all forms of violence. There are well known cost-effective interventions that promote healthy emotional and social development, including investment in parenting competencies, and protecting children and women from violence in families and communities. Investing in such interventions should not be seen as an optional add-on. These interventions are the equivalent to vaccination; they are essential to prevent many new "morbidities", just as infectious diseases are prevented with vaccines. Essential interventions in the health sector should not stop at biomedical interventions; they should include essential psychosocial and public health interventions.

Illustration of mental health

There are also opportunities and challenges for the global community when considering the best ways to invest in mental health. The good news is that mental health is finally recognized as a global health priority. There is consensus that greater investment is needed to make mental healthcare more available and of better quality. However, there is a lack of agreement about what to invest in. Many experts are enthusiastic about the need to cover the treatment gaps, to invest more so that many more people with mental health needs, especially in low- and middle-income countries, can receive adequate treatment. And there is another group of experts that warns against further investments in the status quo and calls for a shift in the paradigm and to focus on the need to fully integrate a human rights-based approach in mental health policies and services.

My mandate supports the position of this second group. In my reports to UN Human Rights Council in 2017 and 2019 I have provided arguments to support the view that global mental health remains a hostage to the legacy of coercion, institutionalization, and overmedicalization. Should we increase investments in such systems, and recommend such systems to low-resource countries? This is another example of the failure which occurs if human rights and the right to health are addressed selectively. For example, there is a high prevalence of institutional care, coercive practices, and excessive use of biomedical interventions in mental healthcare in the high- and middle-income European region. To a large extent this is an outcome of paternalistic approaches and biomedical models that have been the main drivers of mental health practice for many decades. The prevailing focus on "fixing disorders" and providing people experiencing mental health conditions with only their basic needs (treatment, food, housing), while denying them their civil rights and freedoms, resulted in huge numbers of institutionalized and overmedicalized people in many parts of the world, including in high-income countries where funding restraints have not been the driver of such inadequate care. This type of status quo is absolutely unacceptable.

The last few decades in which the biomedical model has dominated mental healthcare, with its promise to end stigma and discrimination, have had the opposite effect. Such a reductionistic approach has failed as it has disempowered people and undermined their human rights. This scenario, when mental healthcare services are based on discriminatory laws and practices, and thus can do more harm than good, should be a sobering lesson for the global community as it deliberates on how to invest in mental health in low resource countries.

The early AIDS movement provides good lessons for the global community as it develops policies and services to address other health-related issues, such as non-communicable diseases and mental health conditions. Advances in biomedical sciences will work for good only if human rights-based approaches are seriously integrated in global and national efforts to invest effectively in the health of individuals and populations. The principles of non-discrimination, participation, empowerment, and accountability need to be applied in all health-related policies, and there should be no exceptions to the full application of these principles.

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VIEWPOINT

What Does it Mean to Adopt a Human Rights-Based Approach to Drug Policy?

DAMON BARRETT, JULIE HANNAH, AND RICK LINES

The 25th anniversary of *Health and Human Rights* comes at an interesting time in international drug policy. Not long ago, references to human rights could be, and were, easily vetoed from draft UN drug policy resolutions. At best, human rights were included in declaratory preambles of omnibus resolutions, and largely forgotten in any substantive sense. Drug policy NGOs, for the most part, did not tend to foreground human rights, while human rights NGOs all but ignored drugs.

The past decade, however, has seen changes. Human rights are now central to international drug policy debates and are causing considerable controversy. Drug policy NGOs have made significant progress in highlighting the human rights dimensions of the field, while human rights NGOs have more and more come to see the issue as one warranting close attention. Indeed, it has become something of a cliché to say that a 'human rights-based approach to drug policy' should be adopted. The fact that this is so frequently heard, from NGOs and some governments, is a major step forward. But while much of the work to date has involved identifying rights violations in drug control, we still have not unpacked what adopting a human rights-based approach might mean.

Reconceptualising drugs issues as human rights issues

Over the years we have heard a good deal of scepticism about human rights in drug policy. Usually this has to do with the political palatability of human rights language when trying to achieve a certain goal. There is merit to that worry. No sensible human rights advocate claims your best foot forward is always human rights *language*. But if human rights are reduced to simply a functional strategy to some other end, then they can be used or discarded at will. This does not do justice to so fundamental an idea.

A human rights approach to any issue foregrounds the relationship between the individual and State power; this is especially the case with drug control. At present the burden falls on those opposing certain drug laws, such as criminalising personal possession, to explain why they don't work. A human rights approach reverses that burden, placing it instead on the government to justify the limitations on rights and freedoms that such laws entail, and to be accountable for their decisions. Few governments have ever done this. But when these laws have been challenged on human rights grounds in constitutional courts, Governments have lost, as they did with regard to cannabis possession and the right to privacy in South Africa.

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This Viewpoint was originally published on the Journal website on 7 January 2020 and can be viewed here: https://www.hhrjournal.org/2020/01/what-does-it-mean-to-adopt-a-human-rights-based-approach-to-drug-policy/.

What does human rights law say about drugs?

Drug policy work is complicated by the existence of three nearly universally adopted UN drug control treaties that form the basis of national drug laws around the world. Those treaties enshrine a focus on law enforcement and eliminating supply, where a great deal of human rights problems are evident. International human rights law has an important role to play in rebalancing the legal framework for drug control, but until recently, however, there has been no comprehensive study to investigate what human rights law has to say. The *International Guidelines on Human Rights and Drug Policy* are the first effort to do just that. With the financial support of the German and Swiss governments, and United Nations Development Program, the guidelines development involved over three years of research, regional consultations in Colombia, Thailand, and South Africa, including people who grow illicit crops and those who use drugs, as well as multiple expert drafting meetings. The Guidelines address a catalogue of affected rights, as well as specific groups-women, children, indigenous people and people deprived of their liberty. Each section in the Guidelines provides clear, actionable statements clarifying states' legal obligations, supported by an extensive commentary setting out the legal sources used.

A radically different approach: Human rights as the entry point

The Guidelines begin with human rights, and in drug policy this is a radically different starting point. They are not organised by, typically, "demand reduction" and "supply reduction". The framework is not based on drug policy objectives. Rather, the focus is reversed so that human rights are the entry point.

Key to this is the section on 'foundational principles' which frames the Guidelines explicitly in human rights-based approaches to drug policy. These principles, however, can mean little in the abstract. The point is their application in context, and it is these principles that may ask some of the most searching questions of drug policy. For example, the inherent dignity of the human person as the basis for human rights is reflected in Article 1 of the Universal Declaration of Human Rights. However, a widespread view of addiction is that dignity is not inherent, but contingent-lost through addiction and regained through intervention. The Guidelines reject this theory of dignity, because the absence of dignity and the power to restore it, is the absence of rights, and a licence for unaccountable intervention.

The politics of implementation

The Guidelines also include basic structural elements that should be in place. For example, they call on states to:

- review drug laws and policies for human rights compliance
- subject new laws and policies to transparent processes of human rights risk and impact assessment
- undertake budgetary reviews to ensure the realisation of the right to health in relation to drug use and dependence
- incorporate human rights into data collection and indicators.

This, of course, involves complex political work, but foregrounding the politics of such work is also a key feature of a human rights-based approach.

A frequent call at conferences is that drug policy should be based on 'evidence, not ideology'. Usually this just means 'evidence and not the moral objection to drug use some people (or governments) seem to hold'. But rejecting this necessarily entails embracing another view. Some of the biggest debates needed in drug policy are not about evidence, as such, but underlying principles or ideals. The evidence is fundamental, no doubt. But even the most exemplary research will be deployed in the service of a government's policy directives to achieve its political ambitions. There are values and biases underpinning the technical language of, for example, cost benefit analysis or epidemiology, that can make contested ideas seem seductively neutral.

Moreover, what is researched, how one views the evidence, what interventions are put in place and how one measures success are all affected by these underlying values. Consider harm reduction. For some it is a collection of interventions borne out of pragmatic and utilitarian public health thinking-interventions for which the right to health helps argue. But for others harm reduction is a social justice movement, within which inequity is the primary concern. There are many crossovers. But which perspective one takes will have a significant effect on what questions get asked and what solutions come into focus.

Prioritizing human rights over drug policy

A human rights-based approach suggests something simple: a commitment to placing priority on human rights over drug policy objectives. Make no mistake, this is a very controversial position. During the drafting of the Guidelines, this hierarchy was written into the introduction. One reviewer said it would 'kill the document'. Being (seen to be) tough on drugs wins votes. For some governments, moreover, drug control is a constitutional obligation. In international law, addiction is seen as an 'evil' that states have 'a moral duty to combat', and drugs are viewed as a threat to the very foundations of the state. Human rights are a threat too-to the unaccountable power that such rhetoric enables.

There is a tendency, when human rights are discussed, to think of the most egregious abuses. In drug policy it is the death penalty that has dominated. At the UN, states will say we need to adopt a human rights-based approach and immediately follow this with a rejection of the death penalty. But we should take care to avoid setting the bar for a human rights-based approach so low. We should also be concerned about those governments and multilateral agencies that perhaps too easily embrace human rights language. A tokenistic use of human rights might result in them being referred to in the preamble of a strategy but not being included in implementation; or by states criminalising those whose rights they claim to uphold; or states claiming to support harm reduction and the right to health, but failing to take the logical next step and apply the principle of equivalence to prison services. Indeed, states may express concern about the death penalty for drugs, but continue to facilitate cross border drug enforcement in death penalty states. In this way, human rights language risks becoming an egregious form of window dressing for the inequities and power imbalances that human rights-based approaches should disrupt.

In his spirited dissent to a 2002 South African Constitutional Court judgement upholding the prohibition of cannabis, Justice Albie Sachs noted "[T]here is the tendency somnambulistically to sustain the existing system of administration of justice and the mind-set that goes with it, simply because, like Everest, it is there". That decision has recently been overturned. Sach's dissenting vision giving priority to rights protections over drug policy objectives became the majority.

Our challenge now is to realise the transformative potential of human rights in drug policy, while remaining vigilant against their subversion.

Health and Human Rights Journal

VIEWPOINT

Impunity: Undermining the Health and Human Rights Consensus

Chris Beyrer

Impunity: exemption from punishment or freedom from the injurious consequences of an action. A noun. (Oxford English Dictionary, 2019).

There has perhaps always been a greater burden of unpunished human rights violations than punished ones. The newest mechanism for accountability for rights abuses, the International Criminal Court, has to date successfully prosecuted only one charge of the most grievous abuse, genocide, that of the case of the Srebrenica massacre of some 8,000 Muslim men and boys in Bosnia in 1995. Yet the post war consensus enshrined in the 1948 Universal Declaration of Human Rights has continued to serve as a basis for health and human rights thinking, advocacy, scholarship, and action. And impunity for rights violations, including those of the right to health, has been a continued challenge for rights-focused actors, and for those seeking justice and redress. It is now transparently clear, however, that this consensus faces grave threats in the current period of widespread rights violations, toleration for abuses against vulnerable minority groups, and the active denial of health rights by governments and regimes from Myanmar to the United States, Russia, China, and far too many others. What are the drivers of rising impunity and what can those concerned with health and human rights, including scientists, health professional organizations, and civil society groups, realistically do to address these threats?

One particularly grave set of abuses may help us consider these issues. The Assad regime in Syria has been accused of an extraordinary array of rights abuses in the ongoing Syrian civil war—torture, extra-judicial executions, the use of banned weapons of war including chemical agents on civilian populations, and of widespread violations of international humanitarian laws, including the bombing of health care facilities and other attacks on providers.[1] Recent reports by the *New York Times* and others have credibly shown that Assad's allies, notably the Russian military under President Vladimir Putin, have undertaken deliberate bombings of hospitals in civilian areas.[2] Yet it seems highly likely that the Assad regime will prevail in the Syrian conflict and already has regained control of most of the landmass and population of the country. This outcome would serve as a profound threat to the human rights consensus globally. Imagine Nazi Germany and Japan prevailing in WWII, or the Khmer Rouge being allowed to remain in power after their mass killing of civilians in the 1970s. This is precisely what many would argue is the most likely outcome of the Syrian conflict: impunity for mass atrocities. Impunity for the use of chemical weapons. Impunity for the deliberate bombing of hospitals as a tool of state terror. In such a future, what would restrain govern-

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This Viewpoint was originally published on the Journal website on 14 January 2020 and can be viewed here: https://www.hhrjournal.org/2020/01/impunity-undermining-the-health-and-human-rights-consensus/.

ments from these kinds of abuses of state power?

The absence of US leadership at this juncture is deeply concerning, but abrogation of US leadership on human rights, on impunity for abuses, did not, it must be noted, begin with Donald Trump. The retreat from human rights norms and treaty obligations in response to the 9-11 terror attacks began in the early years of the presidency of George W. Bush. Most egregiously in the 2002 torture memos signed by administration officials including John C. Yoo, Jay S. Bybee and Steven G. Bradbury.[3] The policy laid out in these documents was a clear and direct violation of the Geneva Conventions on the rules of war. It has been argued, and indeed it is virtually impossible to argue against the notion, that these policies enabled the horrors of Abu Ghraib, the widespread torture of alleged enemy combatants at CIA-run black sites, and the outsourcing of suspects for torture to allied countries, including the Assad regime in Syria.[4] Early in his first term as president, Barack Obama made clear that his administration would not be pursuing prosecutions against Yoo, and others from the Bush administration, who had engaged in the development of these abusive policies.[5] Whatever the politics of the moment which compelled this decision, it was a major step in the direction of impunity for rights violations. No one would be held accountable for torture done in the name of US citizens. The director of the CIA black site in Thailand, where suspects were subjected to water boarding and other forms of torture, Gina Haspell, is now the Director of the CIA.[6]

Impunity for rights violations does not only allow abuses to go unpunished and the truth to remain hidden or denied. It has an undermining effect on efforts to redress rights violations. What hope can victims have for justice when it is made clear that widespread extrajudicial executions will be tolerated, as those conducted against alleged drug users under the Duterte regime in the Philippines have been? Or when all nine fellow member states of ASEAN, the Association of Southeast Asian Nations, have supported Myanmar in its denial of abuses against the Rohingya minority—despite what the UN High Commissioner for Human Rights called 'a textbook case of ethnic cleansing'?[7] In one step against impunity, Gambia, on behalf of the Organization of Islamic Cooperation, has successfully brought charges against Myanmar for the Rohingya genocide, in a case that commenced in December 2019 at the UN's International Court of Justice in the Hague.[8] Will it be enough to bring some justice to the Rohingya survivors?

What else can be done to address impunity?

First, it seems essential to strengthen and broaden the evidence base for rights abuses, and for the relationships between rights violations or protections and human health. We have ever more powerful tools, including the explosion of genetic and other forms of biometric data and evidence, to bolster human rights investigations. This is true on the micro-level of forensic DNA evidence, and on the macro-level, such as the use of satellite imagery, which has helped document the burning and razing of Rohingya villages and undermine the regime's claims that such destruction had not occurred.[9] Medicine, and science more broadly, has critical roles to play in addressing impunity with more and better methodologic approaches to human rights evidence collection, analysis, and reporting.

Second, it is more critical than ever for professional bodies and organizations to stand against impunity for rights violations, particularly those which involve medical or other health personnel. The denial of basic health rights to detained migrants and asylum seekers in the United States is an example. The advocacy of the American Academy of Pediatrics on behalf of detained children played a key role in reducing the abusive policy of family separations imposed by the Trump Administration in 2018. In December 2019, physicians in Texas were arrested for demonstrating in support of influenza immunizations for those held in US immigration detention, spurred, at least in part, by the death from influenza of 16-year-old Carlos Gregorio Hernandez Vasquez, an unaccompanied minor from Guatemala, who was found dead in detention on May 20, 2019.[10] He had been diagnosed with influenza a day earlier, given a single oral tablet of Tamiflu, and left without medical supervision overnight.

Third, given that so many of the official bodies charged with protecting rights and addressing impunity, most notably the UN family, have been enormously challenged in this time of nationalism, anti-immigrant sentiment, and rising intolerance, it is all the more critical for civil society to engage in protecting against abuses and demanding accountability. It will take enormous efforts for grassroots organizations to counter the current trend toward impunity. But we have no choice—impunity must be resisted. Imagine a world where it is not.

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VIEWPOINT

How Can We Overcome the Great Procrastination to Respond to the Climate Emergency?

RACHEL HAMMONDS

The climate emergency is undermining human rights progress globally, presenting humanity with a complex problem that demands a transformative approach to our fundamental existence, including what we eat, how we live, and how we travel and commute. Five years ago the editorial in this Journal's issue on Climate Justice and the Right to Health asked if our era will be viewed as the era of the "Great Procrastination" guilty of "Squandering time, dithering on action, and engaging in half-measures woefully incapable of addressing a threat that our best science warns will be more catastrophic and less reversible each year."

International cooperation to address climate change is centered around the Framework Convention on Climate Change (FCCC) and related processes, but in the words of UN Secretary General António Guterres the outcomes of the 2019 25th Conference of the Parties (COP25) to the FCCC were "disappointing". At COP25 state parties failed to advance on 2015 Paris Agreement commitments to act collectively to increase ambition on climate change mitigation and adaptation efforts and related financing mechanisms. Specifically they did not: agree the set of rules governing the new global carbon market (including the introduction of a human rights review), agree terms related to the level of ambition found in their emissions pledges or agree on steps to ensure that climate adaptation financing, including to the Green Climate Fund, is sufficient, predictable, and respected as a legal obligation. These failures have consequences for human rights, and in particular health-related rights of communities on the front line of climate change. How can the health and human rights community contribute to driving the global action and cooperation needed to address climate change and human rights?

Human rights and climate change

Mary Robinson characterizes climate change as, "the greatest threat to human rights in the 21st century" and getting global political leaders to stop talking and act effectively is clearly eluding humanity. The seven Climate Justice Principles developed by the Mary Robinson Foundation offer a rights-based path to engaging with climate change debate and decision making (Table 1).

This approach helps preempt human rights violations by demanding access to information related to the development of all climate-relevant policies and ensuring the engagement of diverse civil society groups in decision-making processes. It includes accountability and rule of law components which ensure access to justice and effective remedies for people whose rights are violated by climate change impacts.

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This Viewpoint was originally published on the Journal website on 10 February 2020 and can be viewed here:
https://www.hhrjournal.org/2020/02/how-can-we-overcome-the-great-procrastination-to-respond-to-the-climate-emergency/.

However, after 20 years of health and human rights advocacy, I question whether these and other human rights principles, are fit for addressing an emergency. How will these principles push the urgent, radical type of global cooperation needed to tackle the climate emergency? If, in the words of Greta Thunberg at the 2019 Davos Forum, "our house is on fire" what do we need to do differently? Wrestling with these questions has led me to identify key challenges with which health and human rights scholars and advocates must engage to be relevant in the Anthropocene Era.

Challenging the economic neutrality of human rights

Firstly we must interrogate the dominant capitalist economic model's role in driving climate change. We need to engage with the arguments advanced by Naomi Klein, among others, about neoliberalism and its promotion of rampant consumption that is hostile to health and the planet. International human rights principles purport to be neutral *vis a vis* economics. However, the role of international law and international human rights in legitimizing the current economic system needs greater exploration. If the current neoliberal capitalist system undermines rights and is a key driver of the climate emergency, human rights scholars need to analyze and advocate for innovative economic climate-friendly models, like the circular economy, that extend beyond focusing on short term profits.[1] Changes are also needed in the global trade regime which exacerbates global inequality, including health inequalities, and contributes to climate change.[2]

Remaining relevant and effective by engaging across disciplinary boundaries

Evidence has shown that development programs and policies are not co-terminus with advancing rights. Similarly, the risk that climate change action may undermine or compromise progress on human rights requires the focused attention of the health and human rights community. Important work is being done to integrate action on climate change and CO2 emissions into sustainable development. For example, Jason Hickel's innovative work challenges us to assess "human development" by linking it with planetary boundaries. Hickel's Sustainable Development Index (SDI) employs five indicators (life expectancy, education, per capita income, material footprint, and CO2 emissions) to challenge mainstream development assessments.[3] His SDI strips away high carbon consumption "CO2 steroids" and excessive consumption, to question the conventional wisdom (including that applied to the Sustainable Development Goals) about which countries should serve as models for sustainable development. For example, the oft cited Scandinavian countries do not score highly on his model as they achieve their gains through Co2 steroids. His analysis shares the same concerns about neoliberal economics and its impact on environmental and human rights. Roberto Bissio claims that Hickel's analysis does not yet account for governance, human rights, or inequalities, all of which are central to Climate Justice Principles. These principles are appealing because they build on a human rights edifice. Health and human rights scholars can contribute to these innovative analyses and actions through their interdisciplinary approaches to development challenges and paradigms.

Table 1. Climate Justice Principles

1. Respect and Protect Human Rights
2. Ensure that Decisions on Climate Change are Participatory, Transparent, and Accountable
3. Harness the Transformative Power of Education for Climate Stewardship
4. Highlight Gender Equality and Equity
5. Share Benefits and Burdens Equitably
6. Support the Right to Development
7. Use Effective Partnerships to Secure Climate Justice

Interrogating our tools and principles

Human rights activists have encountered implementation and accountability challenges for decades. Unfortunately, our solutions are often fragmentary and the goal of universalizing respect for rights remains elusive. We need to acknowledge that our traditional methods and tools may not be sufficiently robust or time sensitive to respond effectively to the climate emergency. Further, the evidence of human-driven devastation of other species and planetary biodiversity may require a fundamental re-examination of the basic tenets underpinning human rights—namely that humans deserve special rights merely because they are human. How do we align the demands of human rights with the rights of other species to exist? How do we make our tools sharper?

Collective action and cooperation

The climate emergency challenges us to redress past and ongoing injustices, including colonialism, that impact on the future of everyone. The effects of climate change are greatest in those parts of the world that contributed least to the problem and have limited capacity to mitigate the impact. Recognition of this imbalance is reflected in the principle of 'common but differentiated responsibilities' (CBDR) anchored in article 3.1 of the Framework Convention on Climate Change. This echoes the language of the International Covenant on Economic, Social and Cultural Rights, which commits State Parties to take steps individually and through "international assistance and cooperation, especially economic and technical" to realize Covenant rights, including article 12, the right to the highest attainable state of physical and mental health.

In the health and human rights field we know that employing the principle of shared responsibility to expand access to anti-retrovirals (ARVs) and anti-malarials has enjoyed limited success. Long-term civil society efforts, mobilization, and dynamism has been crucial to achieve global access to medicines, and maintain the political will to comply with human rights obligations across all government departments. These ongoing challenges show how difficult it is to sustain attention and commitment to ensure human rights commitments are not overlooked when priorities are set. These experiences and insights should inform the strategies of those who advocate for, amongst others, the Green Climate Fund, which aims to mobilize funding at scale to invest in low-emission and climate-resilient development.

Conclusions

As health and human rights scholars, advocates, and activists, we need to push for transformative, progressive, rights-based engagement with the climate emergency. In parallel with these efforts we need stronger global cooperation and a profound interrogation of the neoliberal ideology that drives the culture of consumption and related economic policies. Growing economic inequality, mass migration, and the climate emergency can push humanity towards greater cooperation or dangerous nationalist policies such as those in countries as diverse as Brazil, the United States, the Philippines, India, Turkey, and Hungary. Clearly, we need to recommit ourselves to working with communities the world over to amplify the voice of those who are marginalized or ignored in decision-making processes that affect their lives or, in the case of small island developing states like Kiribati, their very existence. However, we also need to acknowledge the limitations of our tools and work across disciplinary borders to strengthen global cooperation. The current UN-based multilateral system has many flaws, but it is the only means we have found to bring countries together to address global problems. To remain relevant and influential the UN needs to engage broadly with youth, for the climate emergency is intimately intertwined with the rights of future generations.

When powerful countries, like the United States, actively resist engagement in multilateral efforts to address the climate emergency, while undermining international progress on sexual and reproductive health rights (SRHR), health and human rights advocates must continue to call for global action at every opportunity and engage with other disciplines to achieve the necessary rapid transformative actions. Continuing as we have done is not tenable. People in high carbon consumption countries need to reflect on the global consequences of development that have contributed to the human rights gains they enjoy. To deliver on health rights for all we need a radical rethink of the way we live and interact with the planet.

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Health and Human Rights Journal

VIEWPOINT

COVID-19 and Detention: Respecting Human Rights

JOSEPH J. AMON

The world is increasingly focused on COVID-19. By March 23, 2020, according to the World Health Organization (WHO), 332,935 people had been diagnosed with COVID-19 in 190 countries and territories around the world and 14,510 had died.[1] In the United States, 35,530 people have been diagnosed with the disease and 473 people have died.[2] These numbers are likely an underestimate, due to the lack of availability of testing, and will, without a doubt, rise.

COVID-19 is a serious disease, ranging from no symptoms or mild ones to respiratory failure and death. There is no vaccine to prevent COVID-19. There is no known cure or anti-viral treatment at this time. Those most at risk, according to WHO, include those over 60 years of age and those with cardiovascular disease, diabetes, chronic respiratory disease, and cancer.[3] WHO further states that the risk of severe disease increases with age starting from around 40 years. The US Centers for Disease Control and Prevention (CDC) identifies additional categories at risk, including individuals with blood disorders, chronic kidney or liver disease, compromised immune system, endocrine disorders, including diabetes, metabolic disorders, heart and lung disease, neurological and neurologic and neurodevelopmental conditions, and current or recent pregnancy.[4] That means that a large proportion of people are at risk, especially in middle- and upper-income countries which have aging populations.

Recognizing the importance of physical distancing as the main strategy for preventing transmission, public health officials have recommended extraordinary measures to combat the spread of COVID-19. Schools, courts, sports and cultural spaces, and other congregate settings have been closed. In the US, 50 states, seven territories, and the District of Columbia have taken some type of formal executive action in response to the COVID-19 outbreak.[5] As of March 23, 2020 five states (California, Illinois, New Jersey, New York, and Ohio) prohibit gatherings of any size; nine states prohibit gatherings of more than 10 individuals (Colorado, Hawaii, Louisiana, Maine, Maryland, Texas, Utah, Vermont, and Wisconsin); four states prohibit gatherings of more than 25 individuals (Alabama, Massachusetts, Oregon, and Rhode Island) and eight states prohibit gatherings of more than 50 individuals.[6]

This summary presents a picture of extraordinary numbers already affected and at risk and unprecedented response. However, one area where there has been too limited of a response to date is action to prevent transmission in detention centers, including jails, prisons, and immigration detention facilities. All of these institutions are closed environments, much like the cruise ships that were the site of early concentrated outbreaks of COVID-19. Detention facilities are particularly of concern because of crowding, the proportion of vulnerable people detained, and often limited medical care resources. People in detention facilities cannot achieve the physical distancing needed to effectively prevent the spread of COVID-19.

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This Viewpoint was originally published on the Journal website on 24 March 2020 and can be viewed here: https://www.hhrjournal.org/2020/03/covid-19-and-detention-respecting-human-rights/.

Showers, toilets, and sinks are shared. Food preparation and food service is communal. Staff arrive and leave, providing a link between the community and the detention center, often—because of limited testing and asymptomatic infection—without adequate screening. Yet, more than three months since COVID-19 emerged, the US CDC lists guidance for schools, childcare centers, colleges, workplaces, faith-based organizations, community events, homeless shelters, healthcare professionals and retirement communities but not for jails, prisons, or immigration detention centers.[7]

Police, first responders, and correctional officers are also at risk as they are less able to practice physical distancing in their official duties. Unsurprisingly, we are starting to see this population affected and their colleagues who are exposed to them, ordered into quarantine. For example, in Kirkland, Washington, 27 firefighters and two police officers were in quarantine along with four King County, Washington, paramedics. In San Jose, California 77 firefighters were in quarantine.[8] More than 140 firefighters were quarantined in Washington DC.[9] Six New Jersey police officers tested positive for COVID-19 and another 20 officers were under self-quarantine, as of March 19.[10]

So far, two state prison employees tested positive for COVID-19 in California, two in Michigan, a county jail officer in Washington state, and one Georgia Department of Corrections employee tested positive.[11] A corrections officer at Rikers Island (NY) and an inmate have tested positive; an investigator with NYC's department of corrections died of COVID-19.[12] In Wisconsin, a prison doctor tested positive.[13]

In New Jersey, a member of the medical staff at Elizabeth Detention Center in New Jersey a private immigration detention center tested positive for coronavirus.[14] A correctional officer at Bergen County Jail (NJ), which contracts with Immigration and Customs Enforcement (ICE), also tested positive for COVID-19.[15] As a result of these cases, hunger strikes have broken out in three ICE detention centers in New Jersey "as detainees protest what they describe as deteriorating conditions and a failure to adequately address the potential spread of COVID-19".[16]

If police, first responders, and corrections officers are significantly affected by COVID-19, whether through being infected, exposed by detainees, their fellow officers, or in the community, large numbers will be unavailable to work due to self-quarantine or isolation, at the same time that large numbers of detainees who are potentially exposed will need to be put into individual isolation or transferred to advanced medical care, putting tremendous stress on detention facilities.

States have an obligation to ensure medical care for prisoners at least equivalent to that available to the general population. According to the United Nations Committee on Economic, Social and Cultural Rights, "States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services."[17] The UN Human Rights Committee has also interpreted the International Covenant on Civil and Political Rights as requiring that governments provide "adequate medical care during detention" and the Committee Against Torture has found that failure to provide adequate medical care can violate the Convention Against Torture's prohibition of cruel, inhuman or degrading treatment.[18] The United Nations Standard Minimum Rules for the Treatment of Prisoners (known as the Nelson Mandela Rules) provide further protections.[19]

To address the risk in detention settings, detention centers must first and foremost have plans in place to prevent or limit the outbreak of COVID-19, to protect the health of all detainees, and to treat the disease should any detainee acquire it. Beyond this, to achieve physical distancing and protect individuals at high risk, detention centers should release individuals in detention who are arbitrarily detained as well as asylum seekers, those in pre-trial detention, and migrant children. Detention centers should also consider reducing their populations through appropriate supervised or early release of detainees whose release may be soon or who are in pre-trial detention for non-violent and lesser offenses or whose continued detention is in an equivalent manner unnecessary or unjustified. Finally, individuals who are considered at high risk for severe disease or death should be released or put into alternative forms of custody if facilities cannot ensure their protection or care.

These are not impossible steps and some national and local governments are beginning to take action. In Spain, immigration authorities began releasing people held in immigration detention centers on March 18.[20] In Belgium, federal authorities released an estimated 300 migrants from detention on March 19 because detention conditions did not allow for safe physical distancing.[21] The UK government released 300 people from detention centers following legal action which argued that the government had failed to protect immigration detainees and failed to identify which detainees were at particular risk of serious harm or death if they do contract the virus due to their age or underlying health conditions. In the United States, in Alabama, prison officials announced that they are halting intake of inmates from the state's county jails for the next month.[22] In Chicago, Illinois, the Cook County Jail released several detainees deemed "highly vulnerable to" COVID-19.[23] In Maine, the court system vacated all outstanding warrants (numbering over 12,000) for unpaid court fines and fees and for failure to appear for hearings, to reduce jailing.[24]

However, like everything related to this pandemic, more needs to be done faster. And in lower-income countries which have yet to see a large number of cases, now is the time to act. While these countries may have relatively fewer people incarcerated per capita than middle- and upper-income countries, conditions are often worse, with severe overcrowding, lack of medical facilities, and a high proportion of detainees who are in pre-trial detention and who fall in high risk categories for severe COVID-19 disease or death.[25] Releasing detainees is a critical part of the COVID-19 response and is both good public health and human rights policy.[26]

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VIEWPOINT

Lessons from HIV to Guide COVID-19 Responses in the Central African Republic

Pierre Somse and Patrick M. Eba

Almost 40 years ago, the Central African Republic, like other countries in Africa and around the world, was confronted with the HIV pandemic that would shake the human, social, and economic foundations of entire societies. Since the beginning of that epidemic, more than 32 million people have died of HIV-related illnesses globally.[1]

The HIV epidemic was first presented as a disease of homosexuals, then of people who use drugs, sex workers, and foreigners.[2] The associated stigma to those categorizations remains one of the greatest challenges to the response to HIV.[3] In the Central African Republic, a 2018 study found that 45% of people living with HIV had experienced stigma and more than 85% had faced discrimination, including in health care settings.[4]

Like HIV, the spread of the 2019 coronavirus disease (COVID-19)—which as of March 31, 2020, had infected more than 750,000 people globally and caused 36,405 deaths—is accompanied by rampant stigma.[5] Around the world, stigmatizing behaviour is reported against those diagnosed with COVID-19 and people perceived as potentially infected with the coronavirus, often because of their national origin.[6] In the Central African Republic, the announcement of the first COVID-19 positive person—a Catholic missionary who had lived in the country for many years and had just returned from a trip to Italy—led to verbal and written attacks against the patient, and Catholics and foreigners generally considered to be vectors of the disease.[7] Although several COVID-19 positive people diagnosed in the country were nationals who had returned from abroad, widespread stigma from the first case fuelled through social media, and the sensationalist press has ingrained in the collective imagination that foreigners are the vectors of the disease. Addressing the harms of stigma and misinformation must thus be a priority with COVID-19 and indeed effective responses to the pandemic would greatly benefit from all the lessons of the multi-sectoral and rights-based approaches to the HIV epidemic.

Five lessons from the HIV response

COVID-19 is very different from HIV in its modes of transmission and the rapid global spread of this pandemic—which has led to the quarantine of one fifth of the world's population—is unprecedented.[8] However, the four decades of response to the HIV epidemic offer lessons that are vital for the fight against COVID-19

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This Viewpoint was originally published on the Journal website on 1 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/04/lessons-from-hiv-to-guide-covid-19-responses-in-the-central-african-republic/.

and the stigma that it creates.[9] Five of these lessons are particularly relevant.[10]

1. *Scientific evidence and correct information on the pandemic*

Effective public health responses must be grounded in sound scientific evidence on the modes of transmission of the epidemic, its prevention, and (potential) treatments. Scientific evidence must guide the actions of political leaders and decision-makers. Health experts and health institutions—supported by the World Health Organization (WHO)—play an essential role in the development and dissemination of scientific data on the epidemic and response. Evidence on the prevention and management of COVID-19 must be well communicated to the media and communities, with special efforts made to address 'fake news' and debunk myths.

Positive experiences from countries facing the epidemic should guide responses elsewhere. In the fight against HIV, experiences from Senegal, Thailand, Switzerland, and Uganda were systematically described and used as good practice. In the context of COVID-19, experiences from China and South Korea are already being used and insights from early successes should be made readily available.[11]

1. *Community involvement*

However, scientific evidence by itself is not sufficient to end fear, combat stigma, and ensure community involvement in responses to epidemics. Specific additional efforts are needed to educate and mobilize communities. AIDS activists remind us that "whatever is done without communities is done against them".[12] Thus, community actors, youth and women's organizations, patients' associations, artists, opinion leaders, and traditional leaders, amongst others, must be involved meaningfully from the beginning in national responses.

Community engagement is necessary to ensure understanding and acceptance of isolation and other restrictions, and it also has an essential role in monitoring and accountability. Global and national processes must be set up so the community can effectively hold the government and its agencies leading and implementing responses to account.

3. *Challenging stigma and protecting human rights*

The fight against stigma and discrimination is paramount to the response to any epidemic. It requires a combination of behavioural and structural interventions at individual, community, and national levels.[13] It is a crucial component of rights-based public health responses which involve respect of dignity, the prohibition of torture and degrading treatment, the right to health, and the right to food. Some human rights may be limited or subject to derogation when required for the protection of public health. However, the exceptional measures adopted must be in accordance with the law, limited in time, and necessary to combat the epidemic.[14] Further, although criminal law is already being deployed in some contexts in the response to COVID-19, its use should be minimalised.[15]

Upholding human rights in times of epidemics is not only an obligation for states. It is also a public health imperative because it enables adherence to public health messages and it helps build the trust of populations affected and those most at risk.[16] In the Central African Republic, a National charter on the quality of care and the rights of patients, launched on 1 March 2020—Zero Discrimination Day—is a tool to advance the protection of human rights in the context of COVID-19.[17]

A rights-based approach to health helps ensure that no one is left behind and that particular attention is paid to the most vulnerable. In COVID-19 this includes the elderly, those with pre-existing diseases, prisoners, refugees, and displaced persons.[18]

4. *Global and national leadership at the highest level*

Like HIV, the COVID-19 pandemic is not only a health concern, but is also a social, economic, and human security issue. The United Nations Security Council recognised HIV as a peace and security issue on 10 January 2000 when it met to discuss the impact of the epidemic in Africa. This was the first time the Security Council had addressed a health issue as a threat to peace and security, paving the way for the adoption of Resolution 1308 on HIV/AIDS and international peacekeeping operations.[19]

Responding to pandemics such as HIV and COVID-19 calls for a multi-sectoral approach that mobilizes leadership at the highest level. From Malaysia to Uruguay, to Italy and the Central African Republic, heads of state and government are personally engaged in the response to COVID-19 and are overseeing the implementation of measures to curb its spread. The involvement of heads of state is needed to bring all departments and institutions into the response, to activate crisis mechanisms and resources, and to convey the urgency of the situation.

5. *Partnership and global solidarity*

The HIV epidemic is a formidable example of multilateralism and global cooperation. Thanks to community activism, international solidarity, and cooperation in the fields of science and medicine, 24.5 million people are on antiretroviral treatment today, mostly in low- and middle-income countries.[20]

The United Nations Secretary-General and the Director General of WHO at the G20 Leaders' Extraordinary Summit on COVID-19 on 26 March 2020, stressed the urgent need to accelerate global partnership and solidarity in the response the pandemic.[21] This solidarity must be anchored in a multilateral framework to support and finance the global response and recovery with specific attention to countries most affected and those most fragile. These principles are further articulated in the Secretary General's report, Shared responsibility, global solidarity: Responding to the socio-economic impacts of COVID-19.[22]

With a health system severely weakened by decades of political instability and conflict, one of the lowest ratios of qualified health workers per capita in the world, and more than half its population in need of humanitarian assistance, the Central African Republic is one of the most fragile countries facing COVID-19.[23] Early measures adopted by the government with the support of WHO, MINUSCA, the World Bank, UNICEF, and other UN agencies and partners, appear to have been effective with only six primarily imported cases of COVID-19 recorded at the end of March and limited evidence of local transmission. But the window is narrowing for effective action and for full deployment of international solidarity to beat the pandemic in the Central African Republic and elsewhere.

Time for courageous and multilateral action against COVID-19

Now is the time for bold approaches against COVID-19 grounded in scientific evidence, community involvement, human rights protection, and leadership. Courage in the face of this pandemic means having the strength to recognize that the solutions do not lie within national borders but require a coordinated, transparent, and truly global response. We must mobilise all the technological, medical, and financial resources available globally to act decisively against this pandemic in a multi-sectoral, human rights framework. These are the lessons from our joint response to HIV. We ignore them at our own peril.

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VIEWPOINT

The Evolution of the Right to Health in the Shadow of COVID-19

LISA FORMAN

As a graduate student in the early 2000s coming to grips with the meaning and interpretation of the right to health, few publications had as great an impact on me as the Harvard Law School and Francois-Xavier Bagnoud (FXB) Center's 1993 "Interdisciplinary Discussion on Economic and Social Rights and the Right to Health."[1] It captured a discussion between multiple heavy hitters of the field, including Jonathan Mann, then head of the FXB Center, Philip Alston, chair of the UN Committee on Economic, Social and Cultural Rights, Martha Minow, a Harvard Law School professor, Albie Sachs, soon to be a member of South Africa's first Constitutional Court, and Paul Farmer, at that point an assistant professor at Harvard Medical School. The discussion transformed my understanding of human rights from laws found in 'black-letter' texts and court judgments, to a far more socially-generated, dynamic model of norms and standards. My light-bulb moment came when Martha Minow quoted Judith Shklar's insight that "civilization advances when what was perceived as misfortune is perceived as injustice."[2] In a seemingly impossible fight to expand the right to health to include universal access to affordable antiretroviral medicines during a global pandemic, Shklar articulated the social and political processes necessary for a radical transformation to take place. That global access to antiretrovirals subsequently shifted so dramatically and rapidly deeply underscored for me, as a junior scholar, that global crises could transform both our conceptions of health rights and justice and material outcomes.

It is poignant to revisit that insight in the context of the COVID-19 pandemic. As I write in early April 2020, extraordinary lockdowns and isolation measures affecting billions of people worldwide are in place to stop the explosive spread of SARS-CoV-2. The scale and impact of these measures are such that health and human rights scholars will likely be exploring their legitimacy, necessity, and proportionality for years to come. Some on social media are suggesting these steps show that for once policy-makers have placed health above the economy. But the rampant global spread of COVID-19 is likely a result of many governments' reluctance to take the necessary steps at a far earlier stage, including because they did not want to spook markets. Those steps would have included wide-spread testing, contact tracing, and more adequately preparing health care settings for COVID-19 patients. Health care systems throughout Europe and North America have struggled to mount adequate public health and clinical responses, with facilities overwhelmed, basic testing and protective gear in short supply, and care triaged to those with the best chance of survival.[3] These failures are exposing deep vulnerabilities and inequities within universal health care systems in high-income countries, raising tremendous concerns about what this pandemic will mean for health systems in low and middle-income countries and for the roll-out of universal health coverage (UHC).

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This Viewpoint was originally published on the Journal website on 1 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/04/the-evolution-of-the-right-to-health-in-the-shadow-of-covid-19/.

In many respects, this pandemic is deepening crises of social, economic, and health inequities created by decades of neoliberal economic supremacy. The neoliberalism which was only nascent 25 years ago now dominates global decision-making, manifesting in reduced health spending for all countries (including under austerity) and the growing deregulation, privatization, and commodification of health care like other social sectors.[4] These tensions play in relation to interpretations and implementation of UHC, in particular between whether to focus on strengthening comprehensive health systems or support discrete, vertical, selective pro-poor interventions.[5] Many health and human rights scholars had already been contemplating critiques that a right to health that did not directly address these conflicts risked becoming a 'handmaiden' to a neoliberally-inflected global health policy which reinforced rather than remediated health inequities.[6] Such tensions are being brought clearly to the surface during this pandemic which is ravaging economies, and exposing the inadequacies of universal health care systems, social safety nets and precarious employment. Indeed, just as HIV/AIDS did, COVID-19 is exposing the fault-lines and vulnerabilities of the current social and economic system, with infection rates already mapping income gradients in some places.[7]

How policy-makers respond will fundamentally shape key right to health questions, including how we understand government responsibilities towards health and well-being, and the practical meaning of an entitlement to the highest attainable standard of physical and mental health and to living conditions conducive to their health and wellbeing. Government responses are also raising concerning questions about the impact of the pandemic on civil and political rights. For over 13 years Freedom House has documented a global democratic retreat, marked by rising nationalist populism and civil society crackdowns.[8] Governments around the world, in response to COVID-19 have been rushing to expand emergency powers of surveillance and detention, and to place restrictions on human rights for political purposes.[9] There is a risk that regressive responses to COVID-19 could move us even closer to a 21st century defined by 'neo-illiberalism', in which economic neoliberalism combines with political illiberalism and xenophobic nationalism to erode human rights, deepen health inequalities, and undermine the realization of global health policies like UHC.

COVID-19 as a systemic shock that could bring health and human rights to the fore

COVID-19 infections and responses underscore that the indivisibility of health and a range of human rights is not just a theoretical proposition: effective public health measures rely on public trust and the existence of affordable and accessible testing and health care for those who need it. Now, more than ever, scholars and practitioners of health and human rights must move quickly to assert human rights standards to guide policy and protect those most vulnerable to both infection and neglect. This crisis reinforces the pre-existing challenge for the right to health to evolve to meet the health challenges of our time.

Before COVID-19, I had thought of this evolution in the true Darwinian sense of incremental biological processes of natural selection where organisms must either successfully adapt to shifting external conditions or face extinction. My concern for some time has been that if the post-World War II project of human rights were not to land (like natural law) on the litter-heap of history, it must transform itself from within and adapt to a vastly changed global environment from that in which the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and even General Comment 14 were written. Yet in the early stages of a global health pandemic which is affecting us where we live and work, and where we are most vulnerable, it seems likely this evolution will be not so much slow and incremental than dramatic and precipitous.

British sociologist Graham Scambler suggests that COVID-19 is functioning as a 'breaching experiment': that disrupting the normal social order allows us to see its rules more clearly.[10] Already the dark unspoken rules of economic supremacy are becoming visible, including intimations from policy-makers and media that the cure for COVID-19 cannot be worse than the problem itself, and that saving the economy might require sacrificing those most vulnerable, including the elderly.[11] For those who have long worked in HIV/AIDS, on LGBTQI rights, for the disabled, on racial and indigenous justice, to name a few, this rhetoric is familiar. The global pandemic can help expose such truly disturbing priorities and built-in inequities within our social and political systems.

From a human rights perspective, a 'breaching incident' like COVID-19 could generate tremendous change. Oona Hathaway has suggested that major shifts in human rights practices have often occurred because of "[m]ajor shocks to the system [which] provide limited windows of opportunity for effecting large changes in the system."[12] Indeed, the shock-response impact of crisis is embedded within the genesis of the United Nations and international human rights law, created in response to the atrocities of World War II.

In exposing the shadowy biases of our current economic and health systems and underscoring government responsibilities to assure COVID-related prevention and treatment, this pandemic may illuminate the value and meaning of the right to health: that inaccessible and unaffordable health care for many desperately ill and dying people is less a misfortune than injustice. That sacrificing the poor, elderly, ill, and marginalized for the sake of economic growth is wrong. And that in this moment of global crisis, countries should not turn inwards to self-protection at all costs but should also engage in the acts of solidarity, innovation, and assistance urgently needed to meet the grave health and humanitarian needs of this pandemic.[13]

The imperative to evolve human rights also requires our field to engage in some uncomfortable self-inquiry. We need to identify and eradicate the inequities inherent in our essential precepts, and 'de-colonize' global health and human rights.[14] An illustrative example: when I first read the 1993 Harvard Roundtable discussion, it never occurred to me that of the seventeen participating scholars, only three were women and only two were from outside the United States. That these disparities are so obvious today reflects a significant sea-change in our ability to recognize certain types of inequities, including the startling lack of racial and gender representation in key institutions of public and global health.[15] As Shklar intimates, we have advanced by being able to recognize that these inequities are not misfortunes of nature but inequities socialized into the fabric of social and political life that drive even well-intentioned global health and human rights institutions.

This pandemic may catalyze responses to pre-existing challenges within health and human rights, changing our understanding of the responsibilities governments have to protect domestic and global health. It may also promote a deeper inquiry into the ways that inequities are reinforced by our institutions, systems, and actors, including within human rights and health.

The challenge for our field is to counter regressive policies that do not meet the human rights standards of non-discrimination, accountability, necessity, and proportionality; to consistently push for accessible, affordable care for those who need it; and to bolster and transform the standards, guidance, and protections that human rights offers when it comes to health writ small and large, especially when it comes to regressive and illiberal social and economic policies. Now more than ever we need to transform the right to health to meet the challenges of this moment and to push towards a far different understanding of health justice for the many millions of people who will be infected and affected by this pandemic.

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Health and Human Rights Journal

VIEWPOINT

Anti-Roma Racism is Spiraling during COVID-19 Pandemic

Margareta Matache and Jacqueline Bhabha

There is a new global comity taking shape. Across the world, from the markets of Wuhan to the streets of New York, Rome, Rio, and Delhi, people are sharing the experience of facing the COVID-19 pandemic as a health, social, and economic threat. But there is a darker side to this collective danger—a license to unleash racism against stigmatized groups. We have seen this at national borders, as countries hurry to separate "them" from "us." But we are also seeing this within countries—as the COVID virus compounds the virus of racial hatred via politician, policy-makers, journalists, or social media. The discriminatory treatment of Europe's Roma minority is a brutal case in point.

On April 7, 2020, the European Union (EU) Agency for Fundamental Rights, the Organization for Security and Co-operation in Europe Office for Democratic Institutions and Human Rights, and the Council of Europe issued statements drawing attention to the disproportionate risks that Romani people face in relation to contracting COVID-19.[1] A few days earlier, Helena Dalli, the EU Commissioner for Equality called on EU Member States to implement urgent measures for Romani communities, because COVID-19 exacerbates their exposure to structural inequality. However, despite these requests and the clear mandates of international and European human rights treaties guaranteeing equality, non-discrimination, and dignity for all people, there is a frightening escalation of populist and racist voices intent on blaming the Roma community for this pandemic.

From Slovakia to Romania and Bulgaria, states have enacted disproportionate or militarized measures targeting Romani neighborhoods or towns. Some of these measures are driven by a racist narrative that casts Roma as a collective health and safety threat. The Bulgarian government has imposed particular measures, including road blocks and police checkpoints, on several Romani neighborhoods despite no evidence of COVID-19 positive test results there.[2] A Bulgarian Member of the European Parliament, Angel Dzhambazki, speculated that Romani "ghettos [could] turn out to be the real nests of contagion."[3]

Early on in the Romanian conversations regarding COVID-19, the prefect of Timis, one of the largest counties in Romania, suggested that the infection of a school pupil had been caused not by virus spread within the classroom but by some "other environment" as the child "belonged to a Romani family."[4] Non government organizations (NGOs) also drew attention to abuses at the local level, including police abuse or restrictions on Roma from entering cities, such as in Ponorâta, Romania. In North Macedonia, nine Romani musicians were singled out of a group of 200 and forced into quarantine, in spite of the Minister of Health's announcement that the whole group was going to be quarantined.[5] The mayor of Kosice in Slovakia

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This Viewpoint was originally published on the Journal website on 7 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/04/anti-roma-racism-is-spiraling-during-covid-19-pandemic/.

suggested Roma could pose a particular health risk because they are a "socially unadaptable people."[6]

Some of these discriminatory pronouncements are harsh reminders of earlier European anti-Roma racist measures. In the centuries of Roma enslavement, enslaved nomadic Romani people were forbidden from entering the city of Bucharest during outbreaks of the plague.[7] Similarly, as the National Centre for Roma Culture noted recently, Romanian fears that Roma would contaminate the "Romanian race" with typhus led to anti-Roma measures in the 1940s.[8] These sentiments are finding favor again today. They must not. Instead, states must act now to protect the rights, including health rights, of all people within their jurisdictions, including their Roma populations.

It is not just politicians who have been uttering racist falsehoods. Across Europe, a range of media outlets have been broadcasting similar narratives blaming Roma, especially those recently returning from other countries, for spreading COVID-19. The Romanian media is one of the worst examples. An unashamedly crude racist narrative has exploded across the country, exploiting the relatively large number of confirmed cases and deaths in Tandarei, a small Romanian town, to sow fear and hatred. The media do not appear to have inquired if, and if so why, young Roma without underlying conditions are over-represented among the dead. A national newspaper, taking another equally unfounded approach, misinformed the public and risked Roma lives by implying that Romani people are immune to the virus—a dangerous idea rooted in the racist assumption of inborn Roma genetic resistance to disease.[9] Local and national newspapers have raged a racist, hateful, and life-threatening campaign of anti-Roma propaganda.[10] As a predictable corollary to this outburst of racist hate speech, countless anti-Roma dehumanizing, degrading, and deeply offensive fake posts and "news" on Facebook remain unaddressed by that platform.

Like other racialized and marginalized communities, Roma need humane and protective measures. These must recognize their structural inequalities and be tailored to the specificities of their racialized vulnerability—access to water, community facilities, health care assistance, direct cash payments, and income supplements to counterbalance inevitable drop offs in daily wage labor. With 80% of European Union's Roma living below the poverty line, 30% with no running water, and 46% without an indoor toilet or shower, access to non-discriminatory and high quality care is critical for their health and well-being.[11] In the Western Balkans, and elsewhere, many impoverished Roma are forced through discrimination and structural injustices into the informal economy and do not have the luxury of work benefits or paid unemployment to stay at home. In Bosnia and Herzegovina alone, only 11% Roma are employed in the formal economy.[12] If Roma human rights entitlements had been fulfilled rather than willfully neglected, these structural inequalities would have decreased long before this current pandemic.

Forced evictions and forced migration in search of survival both result in high levels of homelessness for many Romani people in many EU member states, including Romania, Italy, Sweden, and Denmark. According to the Institute of Global Homelessness, across Europe "Roma populations have been shown to be more at-risk for homelessness than non-Roma groups."[13] They do not have the option of sheltering in place. Because of the acute risks presented by homelessness in a time of pandemic spread, both prudence and humanity require that evictions be stopped, and appropriate shelter provided. This is the lesson to be learnt from forward-looking municipalities across the globe, from Boston to Berlin, municipalities that are rightly concerned with their homeless communities and the wider public within which they live.[14] A rights-based approach to the social and economic impact of COVID-19 also necessitates direct cash payments and stimulus packages for those most in need, regardless of their ethnicity.

Discriminating against Romani people, already marginalized and forced to live and work in toxic and overcrowded conditions, is a grave human rights violation that threatens the public health of all members of the community, Roma and non Roma.[15] To prevent the spread of COVID-19 in all communities, government responses must be informed by human rights principles that protect the most vulnerable, both in the short term and thereafter. An essential aspect of this approach is to seriously and vigorously tackle the structural, racial, and social inequalities that continue to expose Romani people to greater risks of poor health, in times of emergency as much as outside of them.[16]

COVID-19 provides the world with a chance to recognize our joint humanity and interdependence. We call on policy makers, opinion leaders, and public spokespeople to use this time of collective emergency to stamp out racist and inflammatory rhetoric, to promote human rights, justice, equality, and dignity and, as a result, protect global public health.

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HHR Health and Human Rights Journal

VIEWPOINT

COVID-19 Economy vs Human Rights: A Misleading Dichotomy

Juan Pablo Bohoslavsky

On 11 March 2020, the World Health Organization declared the COVID-19 outbreak a global pandemic. In a rapidly evolving situation, states are trying—with different levels of commitment and effectiveness—to curb the progress of the disease. While the virus is a threat to the rights to life and health, the human rights impact of the crisis goes well beyond medical and public health concerns. The health crisis itself and a number of state measures to contain it—mainly isolation and quarantine—are leading the world into an economic recession. The consequences of the decisions taken by national and international stakeholders to address health and economic issues reciprocally affect each other, and so, their joint study is needed.

It is now clear that states and others need to take preventive and mitigating measures urgently to contain the pandemic and these must entail global cooperation and coordination. Just as the health crisis response must be rooted in human rights law, so too must national and international responses to the drastic economic downturn.

In my capacity as United Nations Independent Expert on debt and human rights, on 15 April 2020 I provided urgent recommendations to governments and international financial institutions on specific ways to tackle the economic shock of the COVID-19 crisis through a range of policies that are consistent with human rights obligations.[1] In this Viewpoint I share my general reflections on whether a "saving the economy" approach should prevail over social and human rights-oriented strategies.

I have been concerned about some states' failure to adequately respond to warnings to prepare for pandemics. The lack of effective response from a number of governments to protect people's health through proven measures such as social distancing and quarantines to flatten the curve of the pandemic is also very concerning.[2] Arguing that the cure would be worse than the disease, some governments have opposed these measures to avoid an economic slowdown.

When the life and health of populations are at stake, business as usual must not go on. Governments must ensure that public health systems do not collapse, and that health policies and protections are not eroded, but rather they remain robust and capable of controlling the spread of the disease. When faced with making a decision about protecting lives, or protecting the economy, human rights must inform the debate.

Some governments appear to be promoting an approach of "saving the economy" at any cost, including through risking the health and lives of the majority of their populations. This economy centric approach is often accompanied by a lack of enthusiasm to reduce inequalities, or to ensure the realization of economic and social rights, or acknowledge and address the impacts of pollution and climate change on health. Therefore, "saving the economy" means prioritising the interests of a powerful elite. Such a re-

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This Viewpoint was originally published on the Journal website on 20 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/04/covid-19-economy-vs-human-rights-a-misleading-dichotomy/.

ductionist view of the economy cannot operate as a trump, especially as the broad economy must allow for the majority of people to have their economic and social rights realized.

In this sense, it is necessary to distinguish big corporations' claims of entitlement to profits from the needs of workers earning a daily livelihood. While it is important to minimize the social and economic impact of the economic recession, supporting employment through ensuring the survival of the business sector as a whole is only one way of doing so. Alternatives could include targeted, temporary, and compulsory payment holidays from taxes, rent and mortgages, and other debts. There are other types of relief packages to consider as well. An exclusive focus on employment support can result in those employed in the informal sector, or on short-term contracts, being overlooked. It is of the utmost importance that initiatives focusing on job losses and employment support, do so from a human rights perspective.

Such a perspective would result in states decreasing inequalities and poverty, and not just bailing out large corporations, banks, and investors without social conditions attached. Experience has shown that large corporations and banks do not immediately or spontaneously share financial resource support with those in most need. Bail out packages to "save the economy" that are directed to big corporations help mitigate impacts on the financial and corporate sectors—they are not providing targeted relief measures to individuals to guarantee the enjoyment of their human rights. For this same reason, as the Danish government has just decided, companies which pay out dividends, buy back own shares, or are registered in tax havens should not be eligible for any of the financial support programs.

Public investments must also aim to reach small and mid-size enterprises, creating long term sustainable employment, prioritizing the realization of social rights and the Sustainable Development Goals, and promoting activities to mitigate climate change. For example, states should invest in nutrition, housing, education, and local small-scale environmentally sustainable farming and agricultural production. States should not provide subsidies (bail-outs) and other emergency benefits to sectors whose existence is in direct contradiction the global commitments made in the 2015 Paris Accord on climate change.

Potential impacts of the upcoming recession include challenges to the full enjoyment of human rights including the rights to food, housing, health, education, water and sanitation, social protection, non-discrimination, and just and fair conditions of work. As clearly established under human rights law, individuals should not have to choose between their basic human rights. For instance, it is unacceptable that economic conditions would leave people having to choose between reducing food intakes or having a home, or accessing medical care.

I fear the recession will leave some people with no choice but to rely on debt to meet their basic needs and rights. Without immediate relief, it is likely people forced into debt will then face ever increasing debts.[3] While household debt is not a human rights violation *per se*, it becomes particularly problematic when individuals resort to formal and informal lending networks to access their rights to healthcare, housing, food, water and sanitation, or education. What might be a lifebuoy today, becomes an ever-increasing economic burden. This may extend to impacting migrants and the remittances they send home when these often poorly paid workers are employed in countries that will be badly affected by the pandemic. In turn, the livelihood of the recipients of these remittances, usually in low-income countries, will be drastically reduced.[4]

These concerns are not part of the agenda of those promoting the *economy first* approach. Rather that agenda focuses on stimulating aggregate demand with little consideration given to its public health and social implications.

Economy vs human rights is misleading because they can be aligned. States must protect lives *and* economies so goods and services can continue throughout the pandemic, and when it has passed, there are jobs for people. But this must be done wisely and responsibly with public health and human rights impacts as the primary consideration. There are a number of measures covering a wide range of economic, financial, monetary, fiscal, tax, trade, economic sanctions and social policies that can contribute achieving those goals.[5] These include: boosting cash transfers and help packages, expanding social safety nets and considering universal basic incomes; suspending mortgage repayments and evictions; halting cuts in public or private provision of services such as electricity and water; establishing a waiver of the Trade-Related Aspects of Intellectual Property Rights (TRIPS) stipulations with respect to medicines and other related technologies; suspending private debt-servicing for individuals unable to cope with the public health crisis and without income; implementing a moratorium on sovereign debt repayment for debt-distressed low- and middle-income countries, or those countries suffering heavily from the economic fall out of the pandemic; establishing universal health coverage in line with international human rights norms, including the right to health and guidance provided by human rights mechanisms.

It is gratifying to see most governments considering and implementing many of these rights-based responses to the pandemic, thus protecting their people and their economy.

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VIEWPOINT

Applying Siracusa: A Call for a General Comment on Public Health Emergencies

NINA SUN

The COVID-19 pandemic is a public health emergency—as of 23 April 2020 there were over 2.7 million cases, with over 190,000 deaths globally.[1] Under the International Covenant on Civil and Political Rights (ICCPR), states may restrict certain rights during public emergencies that threaten the life of the nation to the extent that they are "strictly required by the exigencies of the situation."[2] COVID-19 can be a fatal disease without known methods of prevention and treatment. Given this situation, the question is not *if*, but *how* states may restrict rights to try to control the pandemic.

The Siracusa Principles are a foundation on which to build. The principles outline the limits on rights restrictions that states may take during emergencies. Under Siracusa, restrictions are only justified when they support a legitimate aim and are: provided for by law, strictly necessary, proportionate, of limited duration, and subject to review against abusive applications.[3] States' measures must also be evidence-based and neither arbitrary nor discriminatory. Any curtailment of rights must consider the disproportionate impact on specific populations or marginalized groups. However, because these principles are meant to apply broadly to all public emergencies, they are difficult to operationalize in public health crises. This is especially true because public health crises are diverse: the dynamics of transmission, the severity of illness, the availability of treatment, and control measures all vary immensely. For new disease outbreaks, uncertainty around all these factors make assessing the degree to which responses are evidence-based or arbitrary extremely challenging.

Recognizing this gap, some global institutions—including UNAIDS and the Global Fund—have issued guidance on human rights and COVID-19.[4] While these documents are useful in highlighting key human rights concerns, overall legal guidance on human rights is needed from the authoritative body on the interpretation of the ICCPR: the Human Rights Committee.

Through its General Comments, the Human Rights Committee provides useful guidance on how states can craft rights-aligned laws, policies, and practices. To date, however, its General Comments have not specifically addressed rights restrictions in public health emergencies.[5] The COVID-19 pandemic highlights a longstanding need for specific guidance on rights derogations related to public health issues.[6] Key topics for this General Comment may include the necessity and proportionality of state responses and the misuse of emergency powers during the pandemic.

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This Viewpoint was originally published on the Journal website on 7 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/04/applying-siracusa-a-call-for-a-general-comment-on-public-health-emergencies/.

State responses: Quarantines, isolation, and lockdowns

In attempts to slow the spread of COVID-19, over one third of the world's population—an estimated 2.6 billion people—is experiencing some form of broad quarantine and social distancing measures, colloquially known as "lockdowns."[7] These range from measures that cover specific regions or provinces to those that apply to entire countries. The measures also range in severity, with some countries allowing for essential activities regardless of distance or time, while others dictate specific travel limits and apply curfews. In addition to general social distancing measures, if a person is diagnosed with COVID-19, they may be ordered to stay in isolation. Alarmingly, many countries are turning to criminal penalties to enforce compliance with public health measures, including criminalization of COVID-19 exposure and transmission.[8]

When states enact public health measures that restrict rights, they must nevertheless meet certain core human rights obligations. They must ensure that people's basic needs are met, including for food, water, sanitation, and shelter. They must also guard against disproportionately harsh impacts on, or application to, marginalized communities. In addition, people who suffer economic losses due to public health measures are entitled to fair compensation.[9] Importantly, all these measures should be subject to remedy and review. During and after the acute phase of a crisis, there should be analysis and discussion to ensure that public health measures were evidence-based, necessary, and proportionate based on the available science, public health concerns, and human rights norms.

Misuse of emergency powers and political opportunism

Even prior to the emergence of COVID-19, the lack of specific human rights guidance on public health threats, and the lack of definition on what constitutes a public health emergency more generally, has given states the opportunity to restrict rights under the guise of responding to public health crises.[10] Under the COVID-19 pandemic, some states are now openly committing grave human rights violations in the name of controlling the disease.[11] There have been reports of arbitrary arrests, assaults, and even killings related to the enforcement of COVID-19-related lockdowns and curfews.[12] There have been censorship and severe restrictions on freedom of speech—this hinders access to essential health information and quashes the ability of the media and individuals to hold governments accountable for their statements and actions.[13] Moreover, emergency powers, combined with pre-existing societal stigma, exacerbates discrimination against marginalized groups. For example, there have been reports of states and their enforcement mechanisms specifically targeting LGBT individuals, sex workers, as well as ethnic minorities such as the Roma.[14]

Governments are also using the COVID-19 crisis to justify rolling back human rights protections. Laws restricting access to abortion and other reproductive rights have been proposed in Poland and in multiple states within the United States. At least seven US states have categorized abortion as a "non-essential" medical procedure, effectively trying to prohibit the service during the crisis.[15] In Poland, the parliament discussed a bill in mid-April to ban abortion in cases of fatal fetal anomalies, reviving the debate on abortion restrictions which was abandoned due to large public protests in 2016.[16] It also discussed a bill to ban comprehensive sexuality education.[17] In Hungary, the government proposed a bill that ends the possibility of transgender individuals legally changing their gender.[18] As the COVID-19 pandemic continues, the UN human rights mechanisms should call out countries that use the outbreak as a pretext to retrogress on their human rights obligations.

A General Comment on rights restrictions in public health crises

Once the initial COVID-19 crisis subsides, there will be an opportunity for reflection. Have countries responded to COVID-19 in a manner that aligns with human rights and the Siracusa Principles? Looking forward, how can states be more effective and rights-based in responding to similar situations?

A General Comment solidifies the Human Rights Committee's relevant precedents into concrete guidance. But more than that, a General Comment with human rights standards specifying how rights-limiting steps may be operationalized could guide the development and reform of laws, policies and practices related to pandemic preparedness. It could, for example, clarify core and priority state obligations, as well as outline key considerations for areas where rights may be restricted (such as movement, free speech, peaceful assembly).

COVID-19 is not the first pandemic, nor will it be the last. Understanding how to respect, protect, and fulfill human rights during outbreaks and other public health crises is vital not only to ensuring that states effectively address public health issues, but also that they protect people's equality and inherent dignity.

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Health and Human Rights Journal

VIEWPOINT

Upholding Rights Under COVID-19: The Respectful Maternity Care Charter

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The COVID-19 pandemic has strained health systems and exacerbated system deficiencies and subpopulation vulnerabilities, thus "exposing the damaging impact of inequities, in every society."[1] It has also dramatically altered maternal newborn health (MNH) care delivery; some of the efforts to curb the virus violate the rights of women, their newborns, and families.

In times of crisis, it is a common state practice to restrict some rights, on the grounds they are secondary to security, safety, or emergency resource management.[2] However, maintaining the right to essential MNH services, ensuring quality, continuity, and respectful care, is critical to prevent death and disability. Early models estimate significant increases in mortality due to reduced MNH service availability resulting from COVID-19.[3]

Human rights are indivisible and universal. Rights frameworks provide a firm legal and ethical foundation to guide policy and practice in a pandemic. Solutions that uphold fundamental human rights and best clinical practices, including infection control, contribute to stronger health and human rights outcomes overall. The Respectful Maternity Care (RMC) Charter, published in 2011 and updated in 2019, articulates 10 fundamental rights of childbearing women and newborns based on widely accepted human rights instruments, and provides a framework for high-quality care that supports and upholds the dignity of all parties.[4]

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This Viewpoint was originally published on the Journal website on 1 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/05/upholding-rights-under-covid-19-the-respectful-maternity-care-charter/.

Members of the RMC Global Council (a network comprising more than 150 organizations and 350 members from 45 countries), have reported numerous violations of the right to RMC during COVID-19, including:

- **Exacerbated deficiencies in overwhelmed health systems:** lack of personal protective equipment (PPE); personnel diverted from maternity to COVID-19 units; maternity units converted into COVID-19 centers, limiting availability of MNH services[5]
- **Neglect, abandonment, restricted access to care:** unavailability of emergency transport, antenatal and postnatal contacts; neglect in facilities due to fear of infection; unavailability of out-of-hospital options for skilled care leading to unattended births[6]
- **Alteration of proven practices without evidence:** mandatory separation of mother and newborn; restriction of breastfeeding; prohibition of a companion during labor and childbirth
- **Acts curtailing women's decision-making autonomy:** classification of abortion as non-essential; unavailability of contraceptive services and commodities
- **Potentially harmful medical intervention without indication:** increased cesarean sections, instrumental deliveries, induction and augmentation of labor, without medical indication
- **Exacerbation of care inequities:** unequal access to telemedicine or mHealth alternatives.

Healthcare managers, workers, women, and families lack critical information about COVID-19 and need access to evidence-informed standards. Guidance from WHO on quality MNH care has not been widely applied in this crisis.[7] Instead, uncertainty about how COVID-19 impacts women and newborns is affecting clinical and interpersonal quality of care. In the absence of clear, consistent, coordinated guidance, measures are implemented based on fear instead of evidence and rights.

Maintaining high-quality, essential MNH service delivery during COVID-19 upholds the rights of women and newborns. The RMC Charter is based on widely accepted human rights instruments and aligns directly with the WHO definition of quality. As members of the RMC Global Council, we suggest how these Universal Rights of Women and Newborns may be applied during COVID-19:

- **The right to freedom from harm and ill-treatment:** Avoid interventions without clear indication; increase safe options for out-of-hospital birth, e.g. convert hotels into birth centers (ensuring emergency transport), facilitate accreditation of birth centers and access to trained midwives.[8]
- **The right to information, informed consent, respect for choices and preferences including a companion of choice during maternity care, and refusal of medical procedures:** Use digital health services, social and other media to share health information, including available care options and birth settings; allow a companion of choice during labor and birth.[9]
- **The right to privacy and confidentiality:** Protect personal information; ensure facility infrastructure allows privacy and is well equipped and maintained.
- **The right to be treated with dignity and respect for one's personhood from the moment of birth and the right to an identity and nationality from birth:** Ensure that any isolation of women and newborns due to COVID-19 is respectful and dignified; adopt virtual birth registration.[10]
- **The right to equality, freedom from discrimination and equitable care:** Practice universal precautions and treat every woman and newborn, regardless of COVID-19 status, without stigma or discrimination; provide universal health coverage, regardless of insurance or immigration status.[11]
- **The right to healthcare and to the highest attainable level of health:** Maintain essential MNH services, including abortion, contracep-

tive care and commodities; increase telehealth, community healthcare, and access to out-of-hospital birth.[12]

- **The right to liberty, autonomy, self-determination and freedom from arbitrary detention:** Ensure any restrictions, including quarantine for women and newborns with COVID-19, are strictly necessary, the least intrusive and restrictive available, and based on evidence.[13]
- **The right of children to be with parents or guardians:** Keep mothers and newborns together regardless of COVID-19 status if neither requires intensive care; apply guidance for home care of affected family members, i.e., use of PPE, handwashing.
- **The right to adequate nutrition, clean water and sanitation:** Promote breastfeeding for optimal nutrition and passive immunity. Ensure water, sanitation, and hygiene (WASH) and PPE access for infection prevention and control.

Innovation and flexibility to deliver essential MNH services safely should be encouraged, if grounded in evidence, quality, and progressive realization of fundamental human rights in health.[14] Contextualizing best practices to circumstances and protecting vulnerable groups is necessary. Understanding local supply- and demand-side factors is essential in deciding which policies and practices make sense operationally. If rights must be limited in extreme circumstances, limitations must adhere to human rights law, requiring they be strictly necessary, proportionate, reasonable, and the least restrictive available.[15] While undermining rights exacerbates inequities and further disempowers disadvantaged groups, upholding them through best practices that protect women, newborns, and health workers alike promotes a more just health system for all.

Every crisis presents opportunities. The COVID-19 crisis has highlighted deficiencies within and beyond health systems, but provides opportunity for critical examination to strengthen and improve the quality and equitability of MNH care. Mechanisms to protect, uphold, and fulfill the rights of women and newborns while reducing the spread of infection demand collective efforts from all actors to meet their obligations as duty bearers and rights holders. Crises call on us to elevate our highest principles, never to undermine or abandon them. Jawarlal Nehru stated, “Failure comes only when we forget our ideals, objectives, and principles,” to which we add, “our evidence base”. If we abandon these foundations out of fear, the failure we risk is the lives of women and newborns.

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VIEWPOINT

Public Money Creation to Maintain Fundamental Human Rights during the COVID-19 Pandemic

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As governments around the world respond to the COVID-19 pandemic with a range of policies aimed at mitigating the economic fallout, we argue that low- and middle-income countries (LMICs) should prioritize public money creation over foreign borrowing. Experience shows that the cost of servicing foreign debt diverts resources from public services and can undermine fundamental economic, social and cultural rights, such as the rights to clean water, sanitation, basic education and health care. Moreover, the conditions attached to any subsequent debt restructuring can make matters worse.[1]

Background

The COVID-19 pandemic is likely to follow a different trajectory in LMICs than in high-income countries for multiple reasons: for example, their generally younger populations may mitigate its impact, whereas weaker health systems may amplify it. As in other outbreaks, the indirect health effects will be huge, with mortality due to non-COVID-19 conditions also increasing. Furthermore, the social and economic fallout in LMICs will probably be even greater in these countries than in wealthier ones because: 1) multiple sectors of the economy are grinding to a halt as supply chains fragment, commodity prices fall, and capital drains out of these countries; 2) remittances from abroad are waning; 3) currencies are depreciating; 4) many countries are struggling to service their debts. In addition, their international reserves are diminishing and slim government revenues are depleted at a time when public spending needs to escalate dramatically.[2] Globally, the International Monetary Fund (IMF) has requested a standstill on debt servicing, has provided US$1.4 billion in grants to help service debts, and has offered emergency loans to the tune of US$1 trillion. Other interventions have called for debt cancellation, capital controls to prevent more capital hemorrhaging out of LMICs and, as was done in 2009, the distribution of reserve assets held by all IMF member countries which can be issued without extra cost and with no new debt.[3]

Previous experience of debt

During the 1980s debt crisis, despite directing more of their annual budgets to debt servicing than to public services many LMICs were still unable to repay or service their debts after interest rates increased. For

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This Viewpoint was originally published on the Journal website on 6 May 2020 and can be viewed here:
https://www.hhrjournal.org/2020/05/public-money-creation-to-maintain-fundamental-human-rights-during-the-covid-19-pandemic/

example, between 1992 and 1997, Zambia allocated 40% of its budget to debt servicing, and only 6.7% to public services.[4] International financial organizations offered support on certain conditions (deregulation, liberalization, and privatization). Often policy reforms were introduced to boost a country's economy and facilitate debt repayment but these also impacted public services and fundamental rights. For example, reducing tariffs on imported goods reduced government revenue overall, and budgets were diverted towards debt servicing while expenditure on public services was reduced and privatization encouraged.[5] Indeed, the United Nations Human Rights Council has recognized that unsustainable sovereign debt burdens are a "serious impediment" to the realization of fundamental rights and that the conditions attached to financial rescue packages can make it extremely difficult for countries to achieve economic growth.[6] An independent United Nations expert on the effect of foreign debt noted that countries with large illicit financial flows—illegal movements of capital from one country to another, usually to avoid taxes—are especially burdened with external debts and have to make a difficult choice between servicing debt and providing public services.[7] Debt relief initiatives in the 1990s provide further evidence that debt servicing can come at the cost of fundamental rights: when debt was cancelled, many LMICs were able to abolish fees for schools and health care, which increased their use.[8] Nevertheless, many LMICs continued to struggle to pay their debts and some accumulated more debts when interest rates were low after the 2008 financial crisis when capital flowed into these countries seeking better returns. Thus, today most LMIC debt is external and in foreign currencies, exposing countries to fluctuations in global financial markets.[9]

Public money creation

Government expenditure must be met by taxation, borrowing (from either domestic or foreign sources), or money creation. At the heart of a country's financial system is a sovereign government that can create money, which means the government cannot go bankrupt as it can always create money to pay its debts. Normally, however, most of the credit or money in an economy is created (out of thin air) when commercial banks make loans to consumers, usually households and companies. In effect, the bank purchases a loan contract from a consumer and records this as a deposit in their account, thereby creating money. A country's central bank can stimulate this type of money creation by lowering interest rates, which encourages consumers to take out loans and thus increases the credit or money in an economy.

In the process of public money creation, in contrast, the central bank creates new money to directly finance government expenditure by crediting the government's current account at either the central bank or a commercial bank. Public money creation has been used to stimulate economies when interest rates were already so low that lowering them any further would be ineffective.[10] Furthermore, money created for projects that are productive, such as environmental infrastructure projects, will generate economic growth and increase tax revenues, thereby financing public services without causing inflation.[11] In the past, countries in east Asia, including Japan, China, Taiwan, and Korea, used this approach to achieve economic growth quickly. Today, governments in high-income countries are using public money to implement both fiscal measures, such as tax waivers, and monetary policies, such as government-backed loans. The G20 group of countries have created and injected trillions of dollars of credit into their economies.

During and after the COVID-19 pandemic, LMICs are likely to require credit. If they borrow from overseas, credit will be created (out of thin air) by foreign banks, which must be repaid in foreign currencies.[12] As the domestic currencies of LMICs generally depreciate over time, the cost of repaying in foreign currencies is likely to increase and the cost of servicing debts can often exceed the original amount borrowed. In fact, the debt crisis in the 1980s was unnecessary because, for most purposes, countries did not need to borrow from abroad—the credit required for productive investment and economic development could have been created by domestic banks.[13]

We suggest that, in addition to making use of debt cancellation, capital controls, and reserves held at the IMF, LMICs should use the power of productive public money creation and avoid increasing external debt. We know that investing in human capital is productive. For example, an increase in educational expenditure by 1% of gross domestic product (GDP) raises per-capita GDP growth by 1.6% per year, with two-thirds of the impact apparent within five years.[14] Thus, public money creation could be used to meet obligations during the pandemic and reduce the risk that LMICs will acquire unsustainable foreign debts, which will likely compromise the governments' commitment to fulfilling their human rights obligations. A complex balancing act is required: the public money created must be used productively and support must be withdrawn at the right rate and time. Over-reliance on money creation should be avoided and governments should bolster their revenue by other means, such as curtailing tax avoidance due to illicit financial flows.[15] In addition, the international community could help remove impediments to LMIC governments providing public services and meeting their human rights obligations by tackling two yawning gaps in global governance: sovereign debt crisis resolution and international tax cooperation.[16]

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VIRTUAL ROUNDTABLE

A Virtual Roundtable on COVID-19 and Human Rights with Human Rights Watch Researchers

JOSEPH J. AMON AND MARGARET WURTH

Introduction

International human rights law guarantees everyone the right to the highest attainable standard of health and obligates governments to take steps to prevent threats to public health and to provide medical care to those who need it. Human rights law also recognizes that in the context of serious public health threats and public emergencies threatening the life of the nation, restrictions on some rights can be justified when they have a legal basis, are strictly necessary, based on scientific evidence and neither arbitrary nor discriminatory in application, of limited duration, respectful of human dignity, subject to review, and proportionate to achieve the objective.[1]

The scale and severity of the COVID-19 pandemic clearly rises to the level of a public health threat that could justify restrictions on certain rights, such as those that result from the imposition of quarantine or isolation limiting freedom of movement. At the same time, careful attention to human rights such as non-discrimination, and human rights principles such as transparency and respect for human dignity, can foster an effective response amidst the turmoil and disruption that inevitably results in times of crisis. Attention to human rights can also limit the harms that can come from the imposition of overly broad measures that do not meet the above criteria.

Amidst the global response to the COVID-19 pandemic, Human Rights Watch has been documenting rights abuses and conducting advocacy in countries around the globe on a wide range of issues. In early April, a number of researchers agreed to participate in a "virtual roundtable" to talk a little about their work and the challenges that they are seeing (see list of participants' names on next page).

JA and MW: *Thank you everyone for participating in this virtual roundtable amidst all of the work you are doing on the COVID-19 pandemic.*

JA: *Let me start with a question for Corinne, since you closely covered the 2014-2016 Ebola epidemic in West Africa. What are your thoughts on how the human rights issues then might be similar to what we see now with COVID-19?*

Joseph J. Amon is Director of Global Health and Clinical Professor in the Department of Community Health and Prevention at the Drexel Dornsife School of Public Health, and Senior Editor, Health and Human Rights Journal.

Margaret Wurth is Senior Researcher in the Children's Rights Division at Human Rights Watch.

This Virtual Roundtable was originally published on the Journal website on 16 April 2020 and can be viewed here: https://www.hhrjournal.org/2020/04/a-virtual-roundtable-on-covid-19-and-human-rights-with-human-rights-watch-staff/.

Corinne: Some of the key issues that Human Rights Watch addressed in West Africa then were: right to information, protecting human rights amidst quarantines, government obligations to protect health workers, the specific gender dimensions of the epidemic, abusive conduct of state security forces, and accountability issues and monitoring the imposition of emergency powers.[2] Child protection also emerged as a big issue, especially for girls, where we saw increasing rates of teenage pregnancy and transactional sex and exploitation. Clearly, all of these issues are relevant once again, as are the long-term impacts we saw from Ebola, such as the near-collapse of health systems, the need for countries struggling to rebuild to invest in a new generation of health workers and for better systems of financial accountability of funds for health systems and emergency response. The COVID-19 outbreak could be particularly devastating in Africa as a result of weak healthcare infrastructure, challenges in access to clean water, high incidence of malnutrition as well as HIV and other chronic illness, large numbers of displaced people, and poverty which poses a challenge to social distancing.

JA: *One thing that was true with the Ebola outbreak, and with other epidemics like SARS, cholera, or typhoid is that governments often respond first with some degree of denial and censorship. What are some examples from where you are working that you have seen of governments restricting access or covering up information?*

Yaqiu: China's government initially withheld basic information about the coronavirus from the public, underreported cases of infection, downplayed the severity of the infection, and dismissed the likelihood of transmission between humans.[3]

Participants
Heather Barr, Acting Co-Director, Women's Rights Division
Tamara Taraciuk Broner, Acting Deputy Director, Americas Division
Bethany Brown, Researcher on the Rights of Older People
Jane Buchanan, Deputy Director, Disability Rights Division
Eva Cossé, Western Europe Researcher
Rachel Denber, Deputy Director, Europe and Central Asia Division
Corinne Dufka, West Africa Director
Tara Sepehri Far, Iran and Kuwait Researcher
Lydia Gall, Senior Researcher, Eastern Europe and Western Balkans
Meenakshi Ganguly, South Asia Director
Sara Kayyali, Syria Researcher
Amanda Klasing, Acting Co-Director, Women's Rights Division
Kyle Knight, Senior Researcher, LGBT Rights Program
Aya Majzoub, Lebanon and Bahrain Researcher
Hillary Margolis, Senior Women's Rights Researcher
Elin Martínez, Senior Children's Rights Researcher
Grace Meng, Senior Researcher, US Program
Otsieno Namwaya, Senior Researcher, Africa Division
Komala Ramachandra, Senior Researcher, Business and Human Rights
Phil Robertson, Deputy Director, Asia Division
Sarah Saadoun, Researcher, Business and Human Rights Division
Judith Sunderland, Associate Director, Europe and Central Asia Division
Maya Wang, Senior China Researcher
Yaqiu Wang, China Researcher
Hugh Williamson, Director, Europe and Central Asia Division

Authorities detained people for reporting on the epidemic on social media and internet users for "rumor-mongering," censored online discussions of the epidemic, and curbed media reporting.[4] In early January, Li Wenliang, a doctor at a hospital in Wuhan where infected patients were being treated, was summoned by police for "spreading rumors" after he warned of the new virus in an online chatroom. He died in early February from the virus.[5]

Phil: In **Thailand,** whistleblowers in the public health sector and online journalists faced retaliatory lawsuits and intimidation from authorities after they criticized government responses to the outbreak, raised concerns about a possible cover-up, and alleged corruption related to the hoarding and profiteering of surgical masks and other supplies. Some medical personnel were also threatened with disciplinary action—including termination of employment contracts and revocation of their licenses—for speaking out about the severe shortage of essential supplies in hospitals across the country. There have been similar reports in **Cambodia** and **Bangladesh**.[6] In **Sri Lanka**, the police have warned that anyone criticizing public officials will be arrested.[7]

Tamara: In Latin America, the leaders of several countries have downplayed the COVID-19 pandemic. **Mexican** President Andrés Manuel López Obrador directly contradicted the recommendations of health authorities, encouraging Mexicans to continue going out in public.[8] In **Brazil,** President Jair Bolsonaro has minimized the gravity of COVID-19, comparing it to a "little flu" or a "cold," calling it a "fantasy" created by the media, and labeling preventive measures "hysterical."[9] In **Nicaragua,** the Daniel Ortega government has not declared any type of emergency in response to the pandemic and has continued to keep schools and churches open. Local sources have also reported that the government is discouraging Nicaraguans from wearing masks, including health workers, airport staff, and policemen, and pro-government groups have harassed those seen wearing them.[10]

JA: *Ensuring an effective response to an epidemic requires people to have some trust and confidence that their government is looking out for their best interests, especially for governments seeking to get people to accept social distancing or adopt other protective behaviors. There are lots of examples where governments haven't established a great deal of trust, but Iran, which had an early, explosive epidemic, seems like a very clear case of that.*

Tara: Indeed. In **Iran** the outbreak emerged after authorities had severely damaged public trust by brutally repressing widespread anti-government protests and lying about shooting down a civilian airliner.[11] As a result, Iranian authorities have struggled to assure the public that government decision-making around the COVID-19 outbreak has been in the public's best interests. The unusually high rate of reported cases of government officials contracting the virus, as well as the inconsistency in figures announced by officials and domestic media sources, have heightened concerns that the data is either being deliberately underreported or poorly collected and analyzed.[12]

MW: You also often see, in the early stages of epidemics, racism, xenophobia, and discrimination—blaming foreigners, or "others." For example, the H1N1 epidemic, which was responsible for more than 17,000 deaths worldwide and originated in central Mexico, led to attacks on Hispanics in the United States and elsewhere.[13] With the COVID-19 pandemic, we've seen people of Asian descent targeted with racist attacks. What are some examples of where you have documented that?

Grace: In the United States, President Donald Trump continued to defend his use of the term "Chinese virus," even as more and more Asian-Americans were facing discrimination and abuse. His use of the term, as well as Secretary of State Mike Pompeo's use of "Wuhan virus," may have helped spread racialized misinformation that distracted Americans from the reality of the pandemic, and shifted blame onto anyone that people think look Chinese, fueling anti-Asian bigotry and xenophobia within the United States.[14] Interestingly, recent reports have suggested that travelers, including US tourists, brought in the virus mainly from Europe.[15] Ultimately we live in a global world and pointing fingers at groups of people distracts from what is really needed to respond effectively to a pandemic.

Phil: After Cambodia's Health Ministry blamed minority Muslim communities for spreading the virus, members of the public posted hateful Facebook comments. Cambodian Muslims, particularly in Phnom Penh, have since reported facing discrimination, such as people refusing to sell or buy products from them, or to exchange money. Others reported that non-Muslim Cambodians put on face masks as soon as they saw members of the Muslim faith come into their vicinity.[16]

Lydia: In Hungary, COVID-19 fears have been used to stoke xenophobia. Prime Minister Viktor Orban has said there's a link between "coronavirus and illegal migrants," while the Operational Corps, a government group leading the response to COVID-19, accused Iranians previously in quarantine of being uncooperative and threatened to deport them. On March 1, the government announced that it would indefinitely suspend admission to the two transit zones on its border with Serbia, saying that asylum seekers on the Serbian side of the border waiting to be admitted into the zones come from high-risk countries. Never mind that most of them have been waiting on the Serbian side on average nearly a year and a half.[17]

MW: *Let's talk about access to health care and inequality. Even wealthy countries have been hit hard and within those countries the pandemic poses particular threats to the most economically or socially marginalized groups.*

Hugh: People experiencing homelessness, wherever they are, are among the vulnerable groups most at risk in the coronavirus crisis. Many have underlying medical and mental health conditions and have nowhere to go to protect themselves or even just to wash their hands. In **Germany**, the Berlin city government has emergency plans to accommodate 350 homeless people in a former youth hostel and elsewhere, including access to washing facilities and medical and psychological advice. But this is not enough to meet everyone's needs. Elsewhere in Europe, the lockdowns to limit the spread of the virus have raised concerns over police handling of homeless people. Restrictions in many countries have to take into account the needs of such vulnerable groups.[18]

Meenakshi: The **Indian** government is facing an extraordinary challenge to protect over a billion people. On March 24 the government announced a three-week nationwide lockdown to contain the spread of coronavirus in the country. The government gave only a few hours of warning. It left both the authorities and members of the general public unprepared. The lockdown has already disproportionately hurt marginalized communities due to loss of livelihood and lack of food, shelter, health, and other basic needs. Although some relief measures have now been put in place, millions, including suddenly out-of-work migrant workers, were left stranded. Tens of thousands started heading home, and with rail and bus services shut down, some even said they would walk hundreds of miles. The blanket closing of state borders has also caused disruption in the supply of essential goods, leading to inflation and fear of shortages. Thousands of homeless people are in need of protection. Police actions to punish those violating orders have reportedly resulted in abuses against people in need.[19]

Unfortunately, we are seeing similar concerns across South Asia where authorities are struggling to provide for the poor and contain the spread into dense urban settlements or rural communities, which lack an effective health infrastructure. This is particularly true in countries like **Pakistan**, **Nepal** and **Bangladesh**. In the **Maldives**, as tourism shuts down, numerous resorts are closing, leaving their staff without proper wages.

Jane: There are over a billion people with disabilities worldwide. They are among the most marginalized and stigmatized even under normal circumstances. For many people having a disability does not mean higher risk of complications from COVID-19 infection, but they are in danger due to discrimination and barriers to health care, social services, and education. Millions of adults and children with disabilities live in segregated and often overcrowded residential settings where COVID-19 can spread rapidly, and can be exacerbated by neglect, abuse, and inadequate health care, which are serious problems in many institutions. People with disabilities also face challenges getting information that's essential for them to protect themselves, when there isn't sign language interpretation for television or internet broadcasts, for example. With governments implementing policies requiring social isolating to stem the spread of coronavirus, people with mental health conditions, such as anxiety or depression, may be in particular distress.[20]

Komala: Access to health care is a big issue. For example, an uninsured woman in the **United States** recently reported that her COVID-19 testing and treatment cost nearly US$35,000.[21] An uninsured woman in Pennsylvania died after refusing to go to the hospital because she feared not being able to pay for care.[22] There are at least 28 million Americans who are uninsured, and that number is growing as unemployment numbers skyrocket and people lose access to employer-based insurance. People with chronic health issues may struggle to get access to care. For example, for people dependent on opioids there are huge challenges to maintaining their access to methadone or other substitution therapies and harm reduction. The privatization of health care is a trend that is also unfolding in Sub-Saharan Africa. I have been looking closely at **Uganda** where trends show that the government has reduced budget allocations on public health care and increasingly relies on private and public-private partnerships. This could jeopardize access to care for low-income communities.

JA: *One challenge around access to information is that approximately half the world's population—46%—is not connected to the internet.[23] People in the least developed countries remain the least connected, but digital divides exist in better connected countries, too, and then there are targeted blackouts that limit access for specific populations. In addition to the challenge that this poses in terms of access to information, in times of social distancing, people without a reliable connection may be especially isolated. Where are you tracking this issue?*

Meenakshi: It's a big issue in **Bangladesh**, where a Bangladesh government imposed internet blackout and restrictions on phone services in the Rohingya refugee camps in Cox's Bazar are obstructing the ability of humanitarian organizations to effectively address the COVID-19 pandemic. The shutdown—which has been in place for over six months—is risking the lives of nearly 900,000 refugees, as well as the Bangladeshi host community. Emergency health services face real challenges to coordinate prevention measures. After international pressure, Bangladesh restored internet in the Rohingya camps, but after a couple of hours it was shut off again.[24] We've seen the same issue, across the border in **Myanmar**'s Rakhine state, where hundreds of thousands remain under an internet blackout.

Elin: According to UNESCO, 1.5 billion students in 184 countries were out of school due to COVID-19 by the end of March, representing 89.1% of the world's student population. By mid-April most countries had closed schools to limit the spread of the virus, so now even more children are out of school. This is in addition to over 260 million children who were already excluded from education, particularly girls, refugees, and children with disabilities. The crisis has exposed vast disparities in countries' emergency preparedness, governments' abilities to maintain schooling and reaching children when schools are closed, due in part to the lack of internet availability for children, and the very limited availability of learning materials. UNESCO has recommended that states "adopt a variety of hi-tech, low-tech and no tech solutions to assure the continuity of learning." However, that's not happening everywhere. Certain groups of students are at higher risk of exclusion from online or distance learning, such as students with disabilities who require adapted, accessible material, and students from families with low-literacy or those who may not be as acquainted with the curricula used, including refugee or migrant parents.

JA: *Countries that are already experiencing conflict or that are under international economic sanctions are also likely to be ill prepared to respond to COVID-19 and ensure that they have the medical supplies needed to treat people who become ill.*

Tamara: In **Venezuela**, Human Rights Watch has already documented a health system in utter collapse. Hospitals have closed or are operating at a fraction of their capacity, many without regular access to electricity or water. Vaccine-preventable diseases such as measles and diphtheria returned long before the pandemic hit.[25] The lack of access to water is particularly problematic in the face of the COVID-19 pandemic: we're seeing health professionals who cannot even wash their hands in hospitals. Rates of survival for older people and those with underlying health conditions that put them at risk will be abysmal. In the case of Venezuela, although sanctions on the oil sector may further undermine the humanitarian emergency due to the risk of overcompliance, our research shows that the health system collapse predates the sanctions and is largely the responsibility of Venezuelan authorities.

Tara: Broad sanctions imposed by the United States on **Iran** have drastically constrained the ability of the country to finance humanitarian imports, including medicines. While the US government has built exemptions for humanitarian imports into its sanctions regime, Human Rights Watch research in October 2019 found that in practice these exemptions have failed to offset the strong reluctance of US and European companies and banks to risk incurring sanctions and legal action by exporting or financing exempted humanitarian goods. We've called on governments to support Iran's efforts to combat the COVID-19, including by providing access to medical devices and testing kits.[26]

Sara: Nine years of war in Syria have decimated the country's health infrastructure.[27] Most recently in Northwest Syria, attacks by the Syrian-Russian military alliance have not only damaged hospitals and clinics, but led to massive internal displacement that even before the COVID-19 crisis had overwhelmed the humanitarian capacity to respond.[28] Parties to the conflict are also restricting access to aid and essential services, hindering the humanitarian capacity to prepare and protect vulnerable communities in the COVID-19 pandemic. Human Rights Watch had previously documented restrictions imposed by the Syrian government that led to discriminatory provision of humanitarian aid, and these continue in the COVID-19 response.[29] Turkish authorities have also blocked adequate water supplies from reaching Kurdish-held areas in Northeast Syria.

JA: *Many people are very concerned about the risks to people who are in jails, prisons, and other detention centers.[30] Where has Human Rights Watch looked at this and what have you found?*

Tamara: The unsanitary, overcrowded prisons and juvenile detention centers in most Latin American and Caribbean countries offer prime conditions for outbreaks of COVID-19. In March, people in detention facilities in several Latin American countries rose up to protest about both the lack of protective measures against COVID-19 and the efforts to lock them down. Hundreds escaped, dozens of people were injured, and at least 40 people died in connection with protests in **Colombia, Venezuela, Argentina, Peru,** and **Brazil.** We're equally concerned about the situation in migrant detention centers in **Mexico**, where overcrowding and unhygienic conditions put migrants at increased risk of contracting COVID-19. Protests in at least five migrant detention centers in Mexico have led to clashes that left dozens injured and caused at least one death. In some cases, migrants reported excessive force by security forces.[31] With hundreds of people sleeping and eating in the same space and sharing bathroom facilities, it is nearly impossible to implement basic measures to prevent an outbreak. Once COVID-19 enters migrant detention centers, it could quickly spread, infecting detainees and staff who would bring the disease into the surrounding community.

Grace: Many people in **US** jails have not been convicted of a crime but are locked up simply because they cannot afford to pay the bail set in their case.[32] Older men and women are the fastest growing group in US prisons due to lengthy sentences, and prison officials already have difficulty providing them appropriate medical care.[33] At jails in New York City and in Chicago there have been explosive outbreaks with hundreds of detainees and staff infected with COVID-19. Some state actors, including governors, judges, and police, have taken steps to release people from jails and prisons or to reduce arrests that are feeding jail populations.[34] Other state actors have resisted large-scale release. It is uncertain whether any carceral institutions have reduced populations sufficiently to allow adequate social distancing for all people, and non-punitive quarantine and health care for sick people.

Tara: Prisoners in **Iran** have reportedly tested positive for COVID-19, including in Evin prison in Tehran and in the cities of Euromieh and Rasht. In an open letter in February, families of 25 prisoners detained for peaceful activism sought their temporary release amid the outbreak and lack of sufficient prison medical care. In March, the Iranian judiciary released about 85,000 prisoners for the Persian New Year (Nowruz), a substantially greater number than normal for the holiday, apparently because of health concerns surrounding the coronavirus outbreak. However, dozens of human rights defenders and others held on vaguely defined national security crimes remained in prison.[35]

Aya: On March 17, **Bahrain's** Interior Ministry announced it had released 1,486 detainees for "humanitarian reasons, in the backdrop of current circumstances," a likely reference to the COVID-19 pandemic. About 900 of them were granted royal pardons, while 585 were given non-custodial sentences under Bahrain's law on alternative sentencing.[36]

Jude: In **Italy**, prisoners in over 40 prisons have protested over fears of contagion in overcrowded facilities and against bans on family visits and supervised release during the coronavirus pandemic. In response, authorities have authorized for the first time the use of email and Skype for contact between prisoners and their families and for educational purposes and announced a plan to release and place under house arrest prisoners with less than 18 months on their sentence. However, this doesn't go far enough to alleviate overcrowding to allow for social distancing in Italian prisons and local groups are calling for broader release criteria. Civil society organizations have also called for alternatives to detention for all people currently detained in immigration detention centers.[37]

Sara: The **Syrian** government has arbitrarily arrested and forcibly disappeared thousands since the start of the conflict for their participation in peaceful protests or for expressing political dissent. Torture and executions account for many of the deaths among prisoners, but many also die from the horrific conditions in prisons.[38] With the COVID-19 threat looming over the country, we've called on the Syrian government to urgently release arbitrarily held prisoners, and we've called on humanitarian organizations and United Nations agencies to press for access to detention facilities and provide detainees with life-saving assistance.

MW: Migrant detention centers have similar risks. In the United States, the American Civil Liberties Union has filed a lawsuit that seeks to challenge ongoing immigrant detention in the context of the virus.[39] What is happening elsewhere with respect to migrants in detention or in communities?

Eva: In **Greece**, authorities are arbitrarily detaining nearly 2,000 migrants and asylum seekers in unacceptable conditions, and denying them the right to lodge asylum claims, in two recently established detention sites on mainland Greece. Authorities claim they are holding the new arrivals, including children, persons with disabilities, older people, and pregnant women, in quarantine due to COVID-19, but the absence of even basic health precautions is likely to help the virus spread.[40] Even worse, thousands of asylum seekers and migrants are trapped in dangerously overcrowded, deplorable conditions in camps on the Aegean islands. Extremely limited access to running water, toilets, and showers, as well as hours-long lines for food distribution and insufficient medical and nursing personnel, make it impossible to abide by the guidelines for protection from the coronavirus, putting people at significantly heightened risk in the face of the growing threat of widespread COVID-19 transmission.

Aya: At least 21 municipalities in **Lebanon** have introduced discriminatory restrictions on Syrian refugees that do not apply to Lebanese residents as part of their efforts to combat COVID-19. Syrian refugees have also raised concerns about their ability to get health care and the lack of information on how to protect themselves against infection.[41]

MW: *The pandemic is also impacting sexual and reproductive health and rights, including access to abortion and contraception. In the United States, several states have tried to use COVID-19 to shut down abortion clinics and restrict access to abortion. This also affects access to medical abortion because many states require a doctor to be present when pregnant people take the medication.[42] What other gendered impacts can we expect?*

Yaqiu: In **China** and elsewhere, media reports suggest an increase in domestic violence under quarantine. Crises—and lockdowns—can trigger greater incidence of domestic violence because of increased stress, cramped and difficult living conditions, and breakdowns in community support mechanisms. Crises can limit women's ability to get away from abuse and place victims in an environment without appropriate access to safe shelter or to services seeking accountability over abuse.

Heather: Worldwide, 70% of health and social service providers are women—meaning women are at the front lines of containing the spread of COVID-19 and may be heavily exposed to the virus through work in the health sector. Women globally do almost 2.5 times as much unpaid care and domestic work as men, and they are more likely than men to face additional care giving responsibilities when schools close, making it harder to maintain paid employment. Up to 95% of female workers in some regions work in the informal sector where there is no job security, and no safety net if a crisis like COVID-19 destroys their earnings. Informal work includes many occupations most likely to be harmed by a quarantine, social distancing, and economic slowdown, such as street vendors, goods traders, and seasonal workers. Women are also over-represented in service industries that have been among the hardest hit by the response to COVID-19. While more men than women have been dying of COVID-19, the long-term and indirect effects of the pandemic will likely be felt much more severely on women.

JA: *What are some emerging concerns?*

1. Police abuse is a big concern

Meenakshi: In several **Indian** states, photos and videos show police beating people who are trying to get essential supplies.[43] In West Bengal, police allegedly beat a 32-year-old man to death after he stepped out of his home during the lockdown to get milk.[44] A video from Uttar Pradesh shows police forcing migrant workers, who were trying to walk home, to hop on the street to humiliate them.[45] Police in Maharashtra allegedly beat homeless people to evict them from streets.[46] Police have targeted daily wage workers, such as vegetable and fruit vendors, milk sellers, auto rickshaw and taxi drivers, and others delivering essential goods.[47]

Phil: In the **Philippines**, police and local officials in several parts of the country have mistreated people detained for violating COVID-19 regulations, including by confining them to dog cages and forcing them to sit for hours in the midday sun. Children are among those facing cruel, inhuman, and degrading treatment for violating pandemic emergency measures. In Cavite province, two children were locked in a coffin as punishment for violating curfew. In Binondo, Manila, village officials arrested four boys and four girls on March 19 for violating curfew. They forcibly cut the hair of seven of the children while the one who resisted was stripped naked and ordered to walk home.[48]

Otsieno: When **Kenya** announced a curfew on March 25, police across Kenya beat and used teargas on crowds of people on their way home from work. In Mombasa, media reported that police started beating people who were queuing to board the ferry, the only means of transport home to the mainland after work, more than two hours before the curfew. Local television stations and social media showed footage of police apparently beating journalists covering the events. Mombasa police forced crowds of people to lie down together, in some cases on top of each other, as they beat, kicked, and slapped them for allegedly violating curfew. The crowds of travelers who were exposed to teargas and who did not have protective gear, coughed and yelled hysterically as police descended on them with batons, kicks, and blows.[49]

Jude: In **France**, where ethnic profiling by the police is a longstanding, serious problem, citizens with cell phones and activists have documented abusive police stops targeting minorities in the context of enforcing lockdown measures.

2. Growing authoritarian rule

Lydia: In **Hungary**, Prime Minister Viktor Orban has seized the COVID-19 pandemic to undermine fundamental principles of democracy and rule of law in a way that is hard to reconcile as necessary for public health. An emergency law, rushed through parliament, which he controls, gave Orban and the executive branch extraordinary powers to suspend certain laws and implement others by decree for as long as the emergency continues. The law allows Orban as president to sidestep the parliamentary process and gives him and his government the means to exercise arbitrary and unlimited power.[50]

Phil: Seventeen people have been arrested since late January 2020 in **Cambodia** for sharing information about COVID-19. Four members or supporters of the dissolved opposition Cambodia National Rescue Party (CNRP) were arrested, as well as a 14-year-old girl who expressed fears on social media about rumors of positive COVID-19 cases at her school and in her province. The Cambodian government's harassment of political opposition members and others is part of a broader campaign against civil society activists, independent journalists, and ordinary people who express their views both online and offline. The government has repeatedly said it would adopt a "fake news" law, a cybercrime law, and amendments to the media law—all of which are likely to curtail the right to freedom of expression and to facilitate arbitrary and unfettered surveillance of those deemed dissidents.

3. Privacy and surveillance

Maya: The **Chinese** authorities are notorious for using technology for mass surveillance, unconstrained by privacy legislation, a free press, robust civil society, or an independent legal system. Recently, China has been using an app, Health Code, to fight COVID-19. People provide their personal information, including ID number, address, whether they have been with people carrying the virus, and their symptoms. The app then churns out one of three colors: green means they can go anywhere, yellow and red mean seven and 14 days of quarantine, respectively. The app also surreptitiously collects—and shares with the police—people's location data.[51] In addition, it can draw on other government databases, and the algorithms are unknown—and thus impose arbitrary constraints on the freedom of movement, among other rights. This raises serious concerns for the future, not least about what the authorities will do with still more data.

Rachel: In Russia, Moscow officials are forging ahead with installing one of the world's biggest surveillance camera systems equipped with facial recognition technology, despite protests from activists. Even though not designed for that purpose, the system is now being used to ensure that people who test positive for COVID-19, or are required to quarantine, stay at home. The government also tracks geolocation, call, and other data from their cellphones.[52] Currently, most Russian regions are under lockdown regimes. Local authorities in some of these regions have introduced pass systems, which require residents to obtain an SMS or QR code that serves as proof for having a legitimate reason for travel within a particular city.[53] Another country in the region that has imposed a pass system is Azerbaijan. Starting April 5, the Azerbaijani government began requiring residents to obtain such codes to leave the home, with only several tasks considered legitimate reasons, such as buying food or medicine or seeking medical care. Among the penalties for violators is up to 30-day jail sentences. Authorities have so far detained several hundred people for this infraction. Azerbaijan has a highly authoritarian government that has not refrained from using this system to retaliate against critics. Among those detained for infractions are six outspoken political activists, some of whom had in fact obtained passes. Most of them had criticized the government's failure to provide adequate compensation to people struggling financially from the consequences of the pandemic.

4. Older persons' rights

Bethany: The COVID-19 pandemic has both short-term and long-term consequences for older people. In the short term, they are at high risk for serious and life-threatening complications from COVID-19 infection. They also face heightened risk of infection if they live in institutions like nursing homes and may face severe social isolation if they remain at home. Over the longer term, I am hopeful that the understanding and attention to older persons' rights will increase as a result of this pandemic. The abuses we are now seeing, including discriminatory policies and troubling discussions of medical rationing and "culling" or sacrificing older people for the sake of the economy, are antithetical to the core of human rights, which recognizes the equality and dignity of all human beings.[54]

JA: *Portugal has extended some rights protections to migrants and asylum seekers in the country during this crisis.*[55] *What other positive examples have you seen in documenting governments' response to the pandemic?*

Jude: Portugal's decision to temporarily grant all migrants with pending residency applications and all asylum seekers equal access to the national healthcare system as well as other full residency rights is a positive step. **Italy** automatically extended until mid-June all residency permits set to expire during the national lockdown period. Several European countries began releasing people from immigration detention facilities. On March 18, immigration authorities in **Spain** said they would start releasing people from detention following a case-by-case assessment, including whether there was any reasonable possibility of carrying out a deportation. Federal authorities in **Belgium** released an estimated 300 people on March 19 because detention conditions did not allow them to enforce safe social distancing measures. Authorities in the **United Kingdom** released some 300 people in response to a legal challenge brought by Detention Action and lawyers, who said that detention made the people they represent vulnerable to infection.[56]

Maya: Taiwan took swift steps to combat the virus, including promptly making credible information widely available to the public. Daily press briefings by health officials and public service announcements aim to counter misinformation and have helped to calm panic, restore public confidence, and encourage people's cooperation in the crisis. **Singapore's** government published and regularly updated detailed statistics on the number and rate of infections and recoveries.

Hillary: The **UK** government and health departments in England, Scotland and Wales, unlike in the United States, have taken steps to ensure that women are able to manage medical abortions at home. Under the new policy, women can take both medications necessary for medical abortion—mifepristone and misoprostol—at home during the first

10 weeks of pregnancy following a telephone or electronic medical consultation, rather than having to take the first dose at a health facility. Access to early medical abortion at home lets women end unwanted pregnancies safely and privately, avoiding unnecessary surgical procedures.

Kyle: A high-ranking official in Karachi, **Pakistan**'s largest city, reassured the transgender community there that the government would support them during a province-wide lockdown due to COVID-19. Karachi commissioner Iftikhar Shalwani told reporters that transgender people were a part of society, and assured them they would not be left out, stating: "We are committed to providing them with all possible help." It's a small step, but important considering how transgender people in Pakistan have historically faced abuse when accessing health care.[57]

MW: *What is the importance of the human rights to water and sanitation in the context of the pandemic?*

Amanda: Human Rights Watch has worked on the issue of water, sanitation and hygiene for years, and sometimes it has been hard to get traction with governments and even the media about the importance of this issue from a human rights perspective. But, when you have the World Health Organization making recommendations about hand-washing in the context of a pandemic, it exposes how many people there are in the world that don't have continuous access to sufficient and safe water to take even this basic preventative step. From people in detention, to those enduring homelessness, to people who have had services cut because they can't pay, and those living in places where there isn't any piped water, nearly a billion people globally can't do even the minimum to protect themselves and that's a human rights crisis that existed even before the coronavirus.

JA: *An area that I think has been under-addressed so far is the risk of corruption that accompanies the chaos, emergency public procurement, fast-tracked R&D, and large economic stimulus and infrastructure programs. What are some other risks that you see emerging in the post-COVID-19 world?*

Sarah: The response to COVID-19 definitely raises the risk of corruption everywhere in the world. In the **United States**, recent economic stimulus legislation authorizes US$500 billion in loans, loan guarantees, and "other investments" to certain businesses, with minimal oversight requirements and inadequate conflict-of-interest provisions. President Donald Trump, who never divested from his businesses, may benefit from these funds. The International Monetary Fund has committed up to $1 trillion dollars to countries dealing with the economic impact of the pandemic and 90 countries have already requested emergency assistance. The World Bank expects to deploy $160 billion dollars over the next 15 months, both to governments and private sector clients. It's critical that there is transparency and accountability for all money spent.

MW: *Let me ask you one final question, Joe. What do you see as some issues that have not been explored enough?*

JA: I have been surprised how little information we've gotten so far from public health authorities that would help us understand this pandemic. Fundamentally, we need more transparent information on who is getting testing and treated. Some states in the United States have collected no information by race, for example. We know nothing about access to testing or care for indigenous people. There's a lot of discussion about setting up drive-through testing, but what if you don't have a car? There was a small piece in the news about 10,000 families in San Antonio, Texas, coming to a weekly food distribution point that normally serves 200 people.[58] This is basic, it's about the right to food. Looking around the world, and seeing both the slow responses in many countries and the fragile health systems, I think there will be big issues ahead in terms of ensuring that medical supplies and resources are distributed and shared globally—including an eventual vaccine and effective treatment. How can this be done equitably and based upon need? Clearly, WHO has to play a central role in this, and all countries have to see it as in our common interest. And finally, I think WHO has to see the crucial role that civil society plays in pandemic response and reimagine itself and embrace more those working to ensure that equity, accountability, and participation are fundamental and that human rights such as the right to information and to non-discrimination are central to its mission and identity.

JA and MW: *Thank you all for participating in this virtual roundtable and discussing some of the work that you are doing. It is a challenging time for everyone and no doubt a challenging time to document human rights abuses and conduct advocacy. Heather, we'll give you the final word. Can you give us some insight into what it's been like for the Women's Rights Division to work during these trying times?*

Heather: The women's rights team is 13 women based in ten locations in eight countries on four continents. Almost two-thirds are parents, some single parents, some of children who are no longer in school. Several others are caregivers for other family members or have taken on that role during this crisis. Multiple staff members have experienced anti-Asian racism related to the pandemic. We've become used to checking the number of COVID-19 cases in the country we're calling before checking in with a colleague. Colleagues have come up with creative but incredibly difficult solutions to do their work, stay safe, keep others safe, and get through the days—from not leaving the house at all to getting up at 4am to work to taking calls in the bathroom or outside when that's the only bit of quiet—and new ways to work with partners to keep research going during a lockdown. It's been a hell of a time for our team, though they are also feeling acutely aware of how many people have it so much worse.

JA and MW: *Thank you all again.*

Acknowledgments

The moderators and participants would like to thank the activists, journalists, and human rights organizations working to address COVID-19 and human rights issues in countries around the world. The moderators would also like to thank Ashley Jackson, founder of AidEthics.org and a Visiting Global Health Scholar at the Drexel University Dornsife School of Public Health for her support with the preparation of the article.

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