

Health and Human Rights Journal

DECEMBER 2016, VOLUME 18, NUMBER 2

Special Section:

Universal Health Coverage and Human Rights

Publisher: Harvard University Press

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

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EDITORIAL

The Contributions of Human Rights to Universal Health Coverage

AUDREY R. CHAPMAN

Recently, there has been a growing push for countries to achieve universal health coverage (UHC) in order to strengthen health systems and improve health equity and access to health services. UHC has been identified by some as the third global health transition—the first being public health improvements (such as basic sewage and sanitation) and the second being the epidemiological transition that reduced the toll of communicable diseases.¹ Major health and development organizations, including the World Health Organization (WHO), the World Bank Group, the Rockefeller Foundation, Oxfam, the Gates Foundation, the International Labour Organization, and the United Nations Children’s Fund, have endorsed initiatives promoting UHC.² Dr. Margaret Chan, WHO’s director-general, has described universal health coverage as “the single most powerful concept that public health has to offer” and has said that UHC represents the “ultimate expression of fairness.”³ In September 2015, UHC was selected as one of the key targets to implement the health goal in the United Nations Sustainable Development Goals (SDGs).⁴

Importantly, UHC has also been termed “a practical expression of the right to health.”⁵ UHC is explicitly enumerated as a core obligation for the realization of children’s right to health.⁶ It is also implicit in article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which directs states parties to take steps toward the creation of conditions that ensure medical services and attention for all in the event of sickness.⁷ The first of the core right to health obligations identified in General Comment No. 14 (GC 14) of the United Nations Committee on Economic, Social and Cultural Rights is “to ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups.”⁸ The commitment to universality in access to key health services is also implicit in other international and regional human rights instruments. Significant progress toward UHC, consistent with the requirements of the right to health, has the potential to provide the approximately one billion people currently estimated to lack access to necessary health services the opportunity to obtain them.

Importantly, not all potential paths to a universal health system are consistent with human rights requirements. Simply expanding health coverage, especially if it continues to exclude poor and vulnerable communities, is not sufficient from a human rights perspective. As two health policy analysts warn, “beware—universal coverage is more difficult to achieve than to advocate. And people who are poor could

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Competing interests: None declared.

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well gain little until the final stages of the transition from advocacy to achievement if that coverage were to display a trickle-down pattern of spread marked by an increase first in better-off groups and only later in poorer ones.⁹ A recent UHC progress analysis of 11 countries at different levels of development shows that this is often what occurs: UHC expansion usually begins with civil servants or urban, formal sector workers, with poorer people initially losing out. Further skewing the benefits of UHC, the clinical sector commonly favors expensive specialized health services that are accessible primarily to a small, privileged fraction of the population.¹⁰

A human rights approach to UHC imposes distinctive requirements. I have proposed that UHC consistent with the requirements of the right to health would include the following elements:

- Health care reforms designed to achieve universal access to essential health services would be placed within the context of a national effort to provide equitable access to the social determinants of health.
- Access to essential health services and public health protections would be made a legal entitlement, and individuals would have access to adequate means to seek redress for failures to provide these benefits.
- Coverage would be based on a true universality, providing benefits to all residents of a country regardless of their legal status.
- Explicit attention would be paid to equity considerations in the design of the universal health system and throughout the process of expanding coverage, especially to the implementation of measures to reduce barriers for low-income groups, rural populations, women, and other vulnerable groups that are often disadvantaged in terms of service coverage and health.
- An equitable and progressive system of health funding for financial risk protection would be put in place to eliminate or at least significantly reduce financial barriers, especially for poor and disadvantaged groups. The government would underwrite the health costs of the poor.
- Sufficient funding—at least 5% of the gross domestic product and 15% of the total government budget—would be provided for health system strengthening in order to expand health coverage and provide a publicly funded package of priority health services based on people’s needs.
- Health system strengthening would be accorded priority in order to make good-quality health services widely available, especially in currently underserved communities and with a greater balance between rural and urban areas.
- There would be opportunities for consultation with and the participation of the population in the design of the path to UHC and the determination of benefits packages.
- The process for pursuing the progressive realization of UHC would first expand coverage for high-priority services to everyone, with special efforts to ensure that disadvantaged groups are reached.
- A uniform package of health service benefits closely linked to the population’s needs would be universally provided by the government.
- An effective data monitoring system would be put in place to evaluate the distributional effects of efforts to achieve UHC and improve health outcomes. This system would have the capacity to track and assess data on a disaggregated basis in order to facilitate corrective action when necessary.¹¹

Dainius Puras, the current Special Rapporteur on the right to health, has identified additional requirements for UHC to be consistent with the right to health. In his recent report on the 2030 Agenda for Sustainable Development and the Sustainable Development Goals, he references the GC 14 provision that “the right to health requires that health care goods, services and facilities be available in adequate numbers; financially and geographically accessible, as well as accessible on the basis of non-discrimination; acceptable, that is, respectful of the culture of individuals, minorities, peoples and communities and sensitive to gender

and life-cycle requirements; and of good quality.¹² He cites the need for an effective and integrated health system to incorporate the human rights principles of equality and non-discrimination, transparency, accountability, and participation.¹³ He makes the further point that states should ensure that rights-holders, including those from marginalized groups, are provided with the conditions to participate in the design, implementation, and monitoring of laws, policies, and strategies.¹⁴ He underscores the need for UHC policies to make an explicit commitment to prioritize the poor and marginalized in the process of expanding coverage and in determining which services to provide in order to avoid entrenching inequality.¹⁵

Even if there is consensus within the human rights community about the importance of grounding UHC in human rights law, there are many practical questions regarding how this should be done. The seven articles in this special issue of *Health and Human Rights* address some of these questions. They also offer evidence of the challenges and benefits of adopting a rights-based model of UHC.

The goal of achieving UHC can generally be realized only in stages, through a long process of gradual realization, much like the achievement of economic, social, and cultural rights. Moreover, limitations in resource availability and administrative capacity, as well as political constraints, impose difficult trade-offs along the way. In a 2014 report, *Making Fair Choices on the Path to Universal Health Coverage*, the WHO Consultative Group on Equity and Universal Coverage articulates principles for making such trade-offs in an equitable manner consistent with human rights norms. It proposes a three-part strategy: first, categorize services into priority classes on the basis of criteria such as cost-effectiveness, priority to the worse off, and financial risk protection. Second, expand coverage for high-priority services that tend to benefit the worse off and to be the most effective for everyone. Third, as coverage is expanded, take special measures to ensure that disadvantaged groups, such as low-income groups and rural populations, are not left behind.¹⁶ The article written by Alex

Voorhoeve, Tessa Edejer, Lydia Kapiriri, Ole Norheim, and their colleagues applies these principles to three case studies to show how they can guide practical decision making and inform progressive realization of the right to health, including generating the greatest total health gain, priority for those who are worse off in a number of dimensions, and financial risk protection.

Lisa Forman, Claudia Beiersmann, Claire Brolan, Martin McKee, Rachel Hammonds, and Gorik Ooms consider what human rights principles, particularly core obligations related to the right to health, bring to formulating and implementing UHC. One of the limitations they identify is the Committee on Economic, Social and Cultural Rights' interpretation of the right to health in GC 14, which moves from the fairly substantive notion of core obligations in the committee's General Comment No. 3 as requiring the provision of essential primary health care to a far more procedural/structural approach encompassing equitable distribution, non-discrimination, and a comprehensive participatory national plan of action. According to Forman and her colleagues, because the focus of core obligations in GC 14 is more on processes than outcomes, it is not clear which health services fall within the core other than essential medicines and underlying determinants, such as food, basic shelter, housing, sanitation, and water, which are identified in the document. The specific health care services referenced in the general comment are categorized as obligations of comparable priority, and it is unclear what the relationship is between obligations of comparable priority and minimum core obligations. The article concludes that the core obligations identified in GC 14 do not prescribe a globally applicable and fixed set of health care benefits but rather a framework for action encompassing non-discrimination (including affordability), equity, participatory decision-making, essential medicines, and the social determinants of health.

At first glance, the question of who should be included in a universal health system seems quite simple. Universality is a fundamental principle of human rights. Therefore, UHC implies that all

persons in a country, including refugees, asylum seekers, and undocumented and documented migrants, should be provided with health entitlements for affordable and necessary health care. However, the explosion of migration as many thousands of persons flee areas of conflict and large numbers of other persons seek to relocate to countries of greater economic promise, juxtaposed with the bleak post-2008 economic climate, has imposed challenges for the implementation of this principle, even in Europe's affluent countries. Claire Lougarre's article considers the effectiveness of the global health policy commitment to guarantee access to affordable health care for non-nationals. She points out that non-nationals often face obstacles in accessing health care in Europe that nationals do not face, such as restricted legal entitlements, administrative hurdles, and language barriers. Lougarre proposes that the right to health as enshrined in the ICESCR has the potential to promote UHC goals by legally demanding non-nationals' access to affordable health systems; however, she acknowledges that the scope of protection under the ICESCR is unclear. Moreover, provisions in many of the regional human rights instruments restrict the application of the right to health to nationals. She concludes that supranational human rights bodies that are mandated to supervise the implementation of human rights treaties can play a role protecting non-nationals' right to access affordable health systems on the same basis as nationals.

One of the core principles of the right to health is the importance of enshrining the right in national law. By extension, a state's commitment to UHC should also take the form of a binding legal provision. But even if such a legal provision is necessary, is it sufficient? Everaldo Lamprea and Johnattan Garcías's study of Colombia indicates that it may not be. In 1993, Colombia reformed its health law in order to achieve universal health care coverage through a national, comprehensive, and mandatory social insurance system subsidized by the government for the poor in which health care was to be provided through private health insurers. An important 2008 ruling handed down by the Constitutional Court required the integration

of the hitherto unequal baskets of health services provided through the contributory and subsidized regimes. Nevertheless, despite the legal guarantees of health coverage, 2.3 million people out of Colombia's population of 48.7 million currently lack access to health care; in addition, others have had to resort to legal action to secure their benefits. This situation leads Lamprea and García to make the useful distinction between formal (legal) and material (actual) health coverage in Colombia and to identify factors accounting for this disparity, some of which (such as the unequal unavailability and access to health care in the wealthiest and poorest departments and regions) are likely to impede other countries' efforts to achieve UHC as well.

The type of health system financing adopted is a critical factor in securing universal health care and determining whether it is affordable both for the state and for the system's users. Anja Rudiger's article identifies ways in which the human rights framework offers valuable guidance for designing a financing strategy that meets these goals. Rudiger reports on a rights-based public financing plan and model—which included a new business tax directed against wage disparities—that was a component of recent universal health care reform efforts in the US state of Vermont. According to Rudiger, modeling results suggest that a health system financed through a rights-based public financing plan that includes equitable taxation could produce significant redistributive effects and thus contribute to economic equity while generating sufficient funds to provide comprehensive health care as a universal public good.

After several decades of inadequate funding and insufficient investment in health institutions and services, the health systems of many countries are seriously weakened. According to WHO, in many countries, health systems are underfunded and struggle to provide even basic health service coverage, particularly for rural and poor populations.¹⁷

Faced with this situation, some countries are turning to the private sector for the provision of health care and health services in order to expand health coverage. Antenor Hallo de Wolf and Brigit Toebes's article considers the legal human rights

obligations imposed on states to regulate private sector involvement in health care. They emphasize that the obligation “to protect” the right to health requires that health services be available, accessible, acceptable, and of good quality, regardless of whether they are provided through the state or through private actors. They also propose that governments be encouraged to conduct human rights impact assessments to evaluate the consequences of privatization prior to its introduction. In addition, they identify the duty of governments to mitigate any financial problems related to out-of-pocket expenses charged by private actors.

Four decades ago, the Declaration of Alma-Ata identified comprehensive primary health care as key to the attainment of health for all.¹⁸ Primary health care is both pro-poor and pro-rural. Moreover, there is historical evidence (such as in Thailand and Brazil) of primary health care serving as a foundation for the progressive realization of UHC.¹⁹ Toby Freeman, Fran Baum, Angela Lawless, and their colleagues provide a case study of an Aboriginal community-controlled, universal, rights-based, publicly funded comprehensive primary health care service in Australia. They report how the Central Australian Aboriginal Congress community model of comprehensive primary health care has demonstrated impressive outcomes in a variety of areas—including intersectoral work on the social determinants of health, community participation, cultural respect, accessibility, and preventive and promotive health services—and therefore deserves attention as a promising model of primary health care based on health as a human right.

Like the Special Rapporteur, I would like to celebrate the momentum to progressively achieve UHC in the Sustainable Development Goals and elsewhere. But also like him, I would like to caution against simplifying the challenges and underscore the importance of incorporating a human rights approach.

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FOREWORD

Universal Health Coverage: A Return to Alma-Ata and Ottawa

DAINIUS PURAS

In 1978, the Alma-Ata Declaration established a bold plan for global health action and social justice, identifying primary health care as the lynchpin for achieving health for all.¹ Several years later, the Ottawa Charter for Health Promotion, responding to growing health challenges within industrialized societies, formally recognized underlying determinants as an integrated and vital part of health for all.² United Nations agencies, national governments, and a range of civil society organizations endorsed these declarations, recognizing access to health care and underlying determinants as a human right. Implicit in this recognition was the emerging obligation of nations to establish health policies responsive to underlying determinants and to ensure universally accessible primary health care. This early consensus for universal health care was soon challenged by political and economic developments of the 1980s, when neoliberalism and structural adjustment programs delivered a devastating blow to the health sector and the objectives of Alma-Ata.³ World Bank economists and other development actors successfully exported the case for user fees and private sector financing, which subsequently shaped the trajectory for health systems in many low- and middle-income countries for more than three decades.⁴ These user fees have left a devastating legacy, deepening inequality, and poverty, and are referred to by the current World Bank president as “unjust and unnecessary.”⁵ For those countries isolated from neoliberalism during the Cold War, specifically in Soviet bloc countries, state-run, centralized health bureaucracies flourished, where excessive biomedical treatments and specialization were privileged at the cost of evidence-based prevention, health promotion, and respect for the human rights of all users of health services—particularly undermining the values expressed in Ottawa. These publicly financed health systems, while claiming universalism, left an equally devastating legacy of inequality, corruption, and systematic human rights abuse within health care systems.

How we overcome these inherited legacies of health financing, how we define health, and how we achieve equitable access is at the heart of the current struggle for universal health coverage (UHC), one of the most ambitious global health developments of our time. Calls from the World Health Assembly urging states to strive for “affordable universal coverage and access for all citizens on the basis of equity and solidarity” signal a welcome return to the principles of Alma-Ata and Ottawa.⁶ The World Bank’s current president, Jim Yong Kim, has promisingly affirmed that the values of Alma-Ata must be harnessed in the movement toward UHC.⁷ UHC is now part of the Sustainable Development Goals, a global political com-

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mitment adopted by the United Nations General Assembly in 2015. In November of this year, national governments and international organizations will renew the spirit of Ottawa in light of the 2030 agenda with the Shanghai Declaration and Plan of Action on Health Promotion.⁸ Today, achieving UHC is not merely an aspirational call for action—it is an attainable global health imperative within our reach. However, in this global transition toward UHC, the world's poorest and most marginalized remain at risk of being left behind. The effective integration of human rights standards and principles within national, regional, and international UHC implementation strategies and programs can mitigate these risks, fortify health and well-being, and further the promotion and protection of human rights for all.

In the decades since Alma-Ata and Ottawa, human rights, particularly the right to the highest standard of physical and mental health, have evolved in both substance and content. This rich understanding of the right to health can now be applied to health policy in an operational, practical, and systematic way and is of particular relevance as states advance in their SDG commitments to achieve UHC by 2030.

It is this convergence of global processes and commitments, the renewed spirit of Alma-Ata and Ottawa, and the practical and legally binding nature of the right to the highest attainable standard of health that led me to address (albeit not in depth) UHC, the right to health, and the Sustainable Development Goals in my latest report to the United Nations General Assembly.⁹

Moving toward rights-based UHC

While UHC has been called “a practical expression” of the right to health, not all paths to UHC are consistent with human rights requirements.¹⁰ In my report to the General Assembly, I emphasized that UHC *must* be understood to be consistent with the right to health. Therefore, UHC cannot be narrowly defined as economic access but must integrate a right to health framework that secures promotive, preventive, curative, and palliative

care services for all without discrimination.¹¹ The intersection of UHC and human rights is a large, complex topic that, from the perspective of the right to health, must include a number of elements. To explore these in depth within the scope of my report to the General Assembly would have been impossible. While I plan to devote space to UHC in my future work, I chose to focus this report on but a few features required to establish rights-based UHC, some of which I highlight for readers below.

Ensuring the prioritization and participation of the world's most vulnerable

The 17 Sustainable Development Goals of the 2030 agenda reflect a holistic approach to transforming the world into a more peaceful, just, and inclusive global community. Health is central to the SDGs as both a path and an outcome to ending poverty and achieving sustainable human development. There is an overarching commitment to implement the SDGs in a manner that is consistent with international human rights law. However, as we move from the 17 goals to their associated targets and indicators to measure progress and set priorities for action, critical rights elements, particularly the right to health, are absent. Goal 3, particularly Goal 3.8 on UHC, and its indicators are entirely reductive in content. There is no explicit commitment to confer priority to the poor and marginalized, either in the process of expanding coverage or in developing priorities as to which services to provide. This is despite core obligations under the right to health to guarantee access to health services without discrimination and to take deliberate, targeted, and concrete steps to ensure the effective realization of that guarantee, especially for the most marginalized.

Ensuring the participation of the world's most vulnerable is vital to defining and achieving equitable UHC. States have a core obligation to guarantee effective and meaningful participation in the development of national health plans, including strategies for UHC that, at a minimum, ensure the incorporation of the views of the poor and most marginalized. If the furthest behind are not prioritized, and if progressive strategies for expanding coverage for the most marginalized are

not immediately established with their active participation, there is little hope this target will be met by 2030. Equally, some have argued that this risks a situation where the easiest way to report progress on UHC is to focus provision on those portions of the population who are already closest to the target, deepening inequality and poverty.¹²

Strategies to define health packages

I also emphasize in my report that UHC cannot be achieved without health care services meeting the core requirements of availability, accessibility, acceptability, and quality under the right to health. Among other things, services must be safely and geographically accessible without discrimination. The right to health requires that essential services include those for populations with specialized needs, such as sexual and reproductive health services adapted to the needs of women, girls, persons with disabilities, and transgender persons. Health services and access to underlying determinants must also be economically accessible. Even where there is widespread access to health services, the right to health demands that they be of sufficient quality, including in good working condition and medically and scientifically appropriate. The right to health recognizes the importance of prioritizing investments in primary and preventive care, which benefits a larger population than expensive specialized health services, often only accessible to a small, privileged fraction of the population. Investing in primary health services prevents illness, promotes mental and physical health, and in turn reduces the need for specialized care. This core framework is entirely absent from the SDG indicators for UHC.

States will not achieve Goal 3 without a robust commitment to addressing social and psychosocial determinants of health, as well as inequalities in income, education, living and working conditions, and distribution of resources. As UHC is a key determinant of success toward achieving Goal 3, how services are defined must not be limited to biomedical interventions such as medicines and vaccines, though the indicators to measure UHC appear to focus on this reductive conceptualization. As I have emphasized in past reports, the achievement of the

highest attainable standard of health requires scaled up investment in modern interventions that go beyond the biomedical model, including psychosocial and other interventions that address structural and environmental barriers to health. This vital component to achieving equitable expansion and access to UHC and securing the right to health remains absent from the targets and indicators for health.

As a mental health professional and as Special Rapporteur on the right to the highest attainable standard of *mental* and physical health, I have consistently raised concerns regarding the grossly unmet global need for rights-based mental health services. While the 2030 agenda affirms that UHC and access to quality health care are necessary to promote mental health and well-being, this falls short of the World Health Organization's Comprehensive Mental Health Action Plan, which requires comprehensive strategies for promotion, prevention, treatment, *and* recovery.¹³ UHC is a crosscutting principle to ensure equity for those in need of mental health services and to promote societal well-being. Lack of political will to address mental health as an emerging priority has given rise to two scenarios that are equally problematic from a right to health perspective: either mental health services are not available for those who need them (particularly in low- and middle-income countries), or, where services do exist, they often violate the rights of people receiving care. The progressive move toward UHC is a window of opportunity to reform and scale up mental health services that respect, protect, and fulfil the right to health. Psychosocial and public health interventions that empower people, increase their resilience, and address structural factors that contribute to mental ill health must be the touchstone by which to define services, on par with the provision of appropriate and high-quality medications. These interventions must be viewed as part of primary, community-based health care and as an integral part of UHC.¹⁴

Financial risk protection

As already referred to, the legacy of user fees and catastrophic out-of-pocket health expenditures is why many countries find themselves still strug-

gling to achieve UHC 30 years after Alma-Ata. Still today, in many countries, out-of-pocket payments—such as user fees and co-payments, fees for treatment, and indirect fees related to the costs of seeking health care (transportation costs, informal charges, opportunity costs/loss of work, discrimination)—create major barriers to health care.

These costs are often significant and disproportionately affect the poor, who spend a considerably larger portion of their total income on health. In turn, they drive many households into poverty or deepen the poverty of those who are already poor. These fees may bar those without the means to pay from receiving needed care, as well as discourage people from seeking care in the first place.

Despite this, private, out-of-pocket payments account for around 50% of total health expenditures in countries where more than 50% of the population is living on less than US\$2 a day. This means that it is the poorest and most in need who suffer from these payments.¹⁵ UHC consistent with the right to health requires establishing a financing system that is equitable and that pays special attention to the poor and others unable to pay for health care services, such as children and adolescents.

Conclusion

While the momentum to progressively achieve UHC presents a host of complex human rights and political challenges in both defining and financing health care packages, the momentum toward achieving equitable expansion is stronger today than ever before. In health-related policies, the implementation of good ideas has always been complicated. Although UHC is a simple and noble proposal, based on common sense and the need for basic health care to reach everybody, I wish to warn against the perils of the low-hanging fruit and of simplifying approaches to UHC and the process toward reaching it. How we understand UHC in relation to human rights is critical to achieving health equity and well-being for our global community. It is precisely these challenges that this special section on UHC seeks to begin to address, making this

publication an important and timely contribution to this next transition in global health.

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Three Case Studies in Making Fair Choices on the Path to Universal Health Coverage

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Competing interests: None declared.

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Abstract

The goal of achieving Universal Health Coverage (UHC) can generally be realized only in stages. Moreover, resource, capacity, and political constraints mean governments often face difficult trade-offs on the path to UHC. In a 2014 report, *Making fair choices on the path to UHC*, the WHO Consultative Group on Equity and Universal Health Coverage articulated principles for making such trade-offs in an equitable manner. We present three case studies which illustrate how these principles can guide practical decision-making. These case studies show how progressive realization of the right to health can be effectively guided by priority-setting principles, including generating the greatest total health gain, priority for those who are worse off in a number of dimensions (including health, access to health services, and social and economic status), and financial risk protection. They also demonstrate the value of a fair and accountable process of priority setting.

Introduction

Universal health coverage (UHC) is at the center of current efforts to strengthen health systems and improve the level and distribution of health and health services. The values that motivate this goal—improving population health, fairness in access to health services and in the distribution of health, and financial risk protection—should also determine the path to it. In 2011, the World Health Assembly called on the World Health Organization (WHO) to provide support and advice to countries seeking to move towards UHC. The WHO Consultative Group on Equity and Universal Health Coverage was set up to develop guidance on how countries can best address issues of fairness (or equity) that arise on the path to UHC. The Consultative Group issued its report, *Making fair choices on the path to universal health coverage*, in early 2014.¹ The report has been widely discussed.²

After the publication of *Making fair choices*, work began on a set of case studies intended to illustrate how the principles articulated in the report apply to a diverse set of cases. To develop these cases, the present group of authors, who are academics and health policy professionals, was convened. This paper reports three of these studies.

The case studies are drawn from experience, but have been simplified to allow key ethical issues to be discussed in a compact and accessible manner. They have also been generalized, to highlight

features which apply to choices faced in many countries. Consequently, though they draw inspiration from reality, they are not an evaluation of particular countries' decisions.

In what follows, we first offer a brief summary of *Making fair choices* and then discuss three cases.

Summary of Making fair choices on the path to universal health coverage

WHO has defined UHC as “all people receiving quality health services that meet their needs without being exposed to financial hardship in paying for them.”³ This definition leaves room for interpretation. On the understanding adopted here, given resource constraints, UHC does not require that all possibly effective services are provided to everyone. Rather, it requires that a comprehensive range of services, well-aligned with other social goals, is available to all at bearable cost.

To achieve UHC, countries must advance in at least three dimensions: expanding priority services, including more people, and reducing out-of-pocket payments. In doing so, they face the following critical decisions:

- Which services to expand first?
- Whom to include first?
- How to shift from out-of-pocket payment toward prepayment and pooling of funds?

They also face trade-offs between these dimensions: for example, between covering more services or covering more people.

Making fair choices recognizes that many values are relevant to making these decisions and that their importance will depend on each country's context. Nonetheless, it also argues that, in all contexts, the following three principles should play a central role in evaluating the available alternatives:

1. Health benefit maximization. This involves generating the greatest total health-related well-being gain. This is measured in terms of the total number of healthy life years added through an intervention. (One healthy life year is an amount of health-related well-being that is just as valuable to a person as one year in full health. For example, a person gains a healthy life year by living one extra year without health problems, or by living two extra years with health problems which give them only half the quality of life in a given year that they would have if they were fully healthy. Various measures exist for determining the health-related quality of life for a person in a given year.⁴) For a given budget, one maximizes total health gain by choosing the interventions that cost the least per healthy life year gained. These are referred to as the most cost-effective interventions. (Below, we shall use multiples of a country's income per person—GDP per capita—that an intervention requires to generate one healthy life year as a measure of cost-effectiveness. The lower this number, the more cost-effective an intervention is. For example, for a given budget, an intervention costing two times GDP per capita per healthy life-year will generate three times as many healthy life-years as an intervention costing six times GDP per capita).
2. Fair distribution, which incorporates priority to the worse off. Coverage and use of services should be based on need. Moreover, extra weight should be given to the needs of those who are relatively disadvantaged with respect to health prospects, health outcomes, access to health care, or social and economic status (interpreted

broadly to include groups facing discrimination and marginalization).

3. Fair contribution and financial risk protection. Contributions for needed coverage and services should be based on ability to pay and should not depend on individuals' health risks or the severity of their condition. Moreover, impoverishment due to ill health, associated expenditure, and loss of earnings should be minimized.

There are different acceptable ways of balancing these three substantive principles' requirements. Moreover, these principles are not exhaustive. There is no simple recipe for arriving at the right decision and there may be reasonable disagreement on which decisions are right. Under such circumstances, fair procedures for setting priorities contribute to the legitimacy of decisions. *Making fair choices* therefore also endorses the following procedural principle:

4. Accountability. Citizens are not merely recipients of services, but are also agents who should be able to play a part in evaluating, deliberating about, and influencing health policy. Mechanisms for strong public accountability should therefore be set up to enable them to do so.⁵

We shall now summarize how, drawing on these principles, *Making fair choices* develops a framework for making critical choices about expanding service coverage, including more people, and shifting to prepayment and pooling of funds.

Which services to expand first?

Health services should be sorted into three priority tiers: high, medium, and low, based on their contribution towards health benefit maximization, fair distribution, financial risk protection, and other relevant values. Though there are many reasonable ways of weighing these values, it is sensible to first create a partial classification on the basis of cost-effectiveness (defined as cost per healthy life year gained) and then render the classification more complete by an appeal to other principles.

This involves assigning high priority to highly cost-effective interventions and low priority to very cost-ineffective interventions, and let other criteria help determine the priority class of the intervention only in the (substantial) range in between these extremes. We emphasize that we do not endorse a simple, universally applicable rule. Whether a proposed intervention is relatively cost-effective in a given context is determined by many factors, including the cost-effectiveness of interventions that one could do instead.⁶

One reason for using such a procedure is the extreme variability between the cost-effectiveness of different health services. For example, the cost-effectiveness of interventions in the WHO Choice database, which gives estimates of the cost per healthy life-year gained for an increase in funding for a wide variety of interventions in various regions, is spread over four orders of magnitude.⁷ An initial, partial prioritization on the basis of cost-effectiveness can therefore help focus resources where they will do much more good. Moreover, focusing on the expansion of highly cost-effective services will often offer greatest benefits to the poor, because they disproportionately lack access to even the most cost-effective services.

Nonetheless, there are cases in which pursuing only maximal cost-effectiveness would come at a cost to the worse off (for example, because providing services to poor, remote areas is more expensive) or to financial risk protection. In such cases, the procedure permits concern for the worse off or for financial risk protection (and other relevant concerns) to determine into which priority class a service should fall.

Whom to include first?

Once sufficient progress has been made in classifying services, near-universal coverage for high-priority services should be at the top of countries' lists. Many countries have significant coverage gaps, especially among poor, rural, and marginalized groups. In expanding coverage for high-priority services against a backdrop of inequality, meeting the needs of disadvantaged

groups is especially important. This implies that, all else being equal, an expansion of such services to a marginalized population should take priority over an expansion to a better-off population.

How to shift from out-of-pocket payments to prepayment?

A shift from out-of-pocket payment to mandatory prepayment with pooling of funds can alleviate the risks of catastrophic health expenditure. When making this shift, countries should first reduce out-of-pocket payments for high-priority services. At the same time, countries should endeavor to make prepayments depend on individuals' ability to pay, to ensure that everyone has effective access to the most important services. This will reduce the risk of financial distress caused by high payments or ill health.

Accountability

It is advisable to institutionalize accountability mechanisms, for example, through founding a standing national committee on priority setting. A robust system for monitoring progress and for policy evaluation is essential for accountability and for enabling learning on the path to UHC.

Applying the principles

We shall now discuss how these principles apply in three stylized cases. Although we arrive at a judgment in each case, other judgments may also be reasonable. Moreover, the correct judgment in any real-world case will depend on context-specific factors, including both particular moral considerations and constraints faced by decision-makers. These stylized case studies are therefore not intended to yield prescriptions that apply in all analogous real-world cases. Rather, they are meant to serve as discussion pieces, which can illuminate the implications of the principles endorsed in *Making fair choices* and illustrate the forms of moral and empirical reasoning required to form reasonable judgments about real-world cases.

Case 1: Cover treatment for hepatitis B cirrhosis or extend services to more people?

A middle-income country currently ensures effective access to a basic package of health services for 60% of the population. (People have effective access when they do not incur an excessive financial burden in using needed services and face no other substantial barriers in accessing them, such as a long distance to health services, lack of information, insufficient staffing, and other such considerable obstacles.) Lack of effective access disproportionately affects members of worse-off socioeconomic groups, particularly rural populations. Consequently, those who have access to the package are, on average, better off than those who lack it. The basic package consists mainly of services that are high priority on grounds of cost-effectiveness, priority to the worse off, and financial risk protection. In particular, the vast majority of currently covered services cost up to two times GDP per capita for each healthy life year gained. Among the services not currently included is a treatment for hepatitis B cirrhosis. This disease is quite prevalent in the country and can lead to cancer or liver failure. The incremental cost of including this treatment would be six times GDP per capita for each healthy life year gained.⁸

Some new funding has become available, which the health authorities can use for one of the following:

1. Add the treatment for hepatitis B cirrhosis. This supplements the services provided for the population that currently has effective access to the benefit package, without extending access to other parts of the population.
2. Extend access to the existing package. This offers somewhat more people effective access to this package, without adding services to it.

When faced with this choice, a first step should be to estimate the relevant effects of each option. These effects will be context-specific. Nonetheless,

drawing on country experiences, one can offer the following general considerations.

Health benefit maximization

Adding the treatment for hepatitis B cirrhosis is far less cost-effective than the existing package. Still, one must consider that extending access to the existing package may also be somewhat less cost-effective than providing the basic package to the population which currently enjoys access, because some parts of the population (particularly in rural areas) may be harder and more expensive to reach.⁹ However, given that effective access is currently only at 60% and that newly available resources will finance only a marginal expansion of the population with access, it is unlikely that the cost-effectiveness of extending access to the existing package will be substantially worse than that of the package in the status quo. Extending access to the existing package is therefore very likely to be the more cost-effective alternative and is thus likely to have a greater positive impact on population health.

Priority for the worse off

In determining who is worse off in terms of health, it is reasonable to consider both an individual's health prospects and their health outcomes.¹⁰

In terms of health prospects, adding the treatment for hepatitis B cirrhosis helps people with poor expectations, because hepatitis B sufferers have a low life expectancy if untreated. However, extending access to the existing package also assists people with poor prospects, because those who currently lack effective access (mostly the rural poor) generally have worse health prospects than those who currently have such access.

In terms of health outcomes, adding the treatment for hepatitis B cirrhosis helps people avert a large individual disease burden (29 years of life lost in people who die from it).¹¹ This is larger than many of the diseases targeted by currently covered interventions, although not as large as some life-threatening childhood illnesses, the interventions for which are covered in the current package.

Other grounds for being counted among the worse off are low social or economic status. Those who currently lack effective access are generally of lower social or economic status. Extending access to the existing package will therefore help those who are worse off in this respect.

In sum, priority for the worse off in terms of health prospects and outcomes may give a reason to favor adding the treatment for hepatitis B cirrhosis. On the other hand, priority for the worse off in terms of social and economic status and in terms of access to health services provide reasons to extend access to the remaining population.

Financial risk protection

Adding the treatment for hepatitis B cirrhosis will avert some cases of catastrophic expenditure, because the treatment is very expensive.¹² However, extending access to the existing package for currently underserved populations is also likely to considerably reduce financial distress due to ill health and health expenditure. Health improvements can prevent out-of-pocket payments downstream and can increase the income-earning potential of the beneficiaries. Because services included in the current package are much more cost-effective than the treatment for hepatitis B cirrhosis, one can prevent much more ill health by extending the former. One may therefore be able to offer greater financial risk protection by extending access to the existing package.

Recommendation

Considering all three principles, extending access to the existing package very likely has great advantages in terms of both population health and improving the lot of the socially or economically worse off. While it is a matter of judgment, these considerations seem to outweigh the especially large individual disease burden that one alleviates by adding treatment for hepatitis B cirrhosis. On balance, there is therefore a stronger case for expanding access to the existing package.

More generally, to move fairly towards UHC, a country should categorize services as high, medium, or low priority on the basis of the

three principles. It should then start with measures that move it towards universal coverage for high-priority services before adding medium- or low-priority services to the package.¹³ The existing package consists mostly of high-priority services. By contrast, the treatment for hepatitis B can be properly classified as a medium or low-priority service, because its cost-effectiveness is very low and the comparatively large individual disease burden of hepatitis B is unlikely to provide a sufficiently strong countervailing consideration. (We emphasize, however, that countries should apply their own weight to these considerations.) The general rule therefore recommends extending access to the existing package.

Given the substantial interests at stake, the decision should be made through a fair priority-setting process. The health authorities should also clearly communicate the grounds for their decision to allow for accountability to the population, especially to those affected.

Case 2: Eliminate user fees for maternal services for the poorest or for everyone?

A low-income country with high rates of maternal and under-five mortality currently charges considerable user fees for health services. These fees represent substantial barriers to the use of health services for the poor and near-poor, who make up around 50% of the population.¹⁴ The government aims to increase utilization of a package of high-priority maternal and child services by adjusting user fees for these services. Without raising new taxes, the government only has sufficient budget to abolish user fees for the poorest quintile. If user fees were to be eliminated for all, new revenue would have to be raised for the health system to remain financially sustainable. A policy consensus has been reached that this new revenue would be raised through increasing the value added tax (VAT); to protect the poor, essential items such as food would be exempted from this tax increase.

The government has the following options:

1. Eliminate user fees for the poorest quintile only.
2. Eliminate fees for all while raising VAT (with

exemptions for items such as basic foodstuffs on which the poor spend a large share of their income).

When faced with a choice between these policies, the first step should be an assessment of their expected impacts. The results of this assessment will vary by country. The following analysis draws on common country experiences.

Health benefit maximization

If effectively implemented, eliminating user fees for the poorest quintile is likely to increase service utilization by members of quintile because it reduces their financial barriers to access. Some low-income countries have indeed had success in targeting the poorest for waivers of fees for services or insurance premiums.¹⁵ However, other countries have faced difficulties with such exemptions. In countries where a majority of the population derives its income from the informal sector, it is hard to establish household income. Other difficulties include non-uniform application of exemption criteria, verifying the identity of patients, and lack of information among users about who is eligible.¹⁶ Moreover, those among the poor and near-poor who fall within the remaining 80% of the population for which user fees would be kept in place will continue to be deterred from seeking treatment.

Eliminating user fees for all while raising VAT avoids the drawbacks often associated with targeting and eliminates barriers to the use of some high-priority services for all. It is therefore likely to lead to increased utilization across all income groups.¹⁷ This strategy is therefore likely to secure greater health gains.¹⁸ However, by reducing the disposable income of the poor and near-poor, the VAT increase will make it more difficult for them to improve their lives in other ways. It is therefore important to exempt goods and services that make up a large part of the poor's budget.¹⁹

Priority for the worse off

In terms of health outcomes, pregnant women, mothers, and infants who fall severely ill or die due to lack of access to services are among the worse

off. As argued above, eliminating user fees for all is likely to do more to increase service utilization among the poor and near-poor and thereby avert more of these large individual health burdens.

In terms of economic status, because all income groups pay the same flat fee, the current system of substantial user fees makes the poor pay a larger proportion of their income for access to needed services.²⁰ Eliminating user fees for the poorest quintile will make health system financing fairer in this respect. Nonetheless, the remaining 80% of the population will still pay a flat fee. Among them, the payments remain disproportionately burdensome for the less well off.

If the VAT is designed to exempt goods and services traded by the poor in the informal economy, eliminating user fees for all while raising VAT is likely to more fairly distribute the burden of paying for the health system. Research indicates that in low-income countries, VAT can be implemented so that the better off generally pay a larger proportion of their incomes in VAT than the poor.²¹

Overall, eliminating user fees for all is likely to be best for the worse off in health and, if the VAT is well-designed, is reasonably likely to be best for the economically worse off, since it benefits more of the poor and near-poor.

Financial risk protection

Financing health systems through general taxation rather than user fees means that the cost of health care is spread across the population, rather than concentrated on those who need it. VAT is a predictable expenditure and, unlike large health expenditures, is unlikely to impoverish citizens who pay it. Financial risk protection therefore favors eliminating user fees for all.

Recommendation

Considering all three principles, eliminating user fees for all is likely to be the fairest alternative. First, it avoids the problem of identifying the poorest quintile for free access. Second, by improving access to all poor and near-poor, it promises greater health improvements and does more to help the worse off in health. Third, it improves financial risk

protection for a wider class of poor and near-poor. In pursuing this strategy, governments should keep in mind common challenges in implementation. In particular, they should provide the resources to replace the loss in fee income and to meet the anticipated increase in demand.²² Given the substantial impact of the decision on people's access to health and disposable income, fair public participation in decision-making and public accountability for the decision are required.

Case 3: Who should decide which services are offered: the judiciary or a priority-setting institution?

An upper-middle-income country recognizes the "right to health" at the constitutional level. Disputes about what this right entails are commonly resolved through the judicial system. The Ministry of Health currently formulates a package of health interventions for which everyone is meant to be covered. It faces frequent legal challenges both from citizens who claim that they are not being provided with services to which the package entitles them and from citizens who claim that they should be provided with services not included in the package. The country has a civil law system. Litigation cases take the form of claims made by individual persons and judgments normally apply only to the claimant. Courts make decisions on the basis of the claimants' needs, often without careful consideration of social costs or competing interests. A substantial proportion of claims is for services that have been excluded from the standard benefit package on the grounds that they offer little improvement in health relative to their incremental cost—for example, around 80% of the claims for pharmaceuticals are for medicines excluded from the package for these reasons.²³

Recent years have seen a steep increase in the number of cases of right to health litigation. In a large majority of cases, the courts ruled in favor of the claimants.²⁴ Consequently, a substantial and increasing proportion of public sector health spending is devoted to complying with these rulings. This has an impact on the level of health

provision for other services.²⁵ Legal costs are also large: in about half the cases, they exceed the cost of the services that were sought.²⁶ The government is exploring whether to implement reforms to address this situation.

The government is considering the following options:

1. *Judicial decision-making about service provision.* This involves maintaining the existing reliance on the judiciary to make decisions about specific individuals' claims to services that were initially excluded from the government-provided package.
2. *Priority setting by a dedicated institution.* This involves establishing an entity tasked with making decisions about a benefit package for all using a publicly accountable process and an explicit priority-setting mechanism based upon reasonable principles. A central task of the judiciary will then be to establish whether this process has been followed and this mechanism properly implemented—including whether individuals received services to which they are entitled as part of the agreed benefit package.

In making this decision, the first step is an assessment of the expected impacts the two approaches to priority setting in health. The results of this assessment will vary by country. The following draws on common country experiences.

Health benefit maximization

Judicial decision-making has the drawback that courts are generally not well placed to systematically take account of cost-effectiveness.²⁷ Indeed, at present, courts in the country do not even require robust evidence of medical effectiveness; a substantial share of claims upheld by the courts is based on weak evidence of effectiveness.²⁸ As a consequence, the decision is often made to fund expensive services that offer limited or highly uncertain benefits. This reduces the funds available to provide proven, more cost-effective services.

Priority setting by a dedicated institution can overcome these problems, if the institution is designed to draw on relevant expertise and can

be insulated from undue pressures from interest groups. An entity that makes decisions at a population level, taking into account the system's capacity, the implied trade-offs, and the alternative possible uses of resources would be able to have a greater positive impact on overall population health with a given level of resources.²⁹ Health benefit maximization therefore requires that such an institution be established where the capacity exists to ensure its proper functioning.

Priority for the worse off

Bringing a case to court can require significant financial resources. It also requires time and knowledge of the legal system. Government and charity-provided legal support can substantially improve the ability of the poor to litigate but, in some countries, there are indications that the better off are more able to initiate litigation.³⁰ A reliance on the judiciary to ensure individual coverage can therefore favor the socially and economically better off. Thus, judicial decision-making may exacerbate inequalities in access to health services. Prioritizing the worse off also means giving additional weight to the interests of those who bear the greatest disease burden. However, the propensity of citizens to seek legal remedies varies with features of their situation that have little relation to their disease burden, such as income, social status and access to a lawyer. Since citizens who do not bring cases will not have their interests heard, the results are opposed to equity, which requires equal consideration of cases with the same disease burden. Priority setting by a dedicated institution can avoid this inequity, if care is taken to institutionalize decision-making according to fair principles.

Financial risk protection

Because litigation saves some successful claimants from very large health expenditures, judicial decision-making provides some citizens with financial risk protection. However, as noted, litigation is often for relatively cost-ineffective treatments.³¹ Litigation is therefore likely to divert resources from where they will prevent more illness and illness-related financial distress. Insofar as litigation is dispro-

tionately pursued by the better off, it will also have a particular impact on resources available to meet the needs of the poor and will increase the poor's exposure to the financial risks caused by ill health and health expenditure.³²

Other considerations

Judicial decision-making has implications for accountability. While courts sometimes recognize the need to take into account the aforementioned three principles (and other relevant principles), the process by which they do so is neither explicit nor systematic.³³ Generally, judges are not best-placed to weigh evidence of medical efficacy. Nor are they well-positioned to evaluate the impact of an isolated decision on the fairness of resource allocation in a health system.³⁴ Consequently, it may be difficult to discern a coherent rationale in the complete set of decisions by different courts. There is also no guarantee that relevantly similar cases will be treated similarly. This thwarts accountability. Priority setting by a dedicated institution, in contrast, can enhance fairness and legitimacy by making coverage decisions through mechanisms that employ reasonable, public principles and that allow for like cases to be treated alike.³⁵

Recommendation

Priority setting by a dedicated institution—establishing an independent mechanism or body that sets priorities in an accountable and transparent manner, based on explicit, reasonable criteria—is morally preferable. The judiciary has important roles to play within this framework. First, to check that the priorities pursued by the health authorities are based on reasonable, non-discriminatory criteria which are consistently followed. Second, to ensure that citizens are granted access to those health interventions to which they are entitled under the priority-setting framework. Such recourse to legal action is a crucial way in which marginalized groups can ensure that their interests are properly served.

Despite its promise, one must acknowledge threats to this strategy's success, especially with regards to capacity building, establishing a proper

independence from interest groups (such as the pharmaceutical industry) and short-term political pressure, and earning public confidence for both the dedicated institution's knowledge base and the impartiality of its decision-making. Countries can learn from the experience of nations that have managed these threats.³⁶ In the long run, if this reform is implemented correctly, it has the potential to significantly improve the allocation of scarce resources within the health care system. It can also contribute to greater public awareness of the unavoidability of setting priorities.

Conclusion

Because all governments face resource, institutional, and political constraints, moving towards UHC involves balancing competing interests. The progressive realization of the right to health requires that such trade-offs be made fairly.³⁷ The three case studies presented here show how this can be done by using the principles articulated by the WHO Consultative Group on Equity and Universal Health Coverage. These principles include health benefit maximization, priority for the worse off, financial risk protection, and accountability. There is no simple algorithm for using these principles (and other principles that are relevant in a particular context) to arrive at a correct decision—often, a difficult exercise in judgment is required. Nonetheless, these case studies illustrate that, by employing these principles in careful empirical and moral reasoning, it is possible to arrive at decisions that advance us towards the goal of ensuring everyone has affordable access to a comprehensive range of needed health services.

Acknowledgments

Work on these case studies was supported by the Ministry of Foreign Affairs of Norway, the Norwegian Agency for Development Cooperation (NORAD), the Norwegian Research Council, the Pan-American Health Organization, grant AH/J006033/1 of the British Arts and Humanities Research Council, and the Uehiro Centre for Practical

Ethics. We thank Daniel Cotlear, Agnes Couffinhal, Amanda Glassman, Gina Lagomarsino, Ewan Rodgers, Hasbullah Thabrany, two anonymous referees and the editors of this journal for their comments. The opinions expressed are the views of the authors, who alone are responsible for the views expressed in this publication. They do not represent any position, decision, or policy of Giving What We Can, the Ministries of Health of Burundi, Ghana, Malaysia, or Morocco, the US National Institutes of Health, the US Public Health Service, the US Department of Health and Human Services, the Pan-American Health Organization, the World Bank, or the World Health Organization.

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What Do Core Obligations under the Right to Health Bring to Universal Health Coverage?

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Abstract

Can the right to health, and particularly the core obligations of states specified under this right, assist in formulating and implementing universal health coverage (UHC), now included in the post-2015 Sustainable Development Goals? In this paper, we examine how core obligations under the right to health could lead to a version of UHC that is likely to advance equity and rights. We first address the affinity between the right to health and UHC as evinced through changing definitions of UHC and the health domains that UHC explicitly covers. We then engage with relevant interpretations of the right to health, including core obligations. We turn to analyze what core obligations might bring to UHC, particularly in defining what and who is covered. Finally, we acknowledge some of the risks associated with both UHC and core obligations and consider potential avenues for mitigating these risks.

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Competing interests: None declared.

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Introduction

Can the right to health, and particularly the core obligations of states specified under this right, assist in formulating and implementing universal health coverage (UHC), now included in the post-2015 Sustainable Development Goals (SDGs)?¹ This question has driven research under the Go4Health Consortium, which seeks to embed rights-based approaches in the post-2015 SDG health agenda. The Go4Health Consortium, of which all authors are a part, focuses on what the right to health offers discursively and substantively to this agenda and aims to clarify the contributions of the core obligations that flow from the right to health.² Rights language frames health—not as an externality, investment, or issue of compassion but as a legal entitlement and fundamental matter of social justice.³ Thus, framing global health as a question of human rights guides our understanding of it, identifying the actors that must be engaged and the legally prescribed measures needed to achieve it.⁴ In this paper, we examine how core obligations under the right to health could lead to a version of UHC that is more likely to advance equity and rights. In adopting so specific a focus on core obligations and UHC, we do not intend to obscure or delegitimize important investigations of what the larger right to health canon brings to elaborating and implementing UHC. Indeed, the current authors have produced a significant amount of scholarship focused on this question, exploring what right-to-health components and mechanisms (such as progressive realization and indicators) bring to UHC.⁵ This paper adopts a far narrower focus on what core obligations might offer to UHC, since irrespective of their interpretive deficits and scholarly contestation, core obligations remain a fundamental component of contemporary interpretations of the right to health.⁶ To this extent, this analysis complements discussions of the right to health's broader contribution to formulating and implementing the SDGs.

To explore the question of what core obligations bring to UHC, we first address the affinity between the right to health and UHC as evinced through changing definitions of UHC and the health do-

mains that UHC explicitly covers. We then engage with relevant interpretations of the right to health, including core obligations. We turn to analyze what core obligations might bring to UHC, particularly in defining what and who is covered. Finally, we acknowledge some of the risks associated with both UHC and core obligations and consider potential avenues for mitigating these risks.

UHC and the right to health

Given that the goal of UHC has strong synergies with the commitment to universalism enshrined within the right to health, UHC should be rooted explicitly within this right.⁷ This view is shared by the World Health Organization (WHO) and other institutional actors, who see UHC as a “practical expression of health equity and the right to health” and “deeply embedded” in international law.⁸ In 2012, the United Nations (UN) General Assembly endorsed this view when it called on states to realize UHC while reaffirming the right to health.⁹ More recently, WHO has expanded on this conception:

To support the goal of universal health coverage is also to express concern for equity and for honoring everyone's right to health. These are personal and moral choices regarding the kind of society that people wish to live in, taking universal coverage beyond the technicalities of health financing, public health and clinical care.¹⁰

However, at a practical level, what does the right to health imply for UHC, particularly regarding the crucial questions of the type of health care required to advance the right to health? This has been less clear, not least because of a lack of clarity around what is meant by UHC.¹¹

Changing definitions of UHC

The 2005 World Health Assembly resolution calling for UHC had a strong focus on financing and insurance (as its title suggests), defining UHC as “access to key promotive, preventive, curative and rehabilitative health interventions for all at an affordable cost, thereby achieving equity in access.”¹²

It urged member states “to ensure that health-financing systems include a method for prepayment of financial contributions for health care, with a view to sharing risk among the population and avoiding catastrophic health-care expenditure and impoverishment of individuals as a result of seeking care.”¹³ The 2010 *World Health Report* did little to clarify the content of these services but brought the UHC cube, originally designed by Reinhard Busse et al., to a wide audience.¹⁴ The cube identified three key dimensions around which to measure progress toward UHC: the range of services available, the proportion of costs of services covered, and the proportion of the population covered. While the report acknowledged that funding constraints would mean “trade-offs between the proportions of the population to be covered, the range of services to be made available and the proportion of the total costs to be met,” it reiterated that UHC nonetheless meant that the “entire population in all these countries has the right to use a set of services (prevention, promotion, treatment and rehabilitation).”¹⁵

The UN General Assembly resolution in 2012 offered a fuller, multidimensional definition of UHC, requiring that

*[a]ll people have access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative and rehabilitative basic health services and essential, safe, affordable, effective and quality medicines, while ensuring that the use of these services does not expose the users to financial hardship, with a special emphasis on the poor, vulnerable and marginalized segments of the population.*¹⁶

This resolution offered definitive UN member state political support for UHC, not only reaffirming, in explicit and detailed terms, everyone’s right to health but also recognizing “the responsibility of Governments to urgently and significantly scale up efforts to accelerate the transition towards universal access to affordable and quality health-care services.”¹⁷ This emphasis on non-discriminatory access to basic health services and essential medicines with a special focus on the poor, vulnerable, and marginalized indicates a clear commitment to human rights principles. Emphasizing non-dis-

criminatory access seeks to ensure that UHC does not simply lead to aggregate gains at the expense of the poor; at the same time, it is important to avoid the risk that an *exclusive* focus on the poor and vulnerable will lead to services that are selective—and thus potentially of poor quality—rather than comprehensive.¹⁸

This trajectory from key to basic to essential services is reflected in the somewhat terser final SDG 3.8 formulation, which commits states to “achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.” While the inclusion of UHC in the health SDG reflects a victory for its proponents, there are nonetheless questions about the priority accorded this target vis-à-vis the other nine targets associated with this goal. Moreover, the definition of UHC in the SDGs raises more questions than it answers: What does financial risk protection encompass? Can UHC be achieved through selective health care rather than comprehensive health system strengthening? And crucially, what should essential health care and medicines encompass? Due to space limitations, the remainder of this paper will focus on this last question alone.

What essential health care and medicines does UHC cover?

The health domains which UHC should cover are indicated in the remainder of the SDG health goal, where separate targets are specified for essential health care services. These include goals and targets in relation to maternal and child mortality, infectious and noncommunicable diseases, mental health, sexual and reproductive health, tobacco control and substance abuse, environmental pollution, health financing, and global health risk management.

These domains are fleshed out by the Inter-Agency Expert Group on SDG indicators (IAEG-SDGs), established by the United Nations Statistical Commission and tasked with proposing indicators for each SDG target.¹⁹ The IAEG-SDGs,

which is composed of member states along with agency observers, initially proposed two indicators for UHC: one to monitor coverage of tracer interventions (such as complete childhood immunization, antiretroviral therapy, TB treatment, hypertension treatment, and skilled birth attendance) and the other to monitor the portion of the population protected against catastrophic or impoverishing out-of-pocket health expenditures.²⁰ Perhaps reflecting the contentious nature of the UHC goal (SDG 3.8), in contrast to the other SDG 3 indicators these are the only indicators on which there was no general agreement within the IAEG-SDG team. The team classified the UHC indicators as requiring more in-depth discussion and methodological development. It is notable that the proposed SDG 3.8.2 indicator on catastrophic expenditure has now been replaced by one that aims to measure the number of individuals covered by health insurance or a public health system per 1,000 people.²¹ The new indicator has been critiqued for measuring aggregate outcomes and thus ignoring the kind of catastrophic and impoverishing expenditures addressed by the former indicator.²² It is anticipated that indicators, including SDG 3.8.2, will not be finalized until the UN Statistical Commission's March 2017 session.²³ Certainly, as currently formulated, SDG 3.8.2 would encourage models of UHC that provide selective interventions financed by insurance—an approach unlikely to improve equity in access or outcomes.²⁴

The “content” indicator covering tracer interventions is further specified in various domains of promotion, prevention, and treatment which will act as a global core subset of indicators that all countries are expected to implement.²⁵ Moreover, countries are expected to develop additional national indicators that reflect “their level of development, epidemiological situation, health system and people’s expectations” and that “cover promotion, prevention, treatment, rehabilitation and palliation.”²⁶ These tracer interventions appear to be based largely on a WHO and World Bank publication which proposes selecting tracer interventions according to the criteria of relevance, quality, and

availability. In relation to prevention services, the publication clarifies that

*six indicators are identified: satisfaction of family planning needs, at least four antenatal care visits, measles vaccination in children, improved water source, adequate sanitation and non-use of tobacco. For treatment services, another six indicators are identified for five areas of intervention: skilled birth attendance, antiretroviral therapy, tuberculosis case detection and treatment success (combined into a single indicator), hypertension treatment and diabetes treatment.*²⁷

However, in all of these cases, the selection of indicators appears to be driven by the ease of measurement and availability of data rather than by any clear conceptual or ethical framework. For example, an alternative approach might consider what data would be necessary under UHC grounded in the right to health.

The substantive content of core obligations under the right to health

There is obvious synergy between notions of universal access to affordable health services and the right to the highest attainable standard of health as entrenched in international law. We have previously identified key principles and imperatives stemming from the right to health that should guide the design of UHC:

- The inclusion of health care and the social determinants of health in the right to health;
- The emphasis on non-discrimination as a guiding principle and pragmatic arm of UHC;
- The imperative of participation and participatory decision making;
- The prioritization of vulnerable and marginalized groups;
- A focus on the principles of availability, accessibility, acceptability, and quality;
- Progressive realization;

- Core obligations;
- Shared responsibility and international assistance;
- Accountability;
- The framing influence of rights discourse; and
- Rights-based advocacy and litigation.²⁸

These principles assist in defining some of the more ambiguous and contentious aspects of UHC in relation to coverage/universality, services, and finances.

Furthermore, international human rights treaties provide some direction as to what health services should be covered under UHC anchored in the right to health. For instance, article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) indicates that for states to achieve the goal of the right to the highest attainable standard of physical and mental health, they must take steps to reduce infant mortality; improve environmental and industrial hygiene; prevent, treat, and control epidemic, endemic, occupational, and other diseases; and create conditions to assure medical services and attention in the event of sickness.²⁹ However, what the ICESCR's drafters meant by these steps was not specified at the time of their release. Moreover, much confusion ensued given that state duties under the ICESCR are limited to progressive realization within a maximum of available resources. Since article 12 did not specify what minimum or maximum level of health care satisfied the requirements of progressive realization within maximum available resources, member states ended up applying sometimes dramatically varying standards.

Subsequent authoritative interpretations of the right to health offer two helpful frameworks for assessing essential health care services. The first is the AAAQ framework, which reflects the idea that health facilities, goods, and services should be *available* in sufficient quantities; *accessible* physically, economically, and without discrimination; *acceptable* in medical, ethical, and cultural terms; and of good *quality*. The definition of accessibility is particularly relevant for considerations of

UHC since it includes non-discriminatory access, requiring inclusion of the most vulnerable and marginalized sections of the population. Discrimination is specified as extending to the prohibited grounds recognized in human rights law: race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation, and civil, political, social, or other status. This principle underscores the importance of considering the needs of marginalized groups when implementing and monitoring UHC and in particular to disaggregate data according to the grounds just mentioned. Moreover, "economic accessibility" has significant implications for UHC, since it requires that services be equitable and affordable for all, including socially disadvantaged groups, whether these are privately or publicly provided.

The second and related way that the right to health helps define the content of UHC comes from the concept of core obligations developed by the UN Committee on Economic, Social and Cultural Rights. The committee introduced core obligations in order to limit the risk of governments unjustifiably invoking the principle of progressive realization (whereby achievement of the right to health might take time in light of limited resources) to deny health care or take very little action. Thus, the committee suggests that states hold "minimum core obligations" not subject to progressive realization or resource limitations, which ensures, at the very least, the fulfillment of minimum essential levels of each right.³⁰

The concept of core obligations has drawn considerable scholarly fire given that it is not explicitly referenced in the ICESCR text.³¹ We do not wish to re-litigate this point in great detail here, other than to mention that while it is true that the term "core obligations" does not appear in either the treaty text or drafting papers, several discussions during the treaty's drafting legitimate its later development. These include debates about the imperative of mitigating the risk posed by limitations of the right to health in the name of progressive realization under article 2, including through the elaboration

of minimum standards for ICESCR rights.³² More fundamentally, irrespective of its genealogy, the concept of core obligations has definitively entered legal interpretations of international social and economic rights, such as the right to health.³³ To this extent, we adopt a relatively positivist approach to the legitimacy of core obligations in our analysis of their potential contribution to UHC.

Much of the debate on core obligations arises from the committee's interpretation in General Comment No. 14 on the right to health, published in 2000. Here, the committee expands on its earlier suggestion that under the right to health, core obligations would include "essential primary health care."³⁴ In General Comment No. 14, the committee interprets core obligations under the right to health to include (1) ensuring non-discriminatory access to health facilities, goods, and services, especially for vulnerable and marginalized people; (2) ensuring access to food, basic shelter, housing, sanitation, and water; (3) providing essential drugs as defined by WHO; (4) ensuring the equitable distribution of health facilities, goods, and services and (5) adopting a national public health strategy and plan of action addressing the concerns of the entire population, devised through a participatory process that pays particular attention to vulnerable and marginalized groups.³⁵ In identifying these aspects, the committee indicates that this interpretation is drawn from the Declaration of Alma-Ata, read in conjunction with the Programme of Action of the International Conference on Population and Development.³⁶

What is significant about the 2000 interpretation is that the committee moves from a fairly substantive notion of core obligations as essential primary health care to a far more procedural and structural approach encompassing equitable distribution, non-discrimination, and a participatory national plan of action. The only health care intervention specified is essential medicines; there is far more explication of the social determinants of health (minimum essential food, basic shelter, housing and sanitation, and water). Other substantive components of primary health care are listed separately but as obligations of "comparable

priority" in relation to reproductive, maternal, and child health care; immunization against major infectious diseases; the prevention, treatment, and control of epidemic and endemic diseases; health education and access to information; and appropriate training for health personnel.³⁷

The challenge of interpreting core obligations

General Comment No. 14 is a watershed moment for the core obligations under the right to health, for it demarcates "essential" aspects of the right to health as a baseline of protection regardless of any given country's shortage of national resources or international assistance. In addition, actions to realize these aspects are located within a legally binding framework that can have considerable normative and political effects. However, it is hard for the definition of minimum core obligations in General Comment No. 14 to practically support these ambitions.

First, beyond essential medicines and underlying determinants (such as food, basic shelter, housing, sanitation, and water), it is not clear which health services fall within the core. Primary health care is not explicitly listed as a core obligation; moreover, much of what we might expect to see in an obligation to provide essential primary health care is explicitly placed outside the core obligations, under obligations of comparable priority. Yet it is unclear what the relationship is between obligations of comparable priority and minimum core obligations. In other words, if obligations of comparable priority are not minimum core obligations, can they be limited by progressive realization or limited resources?

General Comment No. 14 does not sufficiently address the question of the resources necessary to meet core obligations; it merely emphasizes that states cannot justify noncompliance under any circumstances.³⁸ The role of international assistance and cooperation—part of the principle of shared responsibility, which is key to ensuring the universality of human rights and is enshrined in

article 2(1) of the ICESCR—is strongly reasserted as applying to core obligations.³⁹ However, the committee fails to develop a process or specify criteria for assessing when a state has expended its maximum available resources, thus triggering the obligations of international assistance and cooperation specified in paragraph 45. The committee also fails to suggest a burden-sharing mechanism for managing this shared responsibility to realize the core obligations.⁴⁰ This failure to clarify the international assistance obligations of wealthy states while specifying that poorer countries hold strong duties to meet core obligations irrespective of resources leaves the core open to the charge that it places financially unrealistic obligations on poorer countries.

Finally, it is unclear whether minimum core obligations are intended to apply universally or to be tailored to national settings. The committee indicates that core obligations should provide a universally applicable “bottom line” of essential health care, in contrast to a standard that shifts from country to country depending on available resources.⁴¹ However, a one-size-fits-all approach to minimum core health services may be inappropriate given differences in the burden of disease, both among countries and within them. For example, notwithstanding the existence of a WHO list, products designated as essential medicines are often determined nationally, or in some cases sub-nationally.⁴²

Other human rights committees have attempted to fill the substantive gap by extending core obligations to primary health services generally. For example, General Comment No. 15 issued in 2003 by the UN Committee on the Rights of the Child (CRC) holds that states have core obligations to ensure universal coverage of high-quality primary health services, including prevention, health promotion, care and treatment, and essential drugs.⁴³ This interpretation goes far beyond General Comment No. 14’s terser definition, which identifies only essential drugs, and even beyond its earlier suggestion that core obligations extended to essential primary health care. The timing and wording of the CRC’s

General Comment No. 15 suggests an effort to define the right to health in the Convention on the Rights of the Child in relation to ongoing debates over the SDGs and to UHC in particular.

What do core obligations under the right to health offer UHC?

While the interpretation of the Committee on Economic, Social and Cultural Rights regarding core obligations is markedly deficient, it is notably clearer than extant definitions of UHC.⁴⁴ In this light, the remainder of this paper considers what the right to health’s core obligations require of “essential health care services and medicines” with respect to achieving SDG 3.8. This question can be addressed in terms of the interrelated questions of *what* health care services and medicines are included and *who* is covered.

Core obligations and services

UHC’s focus on essential services is clearly consistent with the core obligation to provide essential primary health care. However, General Comment No. 14 provides limited guidance on which elements, beyond essential medicines, must incontrovertibly be included in *essential* primary health care. Certainly if the implication of this inclusion is that WHO determinations of “essential” health interventions provide an authoritative indication of other core obligations, then the General Comment No. 14 definition of core obligations could feasibly be expanded accordingly.⁴⁵ Yet even if such interpretations provide clarity on specific services under cognate areas of health care, such as women’s sexual and reproductive health care, they do not necessarily clarify the broader category of health care services. Thus, interpretative clarity on core obligations stalls at essential medicines, a point that becomes crucial given the UN General Assembly’s inclusion of essential medicines in two locations within SDG 3 (as both a target and a means of implementation, in SDG 3.8 and SDG 3.b, respectively), and which indicates access to essential medicine’s high prioritization by UN member states. Such emphasis will be a major challenge for UHC

achievement in light of the exorbitant cost of some pharmaceuticals. The affordability challenge is highlighted since the indicator for SDG 3.8 proposed by the IAEG-SDG relates to “affordable medicines” and not just “affordable essential medicines.”⁴⁶

However, beyond medicines and some social determinants, the focus of the right to health’s core obligations is far more on processes (e.g., non-discrimination, equitable distributions, and plans of actions) than on outcomes. Indeed, this is the case even with regard to essential medicines, since the determination of what is an essential medicine is made nationally, irrespective of WHO’s determination based on global epidemiological and economic conditions.

Thus, the core obligations do not prescribe a globally applicable and fixed set of health care benefits but rather a framework for action that encompasses non-discrimination (including affordability), equity, participatory decision making, essential medicines, and social determinants of health, which may enhance existing approaches to the prioritization of health care interventions.⁴⁷ It is possible that this framework could do much to advance toward an equitable and rights-based health system. We cannot disagree with this as a principled approach, although it is hard to accept a concept of essential care that includes essential drugs but not emergency obstetric care, immunization, or infectious disease control. This anomaly undermines the broader legitimacy of General Comment No. 14’s interpretation of core obligations.

Essential medicines were perhaps included in the core obligations under General Comment No. 14 to acknowledge the contentious and political nature of access to pharmaceuticals. However, and in turn, the committee might have excluded other measures out of a hesitance to place unreasonable demands on poorer countries by identifying too many substantive core obligations. This is one area where instead of looking to the right to health to augment global health policy, we might do the opposite and consider the specification of SDG 3’s health targets and of tracer interventions in these domains as bolstering what should be considered to fall within a state’s core obligations. Certainly the interplay between global health policy and right-

to-health interpretations is a rich area for future research, especially considering the committee’s declaration that the Declaration of Alma-Ata and the International Conference on Population and Development grounded its decision making around the core obligations.

Core obligations and coverage

While the committee adopted a largely procedural approach to core obligations beyond essential medicines and the social determinants of health, non-discrimination, which is the clearest and most definitive of these obligations, is not simply procedural. With respect to UHC, non-discrimination has very substantive implications for what is covered, as well as who is covered, and has the potential to address structural barriers that impede access to health care. Non-discrimination specifies a focus on the most vulnerable and marginalized sections of society, particularly on denials of health care that fall within prohibited grounds (race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status, sexual orientation, and civil, political, social, or other status). These grounds offer critical protection against discriminatory exclusions in nationally determined models of UHC. In addition, the emphasis on affordability elevates socio-economic status to one of the grounds for discrimination, meaning that UHC which is not affordable to all would violate core obligations under the right to health. These grounds will be very important in implementing UHC and especially in monitoring implementation. They bolster the “equity stratifiers” of sex, age, socio-economic position, and geography that the IAEG-SDG has proposed for disaggregating data collection in order to ensure that UHC does not exclude vulnerable groups.⁴⁸ A pressing question for UHC will be the extent to which non-nationals, particularly those lacking documents, are included, given how some high-income countries have excluded certain classes of migrants from health care in the past.⁴⁹

That non-discrimination has very substantive meaning is apparent in the Committee on the Elimination of Discrimination against Women’s

identification of non-discrimination as a core obligation under the Convention on the Elimination of All Forms of Discrimination against Women, recognizing that states have an “immediate and continuous obligation to condemn discrimination.”⁵⁰ In a 2011 decision regarding a woman who died in childbirth, the committee found Brazil in violation of its core obligation of non-discrimination for failing to assure appropriate maternal health services for all.⁵¹ It held that Brazil’s “continued high rates of maternal mortality ... constitute[d] a systematic failure to prioritize and protect women’s basic human rights” and that the grossly negligent health care given to a poor black woman constituted a form of *de facto* discrimination.⁵² This finding indicates that non-discrimination offers a framework for identifying and addressing systemic discriminations in health care that intensify along axes of gender, race, socio-economic status, sexuality, and disability. The implication of the committee’s decision is that inadequate health care affecting primarily marginalized and poor communities violates core obligations under the right to health. This too is a very important frame for shaping UHC, demonstrating the scope for advocacy and litigation.

The risks of UHC and core obligations

While core obligations can shape UHC, there are risks in focusing too narrowly on them to the exclusion of aspects of the wider SDG agenda. The first is the risk that despite the legal obligation to progressively realize the right to health, core obligations will nonetheless act as a ceiling rather than floor for the right to health, transforming it from health for all to basic health care for the poor only. There is a similar danger of UHC reducing health care downwards, without specifying a floor for essential health care itself.⁵³ The other related threat is that even a well-defined essential health package consistent with core obligations will offer selective rather than comprehensive primary health care, and doing so could reinforce stratified systems of health rights.⁵⁴ This is captured in the argument that health care for the poor often ends up being poor health care, so that the more we “target benefits at the poor only ... the less likely

we are to reduce poverty and inequality.”⁵⁵ Indeed, scholarship suggests that societies pursuing universalistic policies have higher levels of equity than those that rely on selectivity, at least in part because there is an “elective affinity between the preference for universalism and other measures, such as high progressive taxes.”⁵⁶

The risk of UHC becoming targeted rather than comprehensive health care, with inadequate attention to health systems strengthening, is great since states live not in an abstracted world dominated by the SDGs but in the real world, where policies to implement UHC exist alongside ongoing austerity, financial crises, free trade agreements, and pressures to commodify health services, all of which directly threaten policies on access to medicines and sustainable health financing.⁵⁷ Indeed, it is argued that the ambiguity of UHC makes it particularly susceptible to exploitation, particularly within the market-driven global environment.⁵⁸

Conclusion

As we shift into an era of implementing and monitoring both UHC and the SDGs, a priority for civil society and academia must be to guard against restrictions on universality, coverage, and financing that fall short of human rights obligations, as well as against overly abstracted notions of UHC. UHC frames, just like the cube popularized by WHO, literally ask us to think inside a box which excludes key enablers of UHC. These key enablers include social movements and rights-based advocacy and litigation, which are critical for developing UHC in all settings, as well as health systems strengthening, which is required to assure the adequacy of services.⁵⁹ Moreover, such frames do not adequately acknowledge the existence of risks, such as those arising from political and economic pressures to commodify and defund health care. National determinations of UHC in particular are likely to become critical battlegrounds around affordability and inclusion; from a human rights perspective, this is where participatory policies and social movements will become critical factors in rolling out a more equitable version of UHC.⁶⁰

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Using the Right to Health to Promote Universal Health Coverage: A Better Tool for Protecting Non-Nationals' Access to Affordable Health Care?

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Abstract

Five years ago, the World Health Assembly adopted a resolution on universal health coverage, followed a year later by a resolution from the United Nations General Assembly. In these resolutions, states promised to deliver affordable health care for everyone, referring to notions of equity and human rights law, particularly a human right to health. However, the explosion of migration coupled with the post-2008 bleak economic climate have led societies worldwide to restrict, or at least challenge, the affordability of access to national health systems for non-nationals. It is in this light that the claims of universality made by universal health coverage should be challenged. This article, therefore, will question the effectiveness of this global health policy in guaranteeing access to affordable health care for non-nationals and will ask whether and how legal avenues such as the right to health should be used to address potential weaknesses.

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Competing interests: None declared.

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Introduction

Four years ago, states agreed to provide universal health coverage (UHC) to their populations in a resolution of the United Nations (UN) General Assembly, finally answering calls from the World Health Organization (WHO).¹ By committing themselves to provide good-quality health care to everyone without exacerbating users' risk of financial ruin or impoverishment, states made a promise which Dr. Margaret Chan, director-general of WHO, believes to be "the single most powerful concept that public health has to offer" and the "ultimate expression of fairness."² However, its inherent claims of "universality" must urgently be verified.

The international community is currently facing an era of migration. Whether asylum seekers, refugees, stateless persons, or undocumented and documented migrants, the number of persons living in a country other than their country of birth amounted to 244 million in 2015—71 million more than in 2000.³ Estimates suggest that the number of undocumented migrants, often victims of sex trafficking or workplace exploitation, represent 10–15% of such figures.⁴ Furthermore, the number of refugees and asylum seekers worldwide hit a sad record of 21 million in 2014, the highest figure since World War II.⁵ The situation of individuals finding themselves in a country other than their country of birth, whom this article refers to as "non-nationals" for purposes of comprehensiveness, thus deserves particular attention.

In addition to encompassing an increasingly large number of vulnerable individuals, non-nationals have also become victims of legislation and policies that limit free or subsidized access to health care to citizens only. The bleak economic climate following the 2008 economic crisis has led societies worldwide to restrict access to national health systems, endangering populations' health as well as the availability and affordability of health care.⁶ However, academics, nongovernmental organizations, and human rights institutions have all highlighted the particularly negative impact that such austerity policies have had on undocumented migrants, asylum seekers, and refugees.⁷

Therefore, this article challenges the effective-

ness of UHC in guaranteeing non-nationals' access to affordable health care and asks whether legal avenues such as the human right to health, mentioned in UHC documents, should be explored to address insufficiencies. Various authors have examined the inherent relation between UHC and international human rights law, in particular the right to health, while others have discussed the impact of austerity policies on human rights, in particular on economic, social, and cultural rights.⁸ Nonetheless, little research has combined both aspects or applied them to the protection of non-nationals. The question I explore in this article contributes to current debates on UHC, access to health care, international migration, citizenship requirements, international human rights law, and the right to health. However, my focus is on whether and how the goals of UHC should be promoted through the right to health in order to better protect non-nationals. To this end, I use doctrinal methods that enable me to formulate an analysis based on a study of primary sources of law alongside relevant scholarly commentaries.

The limited protection of non-nationals' access to affordable health systems under universal health coverage

In order to discuss whether and how the goals of UHC should be promoted through the right to health to better protect non-nationals, it is essential to first demonstrate that the protection afforded by UHC in that regard is limited.

The shaky protection of non-nationals under UHC

UHC, as its name suggests, aims at ensuring that "everyone" can access affordable health systems without increasing the risk of financial ruin or impoverishment.⁹ Both the UN General Assembly and WHO recognize the goal as being directed toward an equitable distribution of health care for all individuals by taking into account the needs of vulnerable groups.¹⁰

However, the formulation of UHC remains unclear regarding non-nationals. In 2005 and 2011, WHO urged states to move toward universal health

coverage for all “citizens” in two resolutions on sustainable health financing, while its 2010 annual report and its 2012 discussion paper on UHC refer to “everyone.”¹¹ In its 2010 annual report, WHO goes even further, by declaring that UHC represents a commitment to cover “100% of the population” and by encouraging states to pay particular attention to vulnerable groups such as “migrants.”¹² Nevertheless, the same report also notes that none of the high-income countries that supposedly fulfill the UHC requirements provide 100% of the services to 100% of their populations for 100% of the costs, with no waiting list.¹³ Therefore, it is uncertain whether countries that fail to guarantee access to affordable health systems to non-nationals could still be identified as providing UHC.

In addition to its ambiguous language, UHC has been criticized on other grounds having the potential to impede demands for further protection of non-nationals’ access to affordable health systems. As argued by Gorik Ooms et al., UHC does not rely on any legally binding treaties and does not demand that decision-making processes in health care prioritize vulnerable groups (for example, refugees).¹⁴ UHC was officially recognized in resolutions of the World Health Assembly and the UN General Assembly, but international law generally considers such documents to be mere “recommendations” for states.¹⁵ Furthermore, Millennium Development Goals 1, 4, 5 and 6, as well as Sustainable Development Goals 1 and 3.8, from which UHC stems, are not legally binding since they are formulated in resolutions from the UN General Assembly.¹⁶ The protection of non-nationals’ access to affordable health systems is thus left to states’ goodwill, as exemplified by research on the Association of Southeast Asian Nations, where member states take different approaches to UHC implementation for migrants.¹⁷ This leap of faith is particularly problematic in contexts of economic inequalities, fueled by states’ failures to ensure equitable provision of services and associated with the resurgence of nationalism, which often results in hostility toward immigrants.¹⁸ Such hostility may trigger the election of leaders opposed to facilitating non-nationals’ access to services such as health

care, which would be compounded by low levels of non-nationals’ participation in decision-making processes.

The shaky protection of non-nationals under UHC is therefore not only problematic as such but also insufficient to fight the rise of health discrimination against non-nationals, as shown by the example of Europe below.

The rise of health discrimination against non-nationals: The example of Europe

As expected by systematic reviews examining the effect of economic crises on populations’ health, the 2008 recession has been coupled with a decrease in access to health systems.¹⁹ This decrease is clearly documented by Marina Karanikolos et al. in the case of Europe.²⁰ However, the negative effects of the economic crisis tend to be exacerbated for non-nationals, who represent an important part of the population following recent increases in migration.²¹ Non-nationals often face unique obstacles in accessing health care, such as restricted legal entitlements, administrative difficulties, and language barriers.²² In 2013, the organization Médecins du Monde found that more than half of the 8,412 patients it treated and interviewed in Europe—mainly non-nationals—had expressed difficulties in accessing national health systems.²³ The organization reported that such difficulties were often associated with a lack of knowledge or understanding of their rights, with administrative problems, or with language barriers.²⁴ Furthermore, Médecins du Monde highlighted that in the case of undocumented migrants, fears of being reported or arrested often discouraged individuals from seeking medical assistance.²⁵ It is nonetheless important to note that the extent of legal protection from which non-nationals benefit in the area of health care depends heavily on their migration status. In the European Union, for instance, citizens from member states tend to enjoy higher protection due to the principle of free movement of persons.²⁶ However, other groups of individuals, such as refugees and undocumented migrants, tend to enjoy a more minimal protection, often limited to emergency services only.²⁷ Furthermore, each group

faces obstacles specific to its migration status (e.g., fear of deportation for undocumented migrants). It is not my intention here to specify which type of health care protection each group should be able to benefit from. However, a more general question ought to be asked regarding the rationale for—and thus the legitimacy of—policies excluding non-nationals from accessing health care services on the same basis as nationals.

What must be stressed in the context of UHC, nonetheless, is the connection between the various obstacles faced by non-nationals when trying to access national health systems and affordable health care. If states do not invest in raising awareness of health rights or in organizing administrative and linguistic assistance that enables non-nationals to access health care, the affordability of services is irrelevant. That is not to say that health care affordability for non-nationals is not a concern. Carin Cuadra, for instance, has put forward disturbing figures regarding access to health care for undocumented migrants in Europe, highlighting different degrees of protection among states.²⁸ She argues that only five European Union states provide undocumented migrants with “more than minimum rights of access health care” (though administrative procedures are still required). Twelve European Union states provide undocumented migrants with “minimal rights” to access health care (i.e., free emergency care), and ten guarantee “less than minimum rights” (i.e., the costs of emergency care are unclear, must be paid upfront, or depend on an affiliation to a conditioned insurance system).²⁹ Considering that undocumented migrants are often exposed to high-risk working and living environments, their exclusion from national health systems is particularly worrying.³⁰

Finally, while data on migrants’ health is often scattered and missing, as is the case in Europe, research clearly highlights this population’s vulnerability to diabetes, certain communicable diseases, and maternal, child, occupational, and mental health problems.³¹ However, how can such vulnerabilities be taken into consideration if states do not collect data to monitor and protect migrants’ health?

To conclude, while the very essence of UHC is to guarantee everyone’s access to affordable national health systems, the ambiguity of its scope and the absence of binding texts provide insufficient protection to non-nationals. This is particularly problematic in light of rising health discrimination against non-nationals in a post-2008 era, as exemplified by the case of Europe. Therefore, it is crucial to discuss whether and how the use of legal tools such as the right to health can improve demands for further protection and promote the goals of UHC for non-nationals.

The right to health: An opportunity to promote universal health coverage for non-nationals

In order to discuss whether and how the goals of UHC should be promoted through the right to health to better protect non-nationals’ access to affordable health systems, this section will explore the opportunities offered by this right.

A legally binding tool intertwined with UHC

The connection between the right to health and UHC is unambiguous. Academics such as Gorik Ooms et al. and Audrey Chapman have discussed interactions between both concepts, while the UN General Assembly’s 2012 resolution on UHC and WHO’s annual reports and policy briefs explicitly refer to the right to health.³²

The right to health, first recognized in WHO’s 1946 Constitution and in the Universal Declaration of Human Rights of 1948, is now enshrined in numerous legally binding instruments at the international and regional levels.³³ The most authoritative among these is the International Covenant on Economic, Social and Cultural Rights (ICESCR).³⁴ Article 12 of the ICESCR defines the right to health as “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health,” a definition to which the UN General Assembly explicitly referred in its 2012 resolution on UHC.³⁵

While article 12 of the ICESCR does not clarify what a right to health entails, the human rights body monitoring its realization (the UN Commit-

tee on Economic, Social and Cultural Rights) has interpreted it extensively in its General Comment No. 14.³⁶ This document, which is not legally binding but has authoritative force, outlines what states parties to the ICESCR ought to do to realize the right to health. General Comment No. 14 establishes that states ought to respect, protect, and fulfil each dimension of the right to health, which include the availability, accessibility, acceptability, and quality of health facilities, goods, and services.³⁷ Interestingly, some of the requirements set forth in General Comment No. 14 under the dimension of “accessibility” are very similar to the requirements (later) established in UHC instruments. For instance, the UN Committee on Economic, Social and Cultural Rights declares that the element of economic accessibility is fundamental to the realization of the right to health. It stresses that “health facilities, goods and services must be affordable for all,”³⁸ while WHO defines UHC as “ensuring that all people can use the health services they need without risk of financial hardship.”³⁹

The right to health is nonetheless in a more advantageous situation than UHC in various respects to effectively protect non-nationals’ access to affordable health systems. The provisions in which it is enshrined are legally binding for the states that have ratified the relevant human rights treaties. In the case of the ICESCR, this concerns 164 states.⁴⁰ International organizations, nongovernmental organizations, and individuals can thus press states to fulfill their obligations on that basis. Furthermore, the implementation of the right to health tends to be periodically monitored by human rights bodies mandated to supervise the application of treaties by states parties. This often takes place through reporting or complaints procedures involving states, nongovernmental organizations, and individuals. Finally, since the right to health has been on the international scene for nearly 70 years, it benefits from a wealth of literature and case law clarifying (to a certain extent) states’ obligations toward non-nationals.

As a result, the right to health has the potential to promote UHC goals by legally demanding non-nationals’ access to affordable health systems.

Such a statement is particularly true when examining this right’s universal scope and its principle of non-discrimination.

The universality and non-discrimination standards to protect non-nationals

The Universal Declaration of Human Rights declares that “all members of the human family” are entitled to “equal and inalienable rights” based on their “inherent dignity” as human beings.⁴¹ The universality of rights and their cross-border effects are often recognized as cornerstones of international human rights law, including in the context of the right to health.⁴² This is often reflected by wording such as “everyone” or “every human being” in right to health provisions, whether they appear in international and regional human rights treaties, or in the preamble of the WHO Constitution.⁴³ Similar wording can also be found in global health instruments adopting a human rights-based approach to fight health inequities, including those promoting UHC.⁴⁴ The promise of universality borne by the right to health could, therefore, strengthen the claim according to which UHC should apply to non-nationals.

However, declaring that everyone is entitled to the same rights is not sufficient. As argued by Martha Fineman, such a formal concept of equality, embedded in the Western philosophy of liberal individualism, fails to combat persistent forms of domination and, consequently, to address social disparities.⁴⁵ This is critical in the area of health care, where costs can often exacerbate the vulnerability of certain groups. Undocumented migrants, for instance, are at particular risk of being excluded from national health systems either because of up-front costs which they cannot afford, or because of complex procedures to access free treatment which they are unfamiliar with or unable to navigate due to language barriers.⁴⁶ It is therefore crucial that states consider the difficulties faced by certain groups of individuals in accessing health care, in order to effectively guarantee affordable national health systems for all.

Historically rooted in fights against exclusion and clearly echoing calls for substantive equality,

international human rights law prohibits discrimination, including in health.⁴⁷ Key human rights treaties (including those recognizing a right to health) prohibit discrimination on grounds such as “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth.”⁴⁸ However, the list is not exhaustive since the same treaties also prohibit discrimination “of any kind” or “based on “other status.”⁴⁹ International human rights law therefore protects non-nationals’ access to affordable health systems by explicitly prohibiting discrimination based on “national origin” or, more implicitly, discrimination based on migration or citizenship status. This is confirmed by General Comment No. 14. In this document, the UN Committee on Economic, Social and Cultural Rights declares that states’ obligation to not discriminate not only applies to non-nationals such as asylum seekers and undocumented migrants but is also a core obligation from which states cannot derogate.⁵⁰ Furthermore, the committee takes a clear stance for substantive equality in health by asking that states design and implement measures fitting with the special needs of vulnerable groups.⁵¹

To conclude, while the right to health and UHC share an inherent connection recognized by the international community, the right to health offers legal avenues to protect non-nationals’ access to affordable health systems, which UHC does not. Its universal scope and its non-discrimination clause are particularly promising. However, limits should also be highlighted with regard to the legal nature and ambiguity of its interpretation.

The right to health: A limit to promoting universal health coverage for non-nationals

In determining whether and how the goals of UHC should be promoted through the right to health to better protect non-nationals’ access to affordable health systems, it is important to highlight the limits of such a protection. To this end, this section examines the key provisions restricting the scope of protection of the right to health to citizens, thus conflicting with the universal scope of internation-

al human rights law and weakening UHC goals.

International provisions restricting the scope of the right to health to nationals

At the international level, two legally binding provisions are particularly problematic. Article 28 of the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families explicitly restricts migrant workers’ right to health to emergency care.⁵² Furthermore, article 2(3) of the ICESCR allows developing countries to determine to what extent they wish to guarantee economic rights to non-nationals.⁵³

Before article 28 of the UN Convention on Migrant Workers was drafted, the UN had already started to differentiate the type of health care that individuals were entitled to according to their nationality and migration status. In 1985, the UN adopted the Declaration on the Human Rights of Individuals Who Are Not Nationals of the Country in Which They Live.⁵⁴ Its article 8 recognizes the existence of a right to health for non-nationals, albeit under strict conditions. It declares that non-nationals can benefit from right to health protection and medical care only if they lawfully reside on the territory of the state and if they respect its regulations for participation. Furthermore, article 8 grants non-nationals a right to health only if the state’s resources are not experiencing “undue strain,” which could be broadly interpreted in the current economic climate.⁵⁵ This instrument, however, is not legally binding. In 1990, the UN adopted the UN Convention on Migrant Workers, a legally binding treaty that came into force in 2003.⁵⁶ While this treaty has been ratified by only 48 states, which excludes major areas of destination for migrants such as European and North American states, it remains open to signature to all UN member states and may one day gain further popularity.⁵⁷ Its article 28 declares that migrant workers and members of their families, whether in a “regular” or “irregular situation” (namely, whether they fulfill a state’s conditions for entry, stay or residence or not), have a right to health. Yet it also restricts this right to emergency care.⁵⁸ Therefore, several issues arise

when reading article 28 of the UN Convention on Migrant Workers together with article 12 ICESCR, since the latter recognizes that “everyone” has a right to the highest standard of health.⁵⁹ Which provision prevails when a state is party to both treaties? Will this conflict of norms affect the possibility for the right to health to protect non-nationals’ access to affordable health systems and weaken its promotion of UHC goals?

Furthermore, the scope of protection of the ICESCR is unclear. Despite the universalist aspirations of article 12, article 2(3) of the same covenant allows developing countries to determine the scope of protection guaranteed to non-nationals when it comes to “economic rights.”⁶⁰ The right to health, often recognized as a social right, also encompasses the right to access affordable health care, which could be labeled as an economic right. More importantly, such a statement highlights that a distinction can be made between nationals and non-nationals in the implementation of the ICESCR. Emmanuel Victor Oware Dankwa argues that when the ICESCR was drafted, developing countries that had recently gained independence wished to protect their economies from nationals of former colonial states, and proposed the inclusion of what is now article 2(3).⁶¹ No explicit relevance can be established with the issues discussed in this article—that is, access to affordable health care for non-nationals in times of economic crisis. However, the UN Committee on Economic, Social and Cultural Rights has not yet indicated how it wishes to interpret article 2(3), if at all, leaving various questions unanswered. Which provision—article 2(3) or article 12—prevails for states that are party to this treaty? Will the conflicting scopes of these two articles affect the protection of non-nationals’ access to affordable health systems, thus weakening UHC goals?

While the universal approach entitles all human beings to a right to health, it is unclear under the UN framework whether everyone has a right to *similar* health care. This is particularly problematic in the context of UHC since the prospect of using the right to health as a legal tool to promote

non-nationals’ access to affordable health care may not bear fruit under this ambiguity.

Regional provisions restricting the scope of the right to health to nationals

At the regional level, all instruments but the Protocol of San Salvador can be read as restricting the scope of the right to health to nationals.⁶² The appendix of the European Social Charter (ESC) explicitly excludes from its scope of protection nationals from states not party to the charter, as well as Europeans illegally working or residing within other states parties.⁶³ The African Charter on Human and Peoples’ Rights is more implicit but potentially restrictive nonetheless. Its article 16 declares that states must ensure the health of “their people,” and article 13(2) states that every “citizen” has the right of equal access to the public services of the country.⁶⁴ Such restrictions are particularly confusing when reading UN instruments, in which, despite a degree of uncertainty, a universal approach tends to be preferred. Which provisions should prevail?

In order to analyze the implications of a potential clash between UN and regional standards, I will focus on the European example, for it has generated promising case law on the matter. Contrary to article 12 of the ICESCR, the scope of article 11 of the ESC is limited to certain individuals. The charter’s appendix specifies that article 11 (among other provisions) protects refugees, stateless persons, and “foreigners only in so far as they are nationals of other Parties lawfully resident or working regularly within the territory of the Party concerned.”⁶⁵ Therefore, article 11 does not apply to documented migrants from non-states parties, except refugees and stateless persons; and it does not apply to undocumented migrants in general. However, the text of the ESC is confusing. Its article E prohibits discrimination on the grounds of national extraction, national minority, birth, or “other status,” which could be interpreted as migration status.⁶⁶ Furthermore, part I of the ESC describes article 11 as the right of “everyone” to benefit from the highest attainable standard of health.⁶⁷ In this light,

the ESC could potentially protect the right of all non-nationals to access affordable health systems, thus promoting the goals of UHC. Nevertheless, uncertainty remains.

The *travaux préparatoires* of the ESC in the 1950s clearly stress the drafters' intention to restrict the scope of the charter to European nationals.⁶⁸ However, this intention was explicitly rooted in the desire to promote freedom of movement among Europeans and to protect states parties' nationals against discrimination based on nationality.⁶⁹ It is unclear whether, at that time, drafters purposefully wanted to exclude other non-nationals from the scope of the ESC.⁷⁰ Nevertheless, when the charter was amended in 1996, states parties did not use this occasion to clarify their position on migrants' rights, reflecting perhaps a more conscious desire to differentiate nationals from non-nationals. The European Committee of Social Rights, nonetheless, has dismissed such an interpretation by extending the protection of article 11 to all non-nationals in recent case law.

To conclude, human rights treaties are sending mixed signals at both the international and regional levels. While clearly recognizing the universal scope of the rights they enshrine, including the right to health, these treaties also differentiate nationals from non-nationals. It is therefore essential to examine how such obstacles may be overcome, in order to enable UHC advocates to use the right to health as a legal tool to promote non-nationals' right to access affordable health systems.

Looking ahead: Advocating non-nationals' right to affordable health systems through supranational monitoring

Discussing whether and how the goals of UHC should be promoted through the right to health in order to better protect non-nationals' access to affordable health systems raises one final question: how can the aforementioned conflicts of norms be addressed? This section explores the potential of supranational human rights bodies to interpret the right to health inclusively, thus strengthening UHC goals.

Advocacy through international human rights bodies

Supranational human rights bodies are mandated to supervise the implementation of human rights treaties, including those recognizing a right to health. Therefore, when having to decide whether the right to health is realized and when justifying why during their monitoring procedures, supranational human rights bodies have the potential to clarify what it entails.⁷¹

At the international level, the body mandated to supervise the ICESCR—the UN Committee on Economic, Social and Cultural Rights—has clearly interpreted the scope of protection of article 12 of the ICESCR as being universal. As reported by Audrey Chapman and Benjamin Carbonetti, the committee often reviews the situation of foreigners, asylum seekers, refugees, and displaced persons in its reporting procedure.⁷² This is relevant under article 12, as the committee frequently highlights health discrimination committed against migrants in regular situations, undocumented migrants, asylum seekers, refugees, and stateless persons. Such monitoring subsequently disregards the differentiation made by article 2(3) (and article 28 of the UN Convention on Migrant Workers) and could promote UHC goals for all.

This is particularly true when examining the committee's comments on European states' reports from its 2016 reporting cycle. For instance, in its 2016 concluding observations on France, Sweden, and Macedonia, the committee called on these governments to provide better access to health care for asylum seekers and refugees, given restrictions in place (for example, administrative barriers in France).⁷³ In the case of Sweden, it even requested that access to basic health care be facilitated for "vulnerable foreigners," which it understood as including citizens of other European countries, notably Roma people.⁷⁴ Finally, in its 2016 concluding observations on the United Kingdom, the committee reminded the state that it was legally obliged to guarantee access to health care for everyone, following the enactment of a piece of legislation restricting access to health care for some non-nationals. This includes, the committee

noted, “temporary migrants and undocumented migrants, asylum seekers, refused asylum seekers, refugees and Roma, Gypsies and Travellers.”⁷⁵ Furthermore, the committee has repeatedly declared that austerity measures should not adversely or disproportionately affect vulnerable groups.⁷⁶ Such an inclusive interpretation could promote the goals of UHC.

However, the Committee on Economic, Social and Cultural Rights fails to systematically review non-nationals’ right to access affordable health care when monitoring article 12 of the ICESCR. In its 2016 reporting cycle, for instance, the committee referred to this issue only when commenting on European countries’ and Canada’s reports. Its concluding observations on Angola, Burkina Faso, Honduras, and Kenya do not examine this issue.⁷⁷ While these states may not experience the same migration flux or may not have the same income as European states, they too ought to protect non-nationals’ right to health. Denying this would otherwise give life to article 2(3) of the covenant. Moreover, even when European states badly hit by the economic crisis are at stake, the committee does not always monitor non-nationals’ access to (affordable) health care. For instance, it failed to discuss this issue in its 2014 concluding observations on Portugal.⁷⁸ Finally, for those states in which the committee verifies the affordability of health care for non-nationals, its comments tend to focus on asylum seekers and refugees, leaving the situation of migrants (documented or not) sometimes unsupervised.

Advocacy through regional human rights bodies

At the regional level, the European Committee of Social Rights (which monitors the implementation of the ESC) has greatly mitigated the conflicts arising between the appendix and article 11 of the ESC, through its jurisprudence on migrants’ health. In *International Federation of Human Rights Leagues v. France*, it recognized undocumented migrants’ right to minimal medical assistance and established that their children had the right to access health care on a similar basis as the rest of the population.⁷⁹ It grounded this decision on the principle of good faith, enshrined in the Vienna Convention on the

Law of Treaties, by declaring that the ESC was based on the values of dignity, autonomy, equality, and solidarity and that “health care [was] a prerequisite for the preservation of human dignity.”⁸⁰ In *Médecins du Monde International v. France*, and in its 2013 conclusions on Spain, the committee further extended the scope of protection of article 11.⁸¹ It recognized that adult migrants, whether in regular or irregular situations, had the right to access adequate health care and that this was not limited to emergency services. The committee explicitly stressed that states had “positive obligations in terms of access to health care for migrants, ‘whatever their residence status,’” referring to standards of “universal accessibility” laid down by the UN in General Comment No. 14.⁸² It even specified that states could not use the economic crisis as a pretext to restrict or deny access to health care in a manner that affected the substance of the right to health.⁸³ As a result, article 11 (the right to protection of health) and article 13 (the right to medical assistance) of the ESC now apply to undocumented migrants.⁸⁴

In the African context, it is unclear whether the African Commission on Human and Peoples’ Rights interprets the right to health as entitling non-nationals to access affordable health care on the same basis as nationals. None of its four merits decisions involving article 16 of the African Charter on Human and Peoples’ Rights concerns non-nationals’ access to health care, and its 2015 concluding observations are inconclusive. Moreover, little research has been carried out with regard to the protection of non-nationals by the African Charter on Human and Peoples’ Rights except in the context of mass expulsions.⁸⁵ However, in two merits decisions on article 16 and in various concluding observations, the commission recognizes the right to health of the “citizens” of the state.⁸⁶ Such a formulation is more restrictive than article 16 of the African Charter on Human and Peoples’ Rights, which requires that states protect the health of their “people,” and not solely their “citizens.”⁸⁷ This does not necessarily mean that the commission wishes to exclude non-nationals from the scope of protection of the right to health. In *Institute for Human Rights and Development in Africa v. Angola*, for in-

stance, it held that the absence of medical attention to migrants in detention camps constituted cruel, inhuman, and degrading treatment.⁸⁸ Nevertheless, nothing was said regarding their right to health. It is therefore desirable that the commission, in future jurisprudence, extend the scope of protection of the right to health to non-nationals. Such an inclusive interpretation could protect non-nationals' right to access affordable health systems and promote the goals of UHC.

To conclude, notwithstanding the potential of supranational human rights bodies to address conflicts of norms and discrepancies on non-nationals' right to health in human rights law, their contributions remain ad hoc and unprincipled. Consequently, the reliance of UHC on the right to health as a legal tool to promote non-nationals' right to access affordable health care offers uncertain opportunities.

Conclusion

According to Dr. Chan, WHO's director-general, by promising access to affordable health systems to all without exacerbating poverty, UHC is "the single most powerful concept that public health has to offer" and represents the "ultimate expression of fairness."⁸⁹ In order for this policy to be effective, it is essential that it reach all individuals whose access to health is under threat. However, asylum seekers, refugees, stateless persons, and undocumented or documented migrants are being increasingly denied access to affordable health care and often remain forgotten at the negotiating table.

This article has explored whether and how UHC should be promoted through the right to health to better protect non-nationals' access to affordable health systems. The first section argued that the protection of non-nationals' access to affordable health care was limited under UHC. Notwithstanding its "universal" quality, UHC provides limited guarantees to non-nationals given its ambiguous scope of protection and its non-legally binding nature. Such limits are problematic since non-nationals often experience difficulties in accessing national health systems, including that of

affordability, following the 2008 economic crisis. The second section then explored the opportunities offered by the right to health as a vehicle to promote UHC for non-nationals. The legally binding nature of the right to health, its worldwide recognition, and the linkages between its goals and those set by UHC represent considerable opportunities to promote non-nationals' access to affordable health systems. Furthermore, the universalist aspirations of the right to health and its inherent principle of non-discrimination provide important legal guarantees for non-nationals. However, as the third section highlighted, the right to health could weaken the promotion of UHC for non-nationals, for its scope of protection is unclear. The restrictive scope of article 28 of the UN Convention on Migrant Workers and the ambiguous meaning of article 2(3) of the ICESCR clash with the universalist aspirations of the right to health. Regrettably, similar restrictions and ambiguity can also be found in regional human rights systems, such as Europe and Africa. Therefore, the fourth section suggested advocating non-nationals' right to affordable health systems through supranational monitoring in order to reinforce the goals of UHC. The monitoring procedures of both the UN Committee on Economic, Social and Cultural Rights and the European Committee of Social Rights clearly show the intention to protect non-nationals' right to access affordable health systems on the same basis as nationals.

The problems discussed in this paper further highlight the urgent need for human rights law to address the conflicts of norms generated by the increasing and fragmented number of treaties at the international and regional levels. This is all the more crucial when such conflicts question the universality of human dignity, reflecting instead states' political interests. Both UHC and human rights advocates would agree that affordable access to health care should be provided to all, regardless of national migration policies.

Acknowledgments

The author wishes to thank the anonymous reviewers for their helpful comments, as well as the panel

'Challenges to realizing the right to health' at the Law and Society Association 2016 Annual Meeting, for its valuable feedback.

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preamble, art. 11 (see also European Social Charter (ESC 1961), ETS No. 035 (1961), preamble, art. 11, for states parties that still refuse to ratify the revised version of the ESC); African Charter on Human and Peoples' Rights, (African Charter) 21 ILM 58 (1981), preamble, art. 16; Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador), OAS Treaty Series No. 69 (1988), preamble, art. 10; WHO Constitution (see note 15), preamble.

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Closing the Gap Between Formal and Material Health Care Coverage in Colombia

EVERALDO LAMPREA AND JOHNATTAN GARCÍA

Abstract

This paper explores Colombia's road toward universal health care coverage. Using a policy-based approach, we show how, in Colombia, the legal expansion of health coverage is not sufficient and requires the development of appropriate and effective institutions. We distinguish between *formal* and *material* health coverage in order to underscore that, despite the rapid legal expansion of health care coverage, a considerable number of Colombians—especially those living in poor regions of the country—still lack material access to health care services. As a result of this gap between formal and material coverage, an individual living in a rich region has a much better chance of accessing basic health care than an inhabitant of a poor region. This gap between formal and material health coverage has also resulted in hundreds of thousands of citizens filing lawsuits—*tutelas*—demanding access to medications and treatments that are covered by the health system, but that health insurance companies—also known as EPS—refuse to provide. We explore why part of the population that is formally insured is still unable to gain material access to health care and has to litigate in order to access mandatory health services. We conclude by discussing the current policy efforts to reform the health sector in order to achieve material, universal health care coverage.

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Competing interests: None declared.

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Introduction

During the period 1991-2016, the growth of health care coverage in Colombia has been remarkable, going from 25% of the population covered in 1992 to approximately 96% today. This rapid surge in health care coverage represents a key dimension of the right to health, because access to health care, previously restricted to a minority of Colombians, has increasingly become a matter of basic rights for the majority of citizens. As the Colombian Constitutional Court stated in opinion T-760 of 2008, if the right to health is to be taken seriously, then the government has to guarantee that all Colombians have access to health care without any type of distinctions.

However, as we will explore in this paper, many regulatory and institutional shortcomings of Colombia's health sector have impeded the fact that all Colombians' can ostensibly access the same basket of health services. Many inhabitants of poor regions carry a social security card as identification, yet their access to basic health care is very limited. As a result, despite the rapid growth in coverage, thousands of vulnerable citizens are not able to enjoy their right to health care, which was mandated by the 1991 Constitution and the precedent of the Constitutional Court.

This paper starts with a discussion of the 1993 congressional bill that introduced Health Sector Reform (HSR) in Colombia. Widely known as Law 100 of 1993, the reform bill uprooted a failed health system that covered less than 25% of the population. The main objective of the 1993 reform was to achieve universal health care coverage through a comprehensive and mandatory social insurance system in which private, public, or mixed health insurers and providers competed for patients among themselves, and also with state-owned institutions such as the Social Security Institute (ISS or Instituto de Seguros Sociales, privatized and ceased to exist in 2007 as a state-owned health insurer and provider). The principles that guided the 1993 health reform were universal health coverage, efficiency, quality, and equity, as explicitly stated in Article 2 of Law 100 of 1993.

Colombia's minister of health at the time coined the term "structured pluralism" to describe

the reform. According to this model, governmental regulation was the key mechanism for ensuring that the new private, public, or mixed health insurers and health care providers were guided in the direction of public interest.¹

Much has been written about the shortcomings of the 1993 health reform.² The abrupt implementation of the bill brought unintended effects, such as the poor performance of key governmental and regulatory agencies that were unable to rein in private stakeholders like health insurance and pharmaceutical companies.³

Largely as a result of the regulatory shortcomings in Colombia's health system, patients who are refused treatments, exams, and pharmaceuticals—whether or not these are included in the baskets of health services—are left with no better alternative than to file a lawsuit using an informal judicial mechanism for the protection of basic rights, widely known as *tutela*, which was incorporated into the 1991 Constitution.⁴ Since the implementation of the 1993 health reform, Colombia has become the most litigious country in Latin America in the area of the right to health.⁵ As Table 1 shows, more than 1.3 million lawsuits were filed between 1999-2014 demanding access to health care services, treatments, and pharmaceuticals.⁶

Some authors suggest that the key variable to explain Colombia's uncommonly high volume of right to health litigation is the institutional arrangement and performance of Colombia's health system. Yamin et al. argue, for instance, that the "characteristics of the Colombian health system are central to understanding why the volume of litigation has been greater in Colombia than anywhere else."⁷

Several authors underline that the agenda of international financial institutions like the World Bank was the most important determinant of Colombia's 1993 health care overhaul.⁸ Authors like Yamin stress that the privatization and deregulation of Colombia's health care system that was unleashed by the 1993 health care reform incentivized health rights litigation. According to Yamin, at the heart of Colombia's uncommon escalation of right to health litigation lies a clash between the health system's neoliberal "push toward com-

modification, commercialization, and privatization [that] undermines both the concept and enjoyment of a right to health” and the reactive role of litigants and courts, which have acted as “bulwarks against the hegemonic onslaught of neoliberalism.”⁹

More concretely, according to this account, Colombia’s implementation of a neoliberal managed competition health care overhaul brought about rapid growth in health care coverage, but also a widespread infringement of patients’ rights, who used the easy access to courts and the highly effective legal mechanisms introduced by the 1991 Constitution to fight off the increased rogue behavior of private health insurance companies. As these companies escalated their infringement of patients’ rights—thanks in great part to the government’s poor regulation of the health system—patients escalated their reliance on health rights litigation. Indeed, patients used litigation consistently as the only effective mechanism to mitigate the harm-

ful effects of privatized/managed competition health care.¹⁰ Furthermore, it was not until 2012 that the government approved integration of the basket of health services for the contributory and subsidized regimes, a change prompted by opinion T-760 of 2008 from the Constitutional Court. From 1993 until 2012, the subsidized population was entitled to fewer health services than the contributory population, which the Constitutional Court ruled an encroachment on the right to equal treatment entrenched in the 1991 Constitution.

Much less has been written about the achievements of the 1993 health reform.¹¹ Arguably, the most remarkable accomplishment of the reform was the abrupt rise in health care insurance coverage. Over 20 years (1993-2013), coverage jumped from 21% of the population to 96%.¹² This dramatic expansion awarded to most Colombians social security entitlements that were previously restricted to a privileged minority, along with a substantial in-

TABLE 1. Growth of *tutela* claims relating to the right to health, 1999-2014

Year	Number of <i>tutelas</i>		Health- related share	Annual growth	
	Health related	Total		Health related	Total
1999	21,301	86,313	24.68%	-	-
2000	24,843	131,764	18.85%	16.63%	52.66%
2001	34,319	133,272	25.75%	38.14%	1.14%
2002	42,734	143,887	29.70%	24.52%	7.96%
2003	51,944	149,439	34.76%	21.55%	3.86%
2004	72,033	198,125	36.36%	38.67%	32.58%
2005	81,017	224,270	36.12%	12.47%	13.20%
2006	96,226	256,166	37.56%	18.77%	14.22%
2007	107,238	283,637	37.81%	11.44%	10.72%
2008	142,957	344,468	41.50%	33.31%	21.45%
2009	100,490	370,640	27.11%	-29.71%	7.60%
2010	94,502	403,380	23.43%	-5.96%	8.83%
2011	105,947	405,359	26.14%	12.11%	0.49%
2012	114,313	424,400	26.94%	7.90%	4.70%
2013	115,147	454,500	25.33%	0.73%	7.09%
2014	118,281	498,240	23.74%	2.72%	9.62%
TOTAL	1,323,292	4,507,860	30.66%		

Source: Defensoría del Pueblo, *La Tutela y los Derechos a la Salud y a la Seguridad Social 2014* (Bogotá: Defensoría del Pueblo, 2015).

crease in equity in access and strengthened financial protection for the most vulnerable population.

This rapid growth came at great cost to the government. Over the two years that followed the 1993 reform, 4.6 million people were included in the subsidized regime.¹³ Public funds committed to subsidize the most vulnerable groups went from US\$42 million in 1994 to US\$550 million in 1995.¹⁴ Furthermore, although coverage rose rapidly across the country, there were marked inequalities between poor and rich departments in terms of health outputs and access to basic health care.

The dramatic surge in right to health litigation in a context of an abrupt rise in health care coverage indicates that despite the formal or legal expansion of coverage, private insurance companies and public hospitals have denied health care services to hundreds of thousands of Colombians. In the following sections, we explore this gap be-

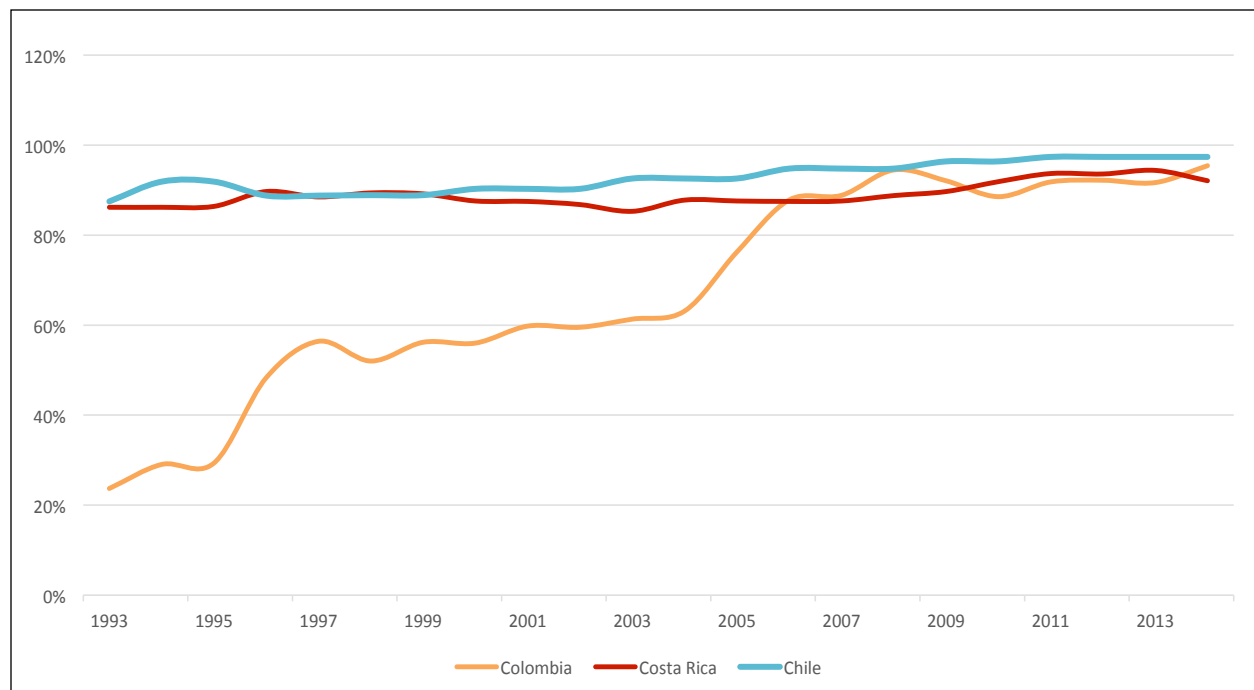
tween formal and material health care coverage and attempt to uncover the main variables driving this phenomenon. We also look at the policies put forward by Colombia's government to deliver not only formal health care coverage, but also material access to health care to all Colombians. The regulatory reform mandated by opinion T-760 was ultimately crystallized in a statute passed by Congress in 2015 (Law 1751).

Evolution of health care coverage in Colombia, 1991-2013

Setting the foundations, 1991-2003

In 1991, the National Constituent Assembly, a democratically elected assembly in charge of drafting a new Constitution, opened the path for the 1993 health care reform, which introduced from scratch a social insurance scheme for the provision of

FIGURE 1. Health care coverage in Colombia, Costa Rica, and Chile, 1993-2013



Source: Authors' own calculations based on Ministerio de Salud y Protección Social, "Informe al Congreso de la República 2014-2015. Sector administrativo de salud y protección social." (Bogotá, 2015); Organization for Economic Co-operation and Development, *OECD Reviews of Health Systems: Colombia 2015* (Paris: OECD Publishing, 2015); U. Giedion and A. Wüllner, *La Unidad de Pago Por Capacitación Y Equilibrio Financiero Del Sistema de Salud* (San José: Fundación para la Educación Superior y el Desarrollo, Fedesarrollo, 1994); Ministerio de Desarrollo Social, *Informe de Desarrollo Social 2015*, (Santiago, 2015); and Programa Estado de la Nación (PEN), *Vigésimo primer Informe Estado de la Nación en Desarrollo Humano Sostenible (Costa Rica)*, (San José, 2015).

health services. Colombia's social insurance model, as outlined by the 1991 Constitution and by Law 100 of 1993, encouraged the regulated competition of private, public, and mixed health providers as a means to accomplish universal health coverage. Yet it was a model that required active governmental intervention and regulation.¹⁵

As displayed in Figure 1, the Colombian health care system experienced a late and abrupt expansion during the 1990s. By 1993, the social security systems in Costa Rica and Chile offered coverage to approximately 90% of the population, whereas Colombia's social security system offered coverage to less than 25%. Over a period of 20 years (1993-2013) health care coverage jumped from 21% of the population to 96%.¹⁶

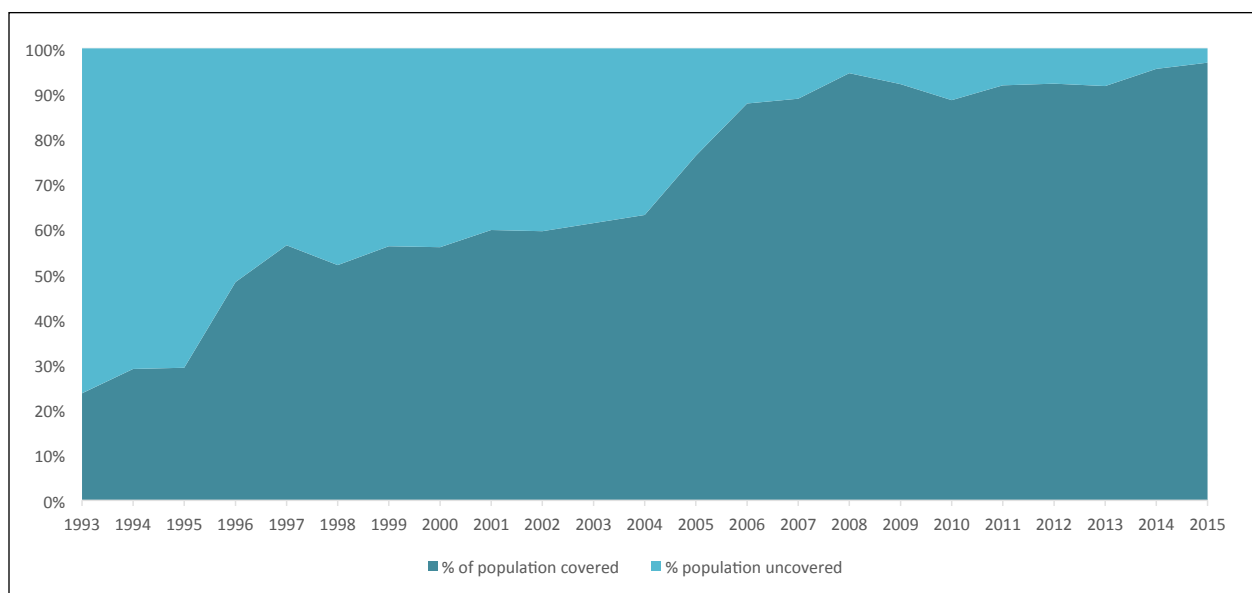
In 1993—the year health reform was implemented—76% of the Colombian population was uninsured (See Figure 2). By 2015, the percentage covered by the contributory regime, composed of the households of pensioners and citizens who are formally employed and who contributed to the social security system with 12.5% of their salaries, amounted to 45% of the population. The percentage

of the population covered by the subsidized regime, composed of the households of the unemployed and informally employed, represented 48% of the population. As a result, only 3% of the population was uninsured by 2015.

As previously mentioned, the touchstone of the 1993 health reform was the creation of two different insurance regimes: the contributive and the subsidized regimes. The contributive regime is funded, primarily, by payroll taxes from formal employees and employers; independent workers who earn more than twice the minimum monthly income; pensioners; and corporate income tax known as the income tax for equality (CREE). Funding for the health insurance companies (EPS) that insure the contributive population and its households comes from the following sources: formally employed Colombians contribute 12.5% of their salaries, retirees contribute 12% of their pensions, and those earning less than 10 minimum monthly wages (approximately US\$2,300) contribute 4% of their wages. Members of the contributive regime also help fund the plan through copayments.

The subsidized regime is financed by public

FIGURE 2. Health care coverage in Colombia, 1993-2013



Source: Authors' own calculations based on Organization for Economic Co-operation and Development, *OECD Reviews of Health Systems: Colombia 2015* (Paris: OECD Publishing, 2015).

funds, which the national government transfers to municipalities and departments. Once municipalities and departments receive the funds from the national government, they transfer the money to insurance companies that provide health care to the subsidized population. These transfers from the national to local governments are known as General System of Participation (SGP or *Sistema General de Participación*). Additionally, formal employees, employers, and independent workers contribute 1.5% of their monthly salaries to the subsidized regime through the “solidarity” mechanism of Law 100 of 1993. Finally, municipalities and departments provide funding by means of regional taxes on liquor, tobacco, and gambling, among others.

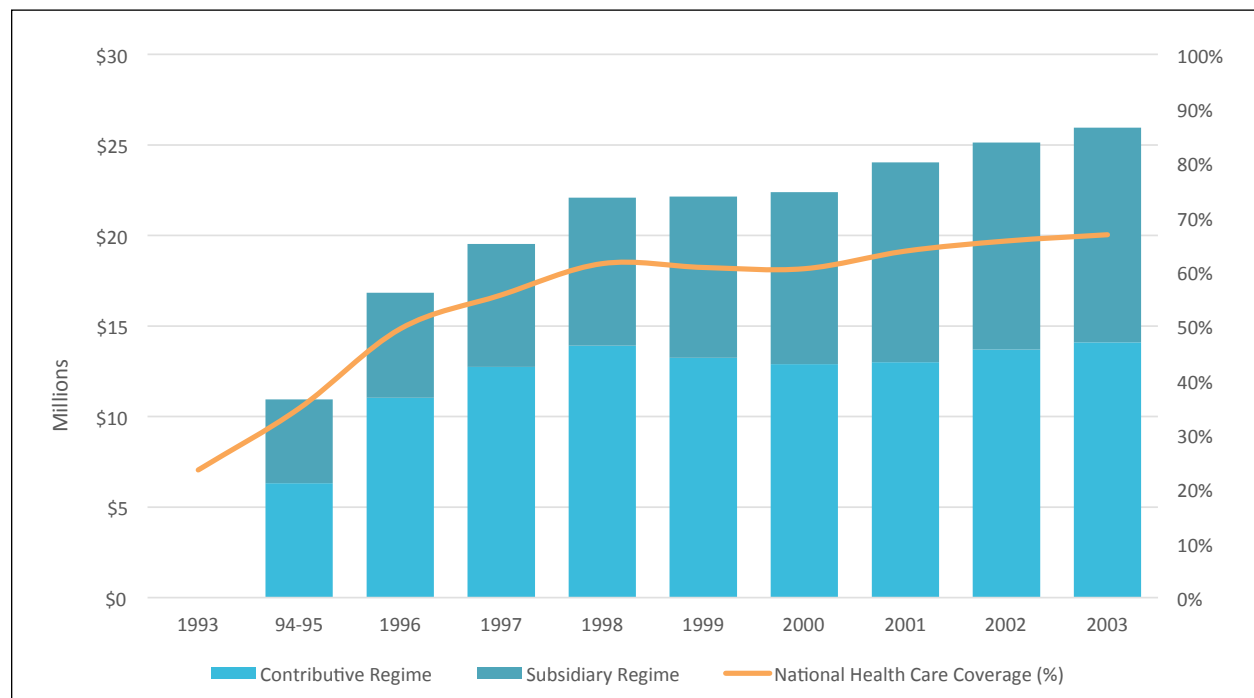
The early expansion of health care coverage among the subsidized population was bolstered by a 1994 presidential decree (Decree 2491 of 1994), which ordered the national government, municipalities, and departments to create specific subsidies in order to incorporate their poorest citizens into the subsidized regime. A nationally established but locally applied

survey, SISBEN, classifies Colombians according to financial need, with the poorest Colombians categorized as SISBEN 1. Those classified as SISBEN 3, although poor, are not as destitute as individuals and families classified as SISBEN 1 and SISBEN 2.

Decree 2491 ordered municipalities and departments to incorporate into the subsidized regime only the population classified as SISBEN 1 and SISBEN 2. As a result of the subsidies created by Decree 2491, more than 5.8 million individuals joined the subsidized regime between 1994 and 1996 (see Figure 3).

However, one of the most important assumptions of the technocrats who designed Law 100 of 1993 was that unemployment and informal labor would decrease over the following decade, resulting in the contributive population growing faster than the subsidized population. Under this assumption, it was expected that the “solidarity mechanism,” whereby the formally employed contribute with 1.5% of their salary, would become the financial bedrock of the subsidized regime. This forecast proved to be wrong, and informal labor and unem-

FIGURE 3. Population insured through the contributive and subsidized regimes and evolution of health care insurance coverage, 1993-2003



Source: Authors' own calculations based on Organization for Economic Co-operation and Development, *OECD Reviews of Health Systems: Colombia 2015* (Paris: OECD Publishing, 2015).

ployment rose.¹⁷ Over the next 20 years (1993-2013), the subsidized population grew faster than the contributory population (see Figure 3), and as a result, the government had to invest heavily to finance the expansion of health care coverage among the subsidized population.

While in 1994 only 579,289 individuals were part of the subsidized regime, in 2000 the subsidized regime covered more than 9.5 million beneficiaries.¹⁸ As previously mentioned, this expansion cost the government dearly: whereas in 1994 they spent US\$42 million financing the subsidized regime, in 2000 they spent US\$594 million (see Table 2).

The cost of expanding coverage among the contributive population was also high. However, in this case it was the workforce—formal employ-

ees and employers—that shouldered the cost of expanding health care coverage among the contributive population. Whereas in 1993, employees and employers contributed US\$1.2 billion through payroll taxes, by 2003 that amount had climbed to US\$3 billion (see Figure 4).

Paying the price of universalization, 2003-2013

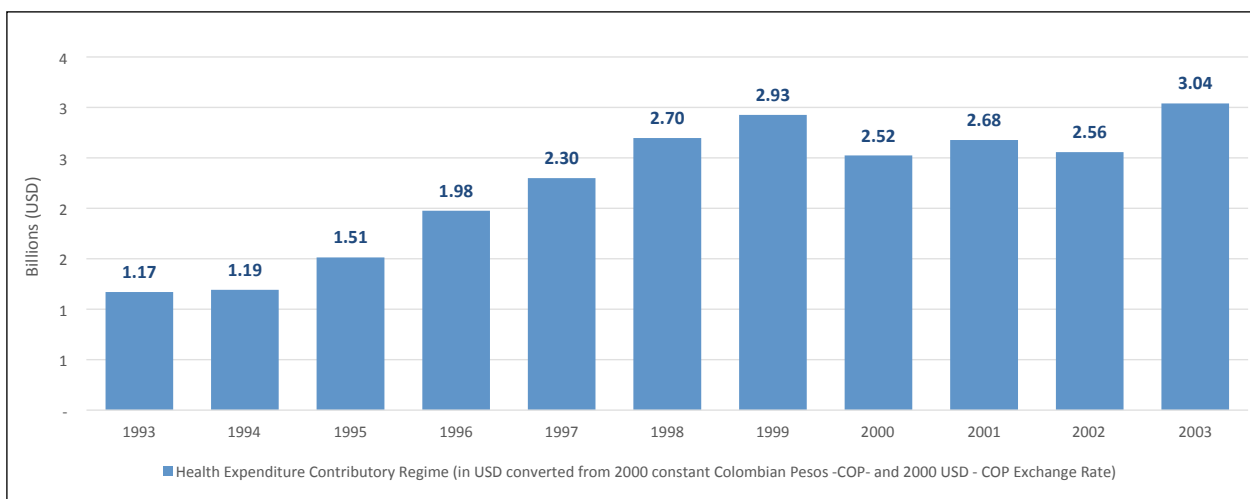
In 2003, health care coverage received an additional boost thanks to an executive order from the health regulatory agency, *Consejo Nacional de Seguridad Social en Salud* or CNSSS.¹⁹ The order created new governmental subsidies geared towards the incorporation into the subsidized regime of individuals

TABLE 2. Number of people covered and public funds invested in the subsidized regime, 1994-2000

Year	Number of people covered by subsidized regime	Public funds (current USD)
1994	579.289	\$42,050,595
1995	4.800.916	\$554,950,810
1996	5.981.774	\$577,603,589
1997	7.026.692	\$655,508,596
1998	8.527.061	\$784,256,413
1999	9.325.832	\$708,187,686
2000	9.510.566	\$594,638,245

Source: Ministerio de la Protección Social, *¿Ha mejorado el acceso en salud? Evaluación de los procesos del régimen subsidiado*, Colección de Estudios sobre Protección Social 3, (Bogotá: Universidad Nacional de Colombia, Centro de Investigaciones para el Desarrollo, 2007), p. 260.

Figure 4. Evolution of payroll taxes in the contributory regime, 1993-2003



Source: Authors' own calculations based on G. Barón, *Cuentas de Salud de Colombia 1993-2003: El Gasto nacional en salud y su financiamiento* (Bogotá: Ministerio de Protección Social and Departamento Nacional de Planeación, 2007).

who were classified as SISBEN 2 and SISBEN 3. Starting in 2004, not only the poorest and most vulnerable Colombians—that is, people classified as SISBEN 1—were able to join the subsidized regime, but also individuals who were not as poor and vulnerable. In 2011, the Ministry of Health issued an executive order (Resolution 3778) that reverted the CNSSS 2004 decision, allowing only SISBEN 1 and 2 populations to join the subsidized regime. But as a result of the CNSSS executive order, more than 3.5 million individuals classified as SISBEN 2 and 3 joined the subsidized regime in 2004.²⁰ As shown in Figure 5, the subsidized population surpassed the contributory population in 2005, a trend that remained constant from 2005 to 2013.

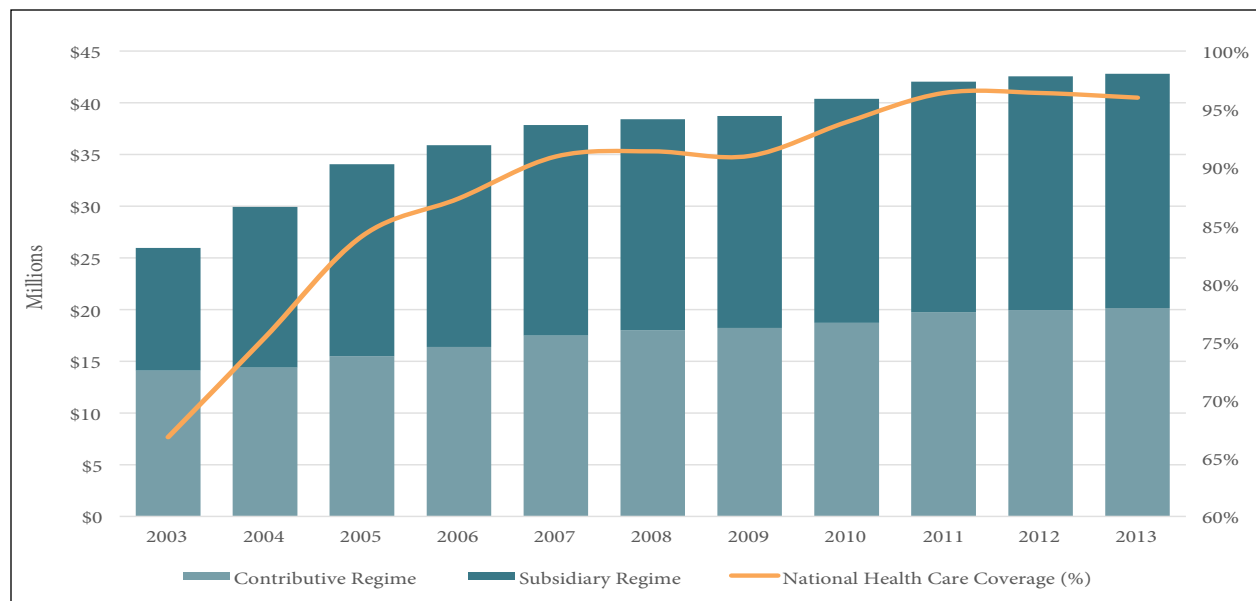
The rapid growth of the subsidized population placed massive pressure on the government’s health budget. In 2011, for example, 68% of the funds used to finance the subsidized regime were public (transfers from the national to the local government through the General System of Participation). Only 25% of the funding came from payroll taxes. Furthermore, municipalities and departments con-

tributed with only 1 and 6% of the funding for the subsidized regime, respectively (see Figure 6).

From 2003-2009, the average yearly health expenditure for the subsidized regime represented 1.1% of Colombia’s GDP, whereas payroll taxes paid by employees and employers amounted to 2.2%.²¹

Given these figures, why did the government push forward with the universalization of health care coverage? The answer is not straightforward. One could argue that the government expanded health care coverage among the subsidized population because the 1991 Constitution and Law 100 1993 ordered Congress and the executive branch to achieve universalization. Additionally, in 2008 the Colombian Constitutional Court (CCC) handed down Opinion T-760 of 2008, a 400-page ruling that instantly captured the attention of experts, civil society organizations, patients’ groups, and the media.²² In Opinion T-760, the CCC reviewed its own vast jurisprudence on the right to health, showing how the evolution of the Court’s precedent led to the conclusion that health care was a basic right which could be autonomously enforced—that is, not only

FIGURE 5. Population insured through the contributory and subsidized regimes and evolution of health care coverage, 2003-2013



Source: Authors’ own calculations based on Organization for Economic Co-operation and Development, *OECD Reviews of Health Systems: Colombia 2015* (Paris: OECD Publishing, 2015).

when the right to life of the plaintiff was threatened. Additionally, the CCC concluded that although the right to health created programmatic duties that the government had to comply with gradually, it also created immediate duties for the government.

Opinion T-760/08 contained 32 orders. The first 16 commanded health insurance companies (EPS) to deliver the health care services demanded by the 22 individual plaintiffs who filed the lawsuits. The remaining 16 were addressed to the Ministry of Health and other regulatory agencies, such as the Regulatory Health Commission (CRES) or the National Superintendence of Health. These “structural” orders cover regulatory measures that the CCC considered the government should implement to protect Colombian patients’ right to health.

Some deal with the government’s duty to reach universal health coverage and provide a unified basket of health services to both the contributive and the subsidized regimes (see Table 3).

Although the CCC’s orders may have persuaded the government to strengthen its commitment to universal health care coverage despite mounting fiscal costs, it must also be acknowledged that in previous decades, the Colombian government used health and social subsidies as a populist mechanism to gain votes among the poorest and most vulnerable citizens.²³ Additionally, members of congress and local politicians pressed the executive branch to expand the SGP. According to some researchers, the transfers of public funds from the national to the municipal and department levels transformed

FIGURE 6. Financial sources for the subsidized regime in 2011

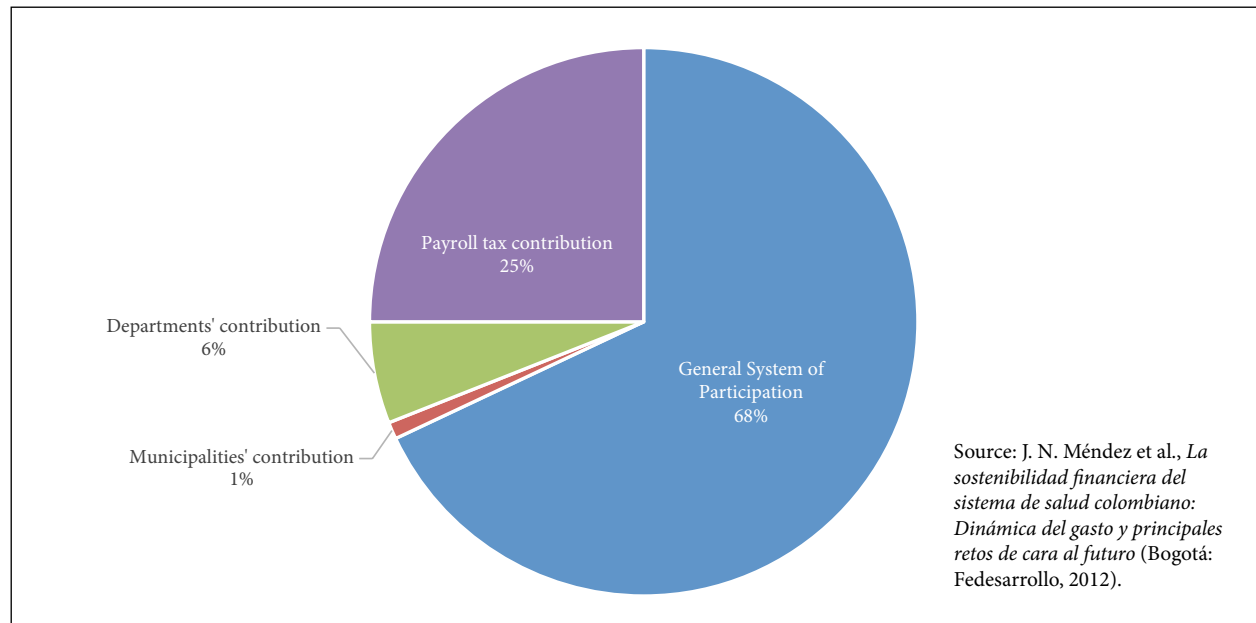


TABLE 3. Colombian Constitutional Court’s orders regarding universal health coverage

Orders 21 and 22	Ordering the Ministry of Health to unify the two existing baskets of health services, incorporating the participation of patients. According to the CCC, having a more comprehensive basket of health services for the “contributive” population who had formal jobs and a less comprehensive for the “subsidized” population who lacked a formal job, ran counter to equity principles entrenched in the Constitution and incentivized right to health litigation.
Order 29	Ordering the Ministry of Health to implement measures aimed at accomplishing universal health care coverage.

the financing mechanisms of the subsidized regime into a source of political grafting and rent-seeking.²⁴

Finally, there are indications that part of the population insured by both the contributive and the subsidized regimes have limited or no access to health care. While most of these individuals are

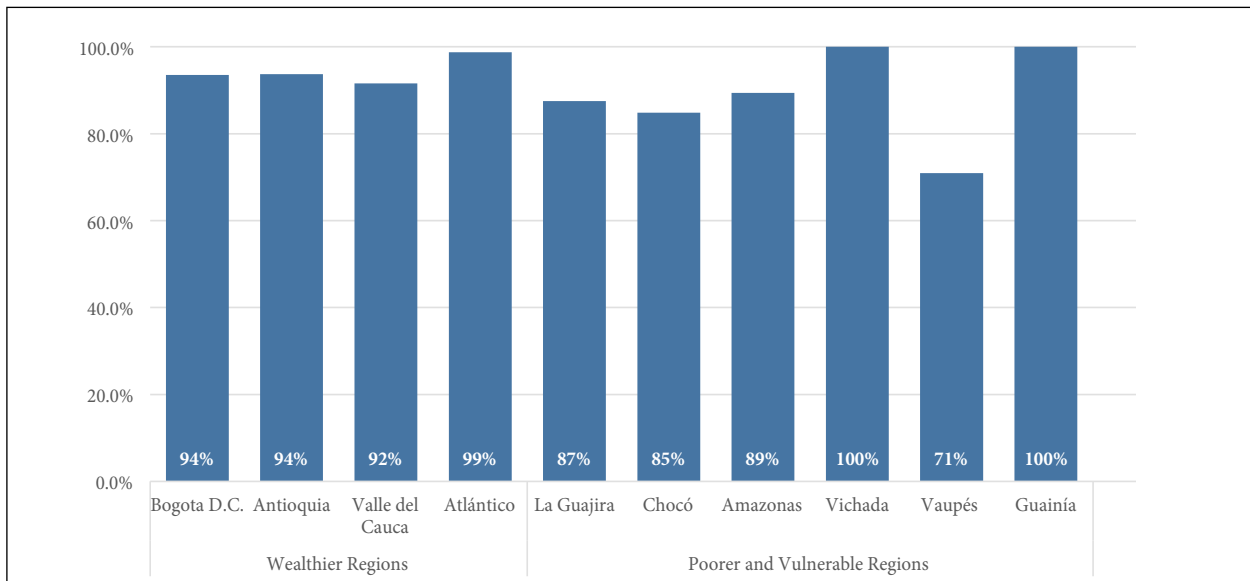
formally covered by the health system—that is, they carry a social security card—they often lack material access to health care. In the final section of this paper we explore the gap between formal and material health care coverage, and also discuss policymakers’ efforts to close that gap.

TABLE 4. Reasons why people remain uninsured despite eligibility for the subsidized or contributive regimes

Reasons	Share of response
Lack of money	14.1%
Too much red tape	13.8%
Uninterested/neglect	16.9%
Unaware that they can be insured	2%
No relation with a formal employee (informal workers)	15.6%
Currently going through the application procedure	27.2%
No health insurance company close to home	1.2%
Other reasons	9.3%

Source: Departamento Administrativo Nacional de Estadística, “Encuesta Nacional de Calidad de Vida 2014” (Bogotá: Departamento Administrativo Nacional de Estadística, 2014).

FIGURE 7. Health care coverage in Colombia by selected departments, 2016



Source: Ministerio de Salud y Protección Social, “Sistema Integral de Información de la Protección Social (SISPRO),” Ficha Departamental y Municipal (October 2016). Available at <http://sispro.gov.co>.

Closing the gap between formal and material health care coverage in Colombia

Uninsured poor population (UPP)

The government has conceded that part of Colombia's population is still uninsured. More significantly, the Ministry of Health has classified this population as the Uninsured Poor Population (UPP).

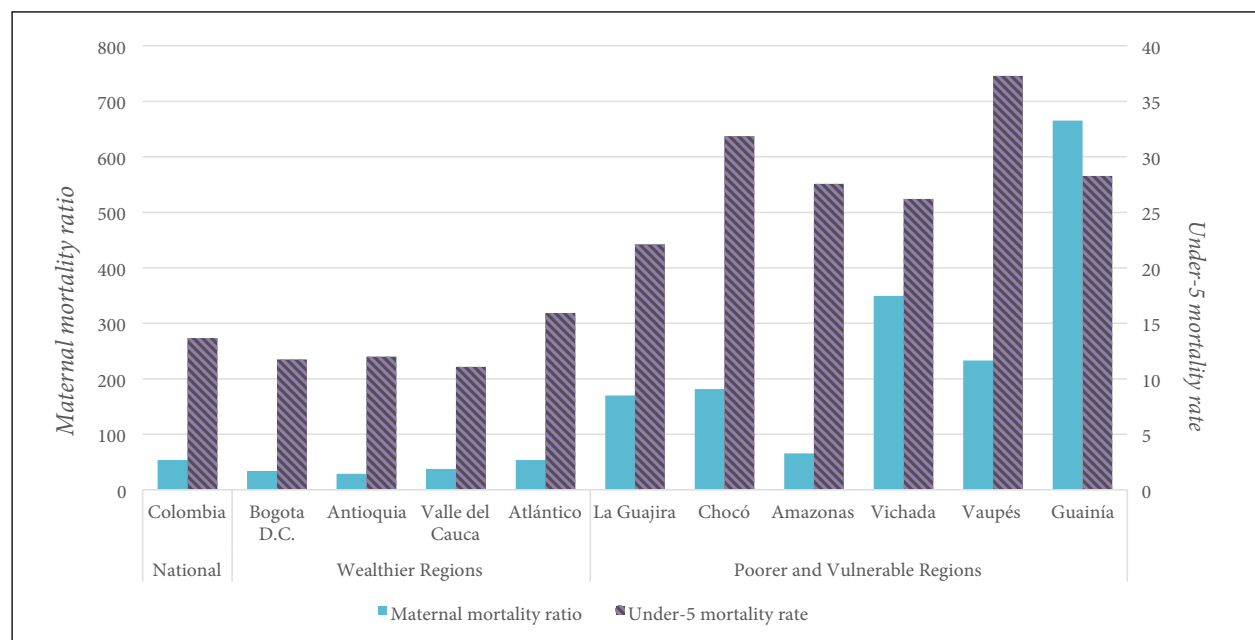
According to recent estimates from the Ministry of Health, 46.4 million people are insured by either the contributive or the subsidized regimes. Official estimates from the government's statistics agency, DANE, put Colombia's population at approximately 48.7 million. Thus, according to the Ministry's data, approximately 2.3 million remain uninsured. However, DANE's 2014 Quality of Life Survey (Encuesta de Calidad de Vida) suggests that the number of uninsured is larger—approximately 2.7 million people. According to this survey, there are multiple reasons why eligible individuals remain uninsured (See Table 4). Some of the UPP have not been included in the government's

SISBEN. Some people who are in the process of applying for insurance are also part of the UPP. And those individuals who are still uninsured despite being poor enough to qualify for the subsidized regime make up another part of the identified UPP.

Perhaps the most worrying category of UPP is “sandwiched” individuals. The first type of “sandwiched” UPP are those who switch jobs frequently or are short-term contract workers. When they are formally employed, they are insured by the contributory regime, but when they become temporarily unemployed, they abandon it. They cannot be incorporated into the subsidized regime because their changing working status makes them difficult to classify as permanently unemployed or as vulnerable individuals (SISBEN 1 and 2).

Another category of “sandwiched” UPP was created in 2011 when the Ministry of Health issued an executive order (Resolution 3778) excluding SISBEN 3 individuals from the subsidized regime. The Ministry reasoned that SISBEN 3 individuals were not as poor and vulnerable as those classified

FIGURE 8. Maternal mortality ratio (per 100,000 live births) and mortality rate of children under 5 years old (per 1,000 live births) in Colombia by selected departments, 2014



Source: Ministerio de Salud y Protección Social, “Sistema Integral de Información de la Protección Social (SISPRO),” Ficha Departamental y Municipal (October 2016). Available at <http://sispro.gov.co>.

SISBEN 1 and 2. On the contrary, many had enough income to join the contributory regime as independent workers earning more than two minimum monthly incomes, but they were getting a free ride in the subsidized regime. It is unclear, though, whether the government had solid data on the socioeconomic composition of SISBEN 3 population. Some individuals are currently uninsured because they are considered to be above the poverty line and therefore are expected to join the contributory regime as independent workers. Yet it is possible that the real incomes of these individuals are lower than expected, and thus they are unable to pay taxes as independent workers. As a result, the “sandwiched” population is in a lose-lose situation: excluded from the subsidized regime because they are not poor enough, and unable to join the contributory regime as independent workers because they are not wealthy enough.

Unequal access to health care across departments and regions

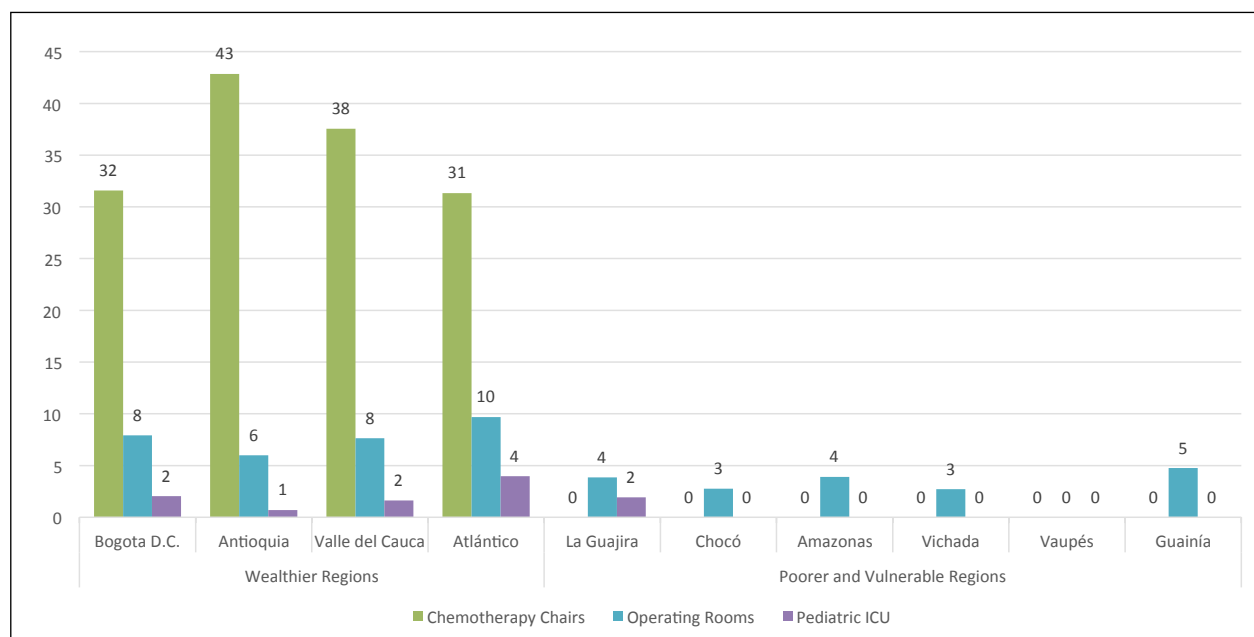
Although health care coverage in Colombia is high and equally distributed among departments, there

are strong indications that health outcomes and actual access to health services vary dramatically.

Consider, for instance, the performance of health care coverage in the four wealthiest departments vis-à-vis the five poorest departments. According to DANE, Bogotá, Antioquia, Valle del Cauca, and Atlántico have the largest participation in the country’s GDP. La Guajira, Chocó, Amazonas, Vichada, and Guainía are the poorest departments in terms of their participation in the country’s GDP. As Figure 7 shows, the variation of health care coverage among poor and wealthy departments is not marked. On the contrary, a poor department like Guainía has better health care insurance coverage than the two richest Colombian departments.

One way to assess the gap between coverage and actual access to health care is by comparing health outcomes and health services between rich and poor departments. We can assess health outcomes, like maternal and child mortality, and health services, such as per capita numbers of health facilities, pediatric intensive care units, operation rooms, chemotherapy units, and ambulances, among others.

Figure 9. Pediatric ICUs, chemotherapy chairs, and operating rooms (per 100,000 inhabitants) in Colombia by selected departments, 2016



Source: Authors’ own calculation based on Ministerio de Salud y Protección Social, *Registro Especial de Prestadores de Servicios de Salud* (March 2016). Available at <http://prestadores.minsalud.gov.co/habilitacion/>.

Figure 8 shows the different patterns of maternal and child mortality in poor and rich departments. In rich departments, the number of women who die from pregnancy-related causes is, on average, 38.4 per 100,000 births, whereas in poor departments the figure is 277.5. Similarly, the number of children younger than 5 years who die per 1,000 live births is, on average, 2.3 times greater in poor departments than in rich ones.

Furthermore, Figure 9 shows major disparities between rich and poor departments in terms of operating rooms (OR). Whereas in rich departments there are on average 8 ORs per 100,000 individuals, poor departments have only 3 per 100,000. The disparities are even greater when it comes to pediatric intensive care units (ICU). La Guajira is the only poor department that has an ICU. Finally, whereas rich departments have, on average, 35 chemotherapy chairs per 100,000 individuals, poor departments do not offer such health services.

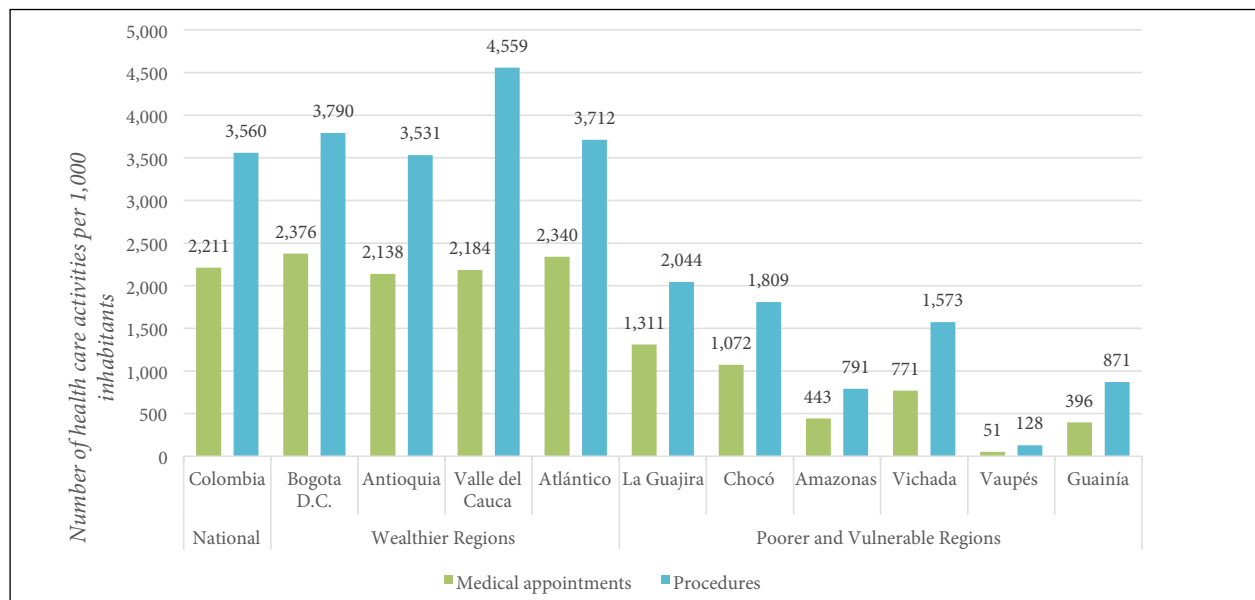
Figure 10 shows two health care activity rates (medical appointments and procedures) in each selected department in 2015 (per 1,000 inhabitants). Medical appointments rate is on average 3.5 times

higher in the four richest departments (2,259) than in the six poorest departments (674). Similarly, whereas in the four richest departments 3,898 procedures on average were performed in 2015 per 1,000 inhabitants, the poorest departments only registered 1,202 medical procedures per 1,000 inhabitants. The procedure rate in 2015 was three times lower in the poorest departments compared to the richest.

The health disparities illustrated in Figures 8, 9, and 10 suggest a profound gap between formal and material health care coverage in poor departments. In other words, in Guainía most people are formally insured but lack access to basic health services such as operating rooms, pediatric ICUs, and chemotherapy units. Similarly, basic health outcomes like maternal and child mortality are much worse in a poor state like Guainía than in rich departments like Bogotá and Antioquia. In Vaupés, the lack of health service infrastructure and poor health care outcomes collide with the lowest medical appointment and procedures rates in the country.

It could be expected that in poor states with low health outcomes levels of health rights litiga-

FIGURE 10. Medical appointments and procedures rates (per 1,000 inhabitants) in Colombia by selected departments, 2015



Source: Authors' own calculation based on Ministerio de Salud y Protección Social, "Sistema Integral de Información de la Protección Social (SISPRO)," Prestaciones (October 2016). Available at <http://sispro.gov.co>.

tions would be higher. However, as shown in Figure 11, departments in both wealthy and poor regions share near the same rate of *tutela* claims relating to the right to health.

Remaining challenges

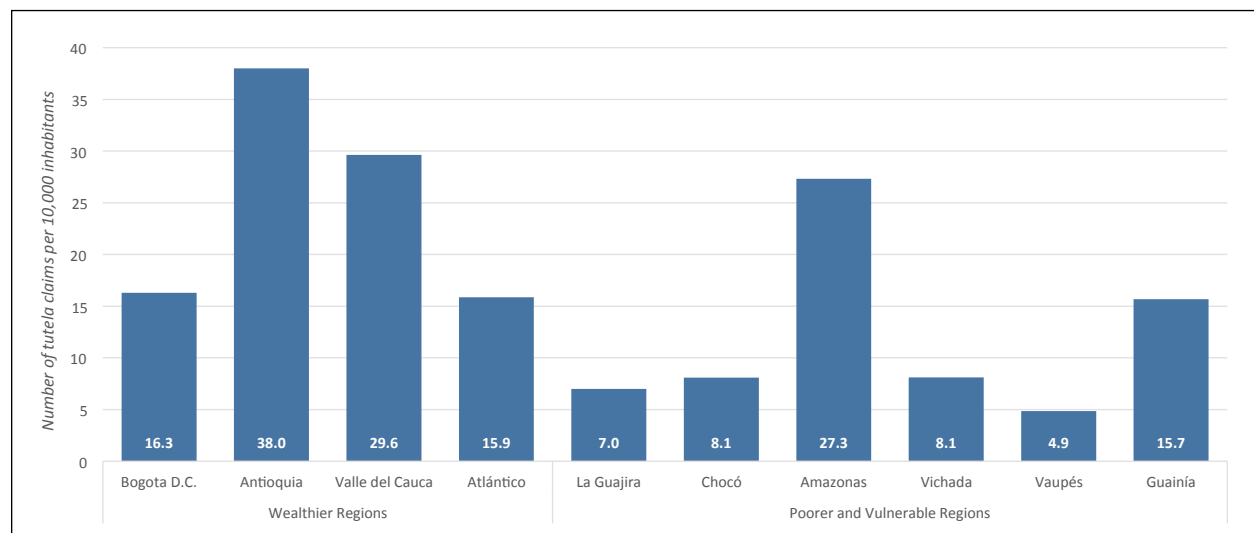
There are several factors that could account for the great divide in terms of health services and outcomes across the country. Corruption, inefficiency, mismanagement, and institutional weakness seem to be more prevalent in poor departments than in rich ones. The Comptroller General's office notes that the national government transferred more than \$US242 million to 17 departments between 2011 and 2013, to be invested in the improvement of health facilities and hospitals, but the departments only spent \$US97 million. Between 2011 and 2013, poor departments like Amazonas, Guainía, and Vaupés received more than \$US4 million from the central government to improve their hospitals and health facilities, but for unknown reasons, none of those departments actually used the money.²⁵

In 2015, the General Attorney's office conducted 49 investigations on grafting and widespread corruption in Chocó's health system. They found that myriad health services were never delivered in Chocó, despite having been paid

by local authorities using public funds.²⁶

Additionally, weak institutions can also explain why health care is so deficient in departments like Guainía. For instance, in 2014, the Ministry of Health concluded that in poor and distant departments like Guainía, the institutional arrangement for the provision of health care should follow a different blueprint than in the rest of the country.²⁷ More particularly, providing health care in Guainía, where the population is scarce and dispersed compared to the rest of the country (56 inhabitants per square kilometer versus 43 inhabitants per square kilometer in the rest of the country), demanded a new health care model capable of achieving five main goals: 1) provision of primary care services adjusted to the real needs of the inhabitants of Guainía; 2) an intercultural model in a region where traditional indigenous knowledge can be incorporated into the local health system; (3) the monopoly of a single health insurer with knowledge and experience in the field, capable of administering scarce resources in a depopulated and vast territory; (4) improvement of existing medical facilities, and creation of new, extramural, and mobile facilities; (5) participation of indigenous communities in the decision-making process.²⁸ This plan has not been fully implemented in Guainía and it seems there is no course of action for the remaining poor de-

FIGURE 11. Number of *tutela* claims relating to the right to health per 10,000 inhabitants by selected departments, 2014



Source: Defensoría del Pueblo, *La Tutela y los Derechos a la Salud y a la Seguridad Social 2014* (Bogotá: Defensoría del Pueblo, 2015).

partments. During the past two years, the CCC has exerted pressure on the government regarding the state of Chocó, one of the poorest in the country. According to the CCC, the Ministry of Health has failed to create and implement a policy plan aimed at solving the dire health situation in Chocó. The CCC argued that the government lacks an overarching policy plan to bring health care coverage to the poorest and most vulnerable regions of Colombia.²⁹

Conclusions

As some authors have argued, the legacy of Colombia's 1993 health reform can be summarized in a single phrase: "from few to many."³⁰ Undoubtedly, the rapid growth of health care coverage is one of the greatest successes of the 1991 Constitution and of Law 100 of 1993. However, the road toward universal health care coverage over the past 20 years has been uneven, especially for individuals who are formally insured but who lack material access to health care.

Although the government has implemented some policies aimed at closing the gap between formal and material health care coverage, much remains to be done. The government has to improve the mechanisms whereby UPP can be identified and studied. This identification process has to be conducted not only at the central level of government, but also at the regional level. The communication between the Ministry of Health, departments, and municipalities is key to understanding why many individuals across the country are still uninsured.

Furthermore, the government should assess the policy mechanisms to "capture" individuals who are eligible to join the subsidized or the contributive regimes but who are currently uninsured. In the case of the "sandwiched" population, the government should reevaluate, using reliable data, whether excluding SISBEN 3 individuals from the subsidized regime is a step backwards in terms of equity and the right to health.

Although the road towards material, universal health care coverage is still long and uncertain, there are indications that the government and Congress are moving in the right direction. Minister of Health Alejandro Gaviria announced major

reforms to the system in September 2012, which Congress finally enacted in 2015 (Law 1751 of 2015). One of the most significant changes wrought by Law 1751 of 2015 is the reversal of the system for identifying covered services and medications. The Law requires that, by the beginning of 2017, the government design and implement a new health benefit plan based on a negative list of non-essential medical services. In the future, all services are to be considered essential, and hence covered by the plan, unless they appear on the negative list of excluded services. Article 15 of Law 1751 establishes that the negative list should be composed of the following categories of treatments: (1) cosmetic or aesthetic, (2) experimental, (3) unregulated and (4) those provided overseas. All other treatments—that is, those not on the negative list—should be considered essential, and therefore must be provided by the government to all Colombians, irrespective of cost.

Furthermore, the CCC ruled that Law 1751 of 2015 was constitutional.³¹ The Court held that the minimum-core obligations to provide health care and protect the right to health furthered the principles defined by WHO and General Comment 14, issued in 2000 by the United Nations Committee on Economic, Social and Cultural Rights. For the CCC, the latter document has become an important source of interpretation as the Committee attempted to flesh out the 'minimum core obligations' of states with respect to the right to health under the International Covenant on Economic, Social and Cultural Rights. These are duties that "a state party cannot, under any circumstances whatsoever, justify its non-compliance."³² According to the CCC, Law 1751 places the protection of the right to health at the center of Colombia's health system.

Law 1751 and the CCC's ruling C-324 are good indicators that Colombian policymakers and judges are trying to close the gap between formal and material health care coverage. We are particularly optimistic about the convergence between the right to health and health care coverage in Law 1751. However, the challenges ahead are considerable. If the government and Congress are not able to correct the institutional and regulatory dysfunctions that have plagued the Colombian health system

since 1993, the efforts to deliver material universal health coverage will have been in vain.

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Human Rights and the Political Economy of Universal Health Care: Designing Equitable Financing

ANJA RUDIGER

Abstract

Health system financing is a critical factor in securing universal health care and achieving equity in access and payment. The human rights framework offers valuable guidance for designing a financing strategy that meets these goals. This article presents a rights-based approach to health care financing developed by the human right to health care movement in the United States. Grounded in a human rights analysis of private, market-based health insurance, advocates make the case for public financing through progressive taxation. Financing mechanisms are measured against the twin goals of guaranteeing access to care and advancing economic equity. The added focus on the redistributive potential of health care financing recasts health reform as an economic policy intervention that can help fulfill broader economic and social rights obligations. Based on a review of recent universal health care reform efforts in the state of Vermont, this article reports on a rights-based public financing plan and model, which includes a new business tax directed against wage disparities. The modeling results suggest that a health system financed through equitable taxation could produce significant redistributive effects, thus increasing economic equity while generating sufficient funds to provide comprehensive health care as a universal public good.

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Competing interests: None declared.

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Introduction

Universal health care is about more than our health—it is also a prescription for economic transformation, budget and tax reform, and public sector strengthening. It can catalyze economic redistribution in countries with fragmented market-based health systems, and resist austerity and privatization policies where universal systems already exist. If the human rights framework is to have a role in shaping this high-stakes political project, the right to health care has to be turned into a conceptual tool to guide systems change.

Health systems goals put forward at the international, national, or sub-national level are not usually measured against human rights standards, and the policy instruments that implement reforms are not assessed for their consistency with the right to health care. In policy terms, universal health care is decidedly under-defined, which opens up space for periodic re-framing efforts based on evolving political contexts and interests, as the transition from the Alma-Ata Declaration's Health For All to universal health coverage (UHC) illustrates.¹ There is a lack of rights-based policy guidance to assess this shift from “care” to “coverage” and its apparent preference for an insurance business model over public service provision. To guide debates about the political economy of universal health care and inform the design of universal systems, it is incumbent on human rights advocates to establish the right to health care as a workable policy tool and engage with policymaking beyond general statements of values or legal defenses of individual rights. Right to health advocates must be able to define both the goals of a health system and the instruments and mechanisms conducive to achieving those goals. A rights-based framework of policy-relevant principles and standards for health system design, and particularly for financing, is needed to set parameters for modeling, implementing, and improving universal health care systems.

This article presents a human rights approach to financing health care, along with the design of a financing mechanism for a sub-national universal system in the United States, including a predictive model simulating equitable revenue generation.

This work, developed—with the author's involvement—by the Vermont Workers' Center's (VWC) Healthcare Is a Human Right campaign (HCHR) between 2008 and 2015, includes a system assessment tool that evolved from a rights-based analytical framework designed to evaluate the most recent round of federal health care reform in the United States.² Although grounded in international legal human rights norms, the example presented here does not make a legal case but offers a normative policy framework, informed by economic analysis and empirical data. All tools were developed collaboratively, with community participation, to advance grassroots human rights campaigns and foster the broad movement building—the coordinated developmental process that creates, strengthens, and sustains social movement infrastructure, membership and strategy—that is required to amass the political power necessary to effect systemic transformation.

Human rights and the US health care market

Over the last decade, rights-based advocacy for universal, publicly financed health care has been gaining traction in the United States, notwithstanding the century-old resistance of industry interests and the failure of the recent federal reform, the Affordable Care Act (ACA), to challenge those interests.³ Although the ACA expanded access to the public Medicaid program, its mandate on individuals to purchase private insurance policies served to channel customers—and public subsidies—to the insurance industry, thus consolidating the private insurance market. While many health advocates responded with plans for improving the ACA, human rights campaigners pointed to the structural inequity of market-based health insurance and redoubled their organizing for a public health care system. The growing movement for the right to health care is best reflected in the Healthcare Is a Human Right Campaign Collaborative, a national movement building initiative inspired by the success of the eponymous campaign in Vermont, which became the first US state to enact a universal

health care law and attempt a transition to a publicly financed universal system.⁴

The focus on health care financing by both policy makers and campaigners has its roots in the particular nature of the US health care crisis. In the only affluent country without a universal health system, the abundance of resources invalidates any argument for a progressive realization of human rights. Health care funding is plentiful (17% GDP in 2013), yet the mechanisms for raising and allocating those funds are deeply inequitable.⁵ While total health expenditure is twice as high as in most European countries, health disparities abound and outcomes are poor, with up to 100,000 deaths annually considered amenable to health care.⁶ Financial barriers are a key predictor of poor access to and quality of health care (oftentimes correlated with structural racism) and a leading cause of debt and impoverishment. The private, market-based insurance system does not function as an effective pre-payment mechanism, even with the public subsidies introduced by the ACA. Because of substantial user fees at the point of service, insurance coverage fails to correlate sufficiently with either improved access to care or ability to pay.⁷ Low-income people with private insurance rather than public (Medicaid, Medicare, or military) not only spend more of their income on health care than the wealthy, they are also more likely to have lower value insurance plans and delay or avoid getting needed care.⁸

It follows that universal health care advocacy is centered on promoting redistributive health care financing that facilitates both universal, equitable access to care and equity in the payment for care. Advocates have turned to human rights principles to inform the analysis and development of health-related economic and fiscal policies. The right to health care has been configured as a tool for shaping decisions about equity and resource redistribution.

During the federal health reform debate, right to health advocates confronted the subjugation of health needs to market imperatives by pointing to the root causes of injustice in health care. Against the hegemony of the market paradigm with its twin

tropes of consumer choice and corporate competition, and against the thinly veiled racist denigration of public services and their users, human rights advocates envisioned health care as a public good shared equitably by all.⁹ Human rights principles inspired the development of a heterodox concept of public goods, defined as the essential goods, services, and infrastructure needed to satisfy human needs and realize human rights, in contrast to the exclusions and inequities entailed in treating health care as a market commodity.¹⁰ Grounded in the understanding that “no individual person can alone satisfy their human needs, and thus no individual can flourish and achieve their full human potential alone,” Vermont’s HCHR campaign pursued a vision of democratic communities sharing resources collectively and providing public goods to meet fundamental needs.¹¹ Whereas single payer health care advocates traditionally employed cost-savings arguments for universal health care, thus relying on the same fiscal prudence and economic efficiency frame as their private market opponents, human rights advocates emphasized the antagonism between market individualism and collective public goods. Moreover, while the mainstream debate focused on access to “coverage”, human rights advocates elevated the goal of providing “care”, replacing the insurance industry concept of risk protection with a public service model of meeting human needs.¹²

Although the passage of the ACA confirmed that federal health reform was largely a market management exercise shaped by the medical-industrial complex that stood to benefit, human rights advocates had sown the seeds for very different discussions in their own communities. The emerging HCHR movement began organizing people most impacted by health care injustice, and developed human rights tools that enabled everyone to participate in state-based health policy initiatives that followed in the wake of the ACA.

Human rights standards for health systems

To achieve emancipatory outcomes, the application of human rights to policymaking must be

grounded in an analysis of the power structures that prevent the collective realization of rights. If rights are conceived solely as legal rights conferred on individuals, they risk depoliticizing collective action and instead legitimize the state as the arbiter of rights claims. In recognition of the history of struggles that have used human rights as an emancipatory tool against the abuse of power, the HCHR movement explicitly conceives of rights as a political strategy for addressing unjust power relations. This approach couples a normative vision of an equitable society that realizes rights for all with the practical use of rights to analyze and politicize power and build people's agency and alignment. The human rights frame thus occupies the intersection between universal values and vision on one side, and particular political demands and policy prescriptions on the other. Though rights derive their strength from their universalizing gesture, their meaning is defined through an analysis of the particular conditions that perpetuate unjust power. In the quest for universal health care, rights can be marshaled both as a normative and as an analytical force to be deployed on a politically contested terrain.

Vermont's HCHR campaign initially developed normative principles—universality, equity, accountability, participation, and transparency—to guide their organizing and advocacy, before refining these into an analytical human rights tool for evaluating health reform designs, inspired by a rights-based assessment framework developed by the National Economic and Social Rights Initiative (NESRI).¹³ While these tools are anchored in international right to health norms, the dearth of existing rights-based policy perspectives on health reform prompted the development of tailor-made guidance. The necessarily general nature of international instruments (for example, General Comment 14 and reports by the Special Rapporteur on the right to health) has required advocates to add political and economic analysis, substantiated by empirical evidence, to render right to health approaches relevant to their own political contexts.¹⁴ Although the World Health Organization (WHO) has recently supported an effort to link health system design with human rights—after largely

ignoring human rights in its health financing report—its new UHC monitoring framework lacks explicit human rights references.¹⁵

When the HCHR campaign designed its analytical tool for assessing the consistency of health reform proposals with human rights norms, it had already achieved a significant win on the path to universal health care.¹⁶ In 2010, Vermont passed a law that mandated the design of three options for establishing a universal health system in the state.¹⁷ Notably, the law included the principles championed by the HCHR campaign, thereby setting a precedent for integrating human rights norms into domestic law and giving advocates an important accountability tool. This achievement signaled the campaign's early success in shifting the public discourse toward a recognition of health care as a human right and public good, and infusing state policy with rights-based language.

The HCHR campaign's assessment tool empowered its members to analyze the system design options mandated by the law and shape policy positions. Anchored by the five human rights principles and the concept of public goods, the tool contains 60 evaluation questions, grouped by principle as passed into law. These questions, with varying level of detail, cover basic right to health care norms such as equal access to care, monitoring of disparities, investments in underserved communities and primary care, as well as policy concerns that remain contentious in the US context, such as elimination of user fees, income-based financing, and full inclusion of immigrants. The tool intends to address all critical system design issues that impact the right to health care, including needs-based allocation of funds, access to all needed health services, price controls, and public administration. Assessment questions were developed based on an analysis of international norms and measured against access barriers and disparities reported in state and federal data.

By taking normative principles as its foundation, rather than the more analytical standards of General Comment 14 (accessibility, affordability, acceptability, and quality), this assessment framework serves as the missing link between general

human rights norms, which inspire vision and values, and specific policy solutions, which define and operationalize universal health care.

The tool can be adapted and applied to any health system reform effort, and it has been shared with other rights-based campaigns to support member education and policy advocacy. Its evaluation questions can be turned into implementation standards to guide the development of policy solutions. The HCHR campaign proceeded to prepare policy standards for both health benefits and financing, which ultimately enabled the campaign to design its own universal health care financing plan.

Human rights standards for equitable financing

The debate over universal health care financing raises macro-economic questions of taxation, public sector involvement, and the role of industry and employers. The Vermont example shows that the human rights framework can offer practical guidance for addressing these political economy challenges of health care reform.

The transition to universal health care in Vermont hinged on the design of an economically feasible and politically acceptable health care financing plan. In 2011, the HCHR campaign was instrumental in achieving the passage of Act 48, the country's first law for a universal, publicly financed health care system, to be established by 2017.¹⁸ While the law required health care to be financed equitably and provided to all residents as a public good, it did not specify revenue sources and instead mandated the preparation of a separate financing plan by January 2013. Health reform advocates, including the HCHR campaign, usually attempt to write at least the outline of a financing mechanism into a health reform law to achieve greater control over the transition process and prevent implementation from being mired in a revenue debate. Yet in the United States, advocates have not had sufficient power to secure the passage of a universal health care law that specified financing, and the HCHR campaign settled for the inclusion of the equity principle in the financing mandate of Act 48.

The design of a financing mechanism determines equity in access to and payment for health care. To inform the preparation of a financing plan, the HCHR campaign looked to the human rights standards in its system assessment tool and to the equity principle in Act 48. The goal was to produce actionable guidance for realizing the principle of equity in financing in a way that generated sufficient revenue for meeting all residents' health needs.

This focus on equity coincided with the Occupy movement's protests against rising inequality, which catalyzed an ongoing debate in US politics about the largest concentration of wealth since the 1930s and the greatest income inequality since the late 1970s.¹⁹ Regressive health care financing is a significant contributor to economic inequality, producing an inverse correlation between household income and household health care spending.²⁰ Conversely, a redistributive universal health care system in the United States would deliver significant financial relief to lower- and middle-income families.²¹ Providing health care as a public good could also pave the way for a broader paradigm shift toward universal public programs, replacing the threadbare safety net of means-tested benefits. Health care could function as a strategic lever for building a more equitable society through the universal provision of the goods and services needed to exercise economic and social rights. In turn, increased equity would further improve health outcomes.²² It follows that health reform goals should reflect the direct correlation between health and equity by measuring not only health but also equity indicators.

This broader equity vision characterizes the HCHR campaign's approach to financing, which aims to disrupt the vicious circle of inequity and poor health fueled by unequal access to care based on income, wealth, and employment. International health systems research confirms that commercialized health systems with significant private sector involvement both impede access to care and deepen inequities.²³ The market-based insurance system in the United States demonstrates that private pre-payment schemes are neither intended nor equipped to guarantee equity in access to and payment for care. Any redistributive potential of

pre-payment is lost when the insurance business model incentivizes access restrictions by means of cost-sharing, narrow provider networks, and prior authorization processes, and when even a slightly more progressive premium structure for low-income policyholders, as mandated by the ACA, requires the channeling of sizable public subsidies to private insurance companies.

When the HCHR campaign set out to propose rights-based financing standards, the Special Rapporteur on the right to health had just called on states to “implement a progressively structured system of general taxation to fund health” in order to comply with right to health norms.²⁴ Buoyed by this intervention and informed by research evidence of improved health and equity outcomes in health systems financed publicly through direct taxes, the HCHR campaign developed detailed implementation standards for financing health care, applying human rights norms to the US context. The campaign’s 10 financing standards, released in a report on Human Rights Day 2012, can be summarized with reference to the three principles of universality, equity, and accountability: 1) financing must be based on health needs and sufficient to meet all needs; 2) it must ensure equitable payment through progressive taxes and guarantee free access to care at the point of service; and 3) it must be public to achieve full accountability for the effective and efficient use of resources necessary to fulfill human rights.²⁵

These standards formed the basis for an analysis of state revenue sources consistent with the principle of equity. Assessing the equity impact of each revenue source and their potential to produce sufficient and stable revenue yields, the HCHR campaign’s report recommended a mix of progressive taxes on earned and unearned income, a wealth tax, and a progressive corporate tax, possibly levied on payroll but graduated by business size and wage scales.

With this report, the HCHR campaign turned general human rights norms into workable tools for revenue design, thus enabling the development of robust policy positions on health care financing. Their intervention exemplifies that human rights

advocates need not remain silent on the political economy of universal health care.

Human rights and the political economy of health care

The proactive engagement with the question of health system financing places right to health care campaigners squarely in the contested terrain of budget and revenue policies. This has long been uncharted territory for human rights advocates, despite the importance of fiscal and economic policymaking to economic and social rights issues. However, since the 2008 economic recession and with the increasing use of neoliberal austerity policies by many governments, the application of human rights standards to fiscal, monetary, and economic policies has become more widespread. Starting with human rights budget analysis to monitor states’ progress in meeting treaty obligations, human rights have now been applied to macroeconomic assessments and used by the UN High Commissioner of Human Rights to caution against austerity measures.²⁶

In Vermont, the health care financing challenge gave rise to the People’s Budget Campaign (a joint VWC-NESRI effort), which developed a human rights approach for re-envisioning budget and tax policies in preparation for shifting health care funding to the public realm.²⁷ The People’s Budget Campaign promoted human rights budgeting as a new policy paradigm that makes human needs the focus of fiscal policymaking. This entails inverting the budget process, which customarily starts with a revenue estimate and proposes spending initiatives based on available funds, thus focusing on balancing the budget with little consideration for meeting fundamental needs. By contrast, a human rights approach requires budgeting to begin with an assessment of needs, then develop a needs-based budget and mobilize the maximum amount of resources in an equitable way to meet budget obligations. Needs assessments, spending initiatives, and tax proposals have to be designed in a participatory way with guidance from human rights principles

and measured by an accountability system centered on rights-based indicators.

Universal health care, a quintessential needs-based system, entails this inversion of the budget process in order to secure equitable, sufficient, and sustainable funding. Funding has to be appropriated based on health needs and the cost of services to meet those needs. It has to be raised in a way that secures both health and financial protection, replacing employment dependent coverage or contributory schemes with a needs-based and tax-funded public service. The process of assessing needs, accountable decision-making based on the scope and depth of need, mobilizing public funds through equitable taxation, and strengthening public sector capacity, is a requisite for fulfilling economic and social rights obligations.

Promoting needs-based, equitable taxation as a rights-based instrument for achieving universal health care, especially in a context where the distribution of resources rather than their availability is at stake, opens up an economic and social rights perspective on health policy. A focus on the redistributive nature of health systems recasts health care reform as a broader economic policy intervention. It serves as a reminder that health care is one of several social and economic rights—alongside housing, food, and education, all key social determinants of health—whose realization is thwarted by the commodification of human needs and the failure to distribute resources equitably to meet those needs. This understanding is reflected in the HCHR movement’s vision of economic and social justice that reaches beyond the right to health and health care and drives a long-term movement building project. Universal health care and human rights budgeting are seen as working in concert to advance an equitable society that funds and delivers the public goods needed to fulfill economic and social rights.

The road toward realizing this vision of equity entails both successes and setbacks, even in the small state of Vermont. In 2012, only one year into the lengthy transition toward publicly financed health care, the People’s Budget Campaign won

new statutory language requiring the state budget to address needs and advance equity.²⁸ This law, another first in the Vermont “laboratory,” could have lent crucial support to universal health care financing, but effective implementation never happened. However, the principles of human rights budgeting, combined with rights-based health care financing standards, equipped advocates with a powerful toolset for developing a health care financing plan.

Rights-based modeling of health care financing

Transforming a multibillion-dollar health care market into an equitably financed public good demands a robust policy plan that can secure economic viability as well as sustain the significant political power required to achieve change. The example of Vermont affords an opportunity to assess the effectiveness of the human rights framework in informing the design of a health care financing plan that is fiscally sound, economically feasible, and meets the political goals of improved health and equity outcomes.

The six-year transition process following the 2011 passage of Vermont’s universal health care law depended on the development of a public financing plan. Yet when the state’s governor finally published a plan on December 30, 2014—missing the law’s deadline by almost two years—it was accompanied by an official statement denouncing the plan’s feasibility and withdrawing the administration’s support for universal health care.²⁹ This announcement effectively ended the state’s transition efforts, despite the legal mandate of Act 48.

The governor’s financing plan included revenue sources centered on income and payroll taxes, and cost projections that largely extended current expenditure trends forward. It offered several cost-benefit scenarios with different combinations of health benefits and tax rates. Some scenarios—including the one presented as the governor’s option—predicted the system would develop a negative fiscal position within five years of im-

plementation. This forecast served as the official justification for abandoning the transition to a universal system. Yet the plan also showed that nine out of ten families would see their incomes rise in a universal health care system, while the system overall would be less costly than a continuation of market-based health care.³⁰

Ultimately, the governor's plan lacked both financial and political viability as its tax designs failed to fully take into account individuals' and businesses' ability to pay. Disregarding the rights-based financing standards offered by the HCHR campaign in 2012, the governor's plan was not guided by the principle of equity. Instead, it proposed to cap tax payments for the wealthy and impose a flat payroll tax regardless of business size, thus disadvantaging the state's over 75% of small businesses with fewer than 10 workers.

In response to the governor's report, the HCHR campaign swiftly developed its own financing plan, aiming to demonstrate the feasibility of a universal system based on human rights principles.³¹ Although to date this plan has not revived the transition process in Vermont, the solutions it presents are instructive for rights-based efforts elsewhere, as it models ideas for implementing rights-based standards, simulates financial impact, and invites a further examination of techniques for operationalizing rights. Methodologically, this plan utilizes much of the governor's data as a baseline to enable comparability; however, new data sources were identified to develop a micro-simulation for an equitable business tax design.

Rights-based revenue sources

The HCHR campaign's financing plan uses the principle of universality to design Green Mountain Care (GMC) as a comprehensive public system providing all medically necessary health services for all residents (except those covered by federal programs), adding dental, vision, and hearing care to the governor's proposed benefits. It applies the principle of equity to determine the revenue mix, with progressive income and wealth taxes and a graduated payroll tax on businesses as the main new funding sources.

Income taxes form the backbone of the financing plan, as they did in the governor's proposal (exempting Medicare, military health care recipients, and those earning less than the Medicaid threshold of 138% of the Federal Poverty Level (FPL)). Yet while the governor's tax rate increased steeply to 9.5% for earners reaching the 400% FPL threshold, but decreased at the top end due to a cap on payments by the wealthy, the HCHR campaign redesigned this tax with a more gradual increase and no cap. As a result, 65% of lower- and middle-income residents would pay lower taxes than under the governor's proposal. The tax rate for three-quarters of families would be lower than 9%, with many paying much less. While this figure remains higher than the tax proposals offered by single payer advocates for a federal universal system, the projections show that a family with an annual income of US\$50,000 would pay an average of 40% less in health care costs than in a market-based insurance system.³² To capture unearned income and reduce wealth inequity, the HCHR campaign's tax plan includes a new wealth tax on stocks, dividends, capital gains, interest, and the trading of stocks and derivatives. The tax design augments a 5% rate with sliding scale credits up to an income threshold of US\$200,000, and an exemption for incomes under \$50,000. More than three-quarters of the revenue from this tax would come from those earning more than \$200,000.

The HCHR campaign's solution for maintaining health care payments from businesses illustrates an innovative application of the principle of equity to tax design. In the current system, employer-sponsored health insurance drives inequity, as lower-earning employees pay a greater share of income in premium contributions than higher earners, yet benefit less from tax exemptions. While employers pay the majority of premium costs, they reduce wages accordingly. A rights-based system would decouple access to care from employment, yet without foregoing businesses' contributions to the public good that protects workers' health. An equitable tax would require companies to contribute based on their ability, measured through profit or surplus revenue. Yet corporate income taxes are

levied only on a minority of businesses, loopholes are numerous, and tax avoidance is widespread.³³

This challenge pointed the HCHR campaign to a payroll tax, with its risks of disincentivizing hiring, depressing wages, and disadvantaging small businesses—the very problems that doomed the governor’s proposal of a flat 11.5% payroll tax. To design an equity mechanism for business contributions, the HCHR campaign’s plan introduces a graduated payroll tax, levied on employers only, that takes into account company size and wage disparity. Tax obligations would be lower for small businesses and for those with low wage difference between top and bottom earners, and higher for larger corporations and those with a greater top-to-bottom wage ratio.

The following design creates a tax that promotes equity based on business size and wage disparity, thereby protecting small businesses, guarding against negative wage effects, and even incentivizing wage increases for the bottom half of wage earners:

- a sliding scale tax rate capped at 20% of payroll, increasing with company size and wage ratio;
- nine size-based tax categories, from businesses with four or fewer full-time equivalent employees to more than 1,000 employees, resulting in gradually increasing tax rates by company size;
- a wage ratio formula that reflects the difference between the wages of the top 1% and the bottom 50% of wage earners in a company, resulting in higher tax rates for companies with greater wage disparity.

The principle of equity is the guiding factor for this design. Only if businesses are asked to pay based on their ability—with size and high executive salaries as proxies—and only if they are encouraged to raise rather than depress the wages of those paid the least, can a payroll tax meet both economic feasibility and rights-based criteria.

Linking public spending and revenue policies to private wage policies is not entirely novel; for example, some economic subsidy programs require businesses to offer above-minimum-wage jobs, and

advocacy is growing for “low-wage employer fees” levied on minimum-wage employers.³⁴ Yet the idea of using wage disparity, a true equity criterion, as a variable in tax design may be unprecedented.

The HCHR campaign’s wage ratio model is designed to promote income equality and prevent negative wage and hiring effects. It provides an incentive for increasing wage equity, since a company can lower its tax rate by reducing executive wages or raising workers’ wages. It prevents negative wage effects for average workers, which are commonly assumed to occur due to a transfer of tax costs onto employees. If a company seeks to pass on costs by reducing the wages of the bottom 50% of workers, its wage ratio will increase and result in a higher tax rate. The wage ratio factor thus prevents the lowering of the wages of the bottom half of workers. If a company passes the cost of taxation onto all workers (including executives) by reducing wages across the board, their tax contribution will be lowered through the decrease in payroll size, yet their tax rate stays the same. Since company size has lower weight in this model than in a size-only tax design, the wage ratio factor also helps mitigate against hiring slowdown and workforce reduction incentives produced by the size variable.

To achieve these equity effects, company-level tax rates have to be calculated according to a formula presented by the HCHR campaign’s plan. Since the modeling was limited to industry-level data, it could only approximate actual tax rates and yields, and it could not calculate compliance costs. For these reasons, the campaign recommended that the state produce a more accurate revenue projection and test compliance challenges by conducting a survey requiring all companies to submit their calculated tax rates for review prior to GMC implementation. The HCHR simulation predicts sufficient tax revenue, with 60% of companies paying an average tax rate of 4%. All companies with fewer than 50 workers—the vast majority of Vermont businesses—would pay a lower tax rate than the governor’s proposed 11.5%.

Economic feasibility, political challenges

The HCHR campaign’s plan models a publicly

financed health care system that guarantees comprehensive care for all and dramatically increases equity in access to and payment for care, compared to both the current system and the governor's model. It improves GMC's fiscal position by more than US\$200 million over the governor's projection—despite adhering to the governor's highly conservative administrative savings forecasts—and it recommends further system expansions in line with human rights principles after the first year of operation. Overall, the HCHR campaign's plan makes a strong case for the fiscal and economic viability of publicly financed universal health care and creates a rights-based tax design that advances income equality.

This financing plan was delivered to state legislators along with an open letter from over 100 economists. "As economists," the letter reads, "we understand that universal, publicly financed health care is not only economically feasible but highly preferable to a fragmented market-based insurance system. Health care is not a service that follows standard market rules; it should be provided as a public good."³⁵ A group of legislators introduced a health care financing bill in the 2015 legislative session, consisting of the tax measures proposed by the HCHR campaign to fund the universal system.³⁶ Yet the bill died in committee, and the proposals have not yet received closer scrutiny.

The setback in Vermont, which may yet prove to be temporary, reflects the political challenge of shifting an entire industry from the market to the public realm. Corporate interests have a sizable stake in maintaining the status quo, which means the political will for change must be shared widely among the population, not just vested in prominent champions. The power to achieve systemic transformation requires broad popular support, which the HCHR campaign built in its early years but struggled to sustain and grow during the lengthy transition process.

From a policy perspective, the debates in Vermont have revealed a number of challenges that advocates in the United States must be prepared to address as the struggle for universal health care continues. For example, campaigners are well-ad-

vised not to foreground the efficiency argument championed by single payer advocates, particularly for reforms at the sub-national level. Since federal health care programs cannot be readily integrated into a state-level universal system, and since smaller states have limited leverage to achieve strong price controls, high expenditure levels are likely to persist, and advocates must not undermine the willingness for public investment by focusing on hard-to-predict savings that may occur gradually over time. Equally important, advocates must be ready to explore ways for severing the link between employment and access to care, while holding businesses accountable and preventing a cost-shift to individuals. The HCHR campaign's rights-based proposals offer valuable examples for tackling such policy challenges.

Learning from Vermont

The battle over universal health care financing in Vermont offers ideas and lessons for rights-based advocacy elsewhere. It exemplifies how human rights can shape both the process of moving toward universal health care and the content of system design and financing. Moreover, it brings into focus the range of policy and political obstacles, the specific power relations producing these obstacles, and the systemic factors contributing to human rights denials.

Anchored in local movement building efforts, the momentum for state-level universal health care reform in the United States continues to grow. Prior to the passage of the ACA, health reforms in a number of states created an impetus for federal legislation, and a domino effect of state-based universal health care initiatives could well catalyze the next federal reform wave. Universal health care campaigns in several states, including Oregon, New York, and Colorado, have put forward financing studies, proposals, and bills, influenced by the movement building in Vermont. Learning from Vermont could inspire a principled advocacy approach, combined with mass organizing, that tackles political resistance through rights-based redistribution models rather than efficiency estimates, and that shifts from a health insurance focus to a

broader lens of public goods. This is the approach adopted by the Healthcare Is a Human Right Campaign Collaborative (currently consisting of groups in Maine, Maryland, and Pennsylvania, in addition to Vermont), which pursues a long-term organizing strategy that links the struggle for universal health care to a transformative agenda for economic and social rights.³⁷

The Vermont experience shows the value of using human rights both as a normative frame for organizing and campaigning, and as an analytical toolset for identifying the barriers to realizing rights and providing policy solutions. Human rights advocates cannot afford to stand on the sidelines of the political economy debates over universal health care. The human rights framework can help determine the factors that continue to thwart the realization of universality and equity, develop policy strategies for health care financing, and strengthen universal health care advocacy by connecting it to rights-based visions for public goods and economic equity.

Acknowledgments

The author would like to thank David Kreindler, based in Hardwick, Vermont, for his assistance in preparing this paper and, more importantly, for supporting Vermont's Healthcare Is a Human Campaign in developing many of the ideas presented here.

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Assessing Private Sector Involvement in Health Care and Universal Health Coverage in Light of the Right to Health

ANTENOR HALLO DE WOLF AND BRIGIT TOEBES

Abstract

The goal of universal health coverage is to “ensure that all people obtain the health services they need without suffering financial hardship when paying for them.” There are many connections between this goal and the state’s legal obligation to realize the human right to health. In the context of this goal, it is important to assess private actors’ involvement in the health sector. For example, private actors may not always have the incentives to deal with externalities that affect the availability, accessibility, acceptability, and quality of health care services; they may not be in a position to provide “public goods”; or they may operate under imperfect information. This paper sets out to answer the question, what legal human rights obligations do states have in terms of regulating private sector involvement in health care?

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Competing interests: None declared.

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Introduction

There are many connections between the goal of universal health coverage (UHC) and the state's legal obligation to realize the human right to the highest attainable standard of health. The right-to-health framework provides a set of legally binding standards directing the state to ensure the availability, accessibility, acceptability, and quality of all health-related services for everyone residing on its territory.¹

This article focuses on the role of the private sector in the direct provision of health care, the supply of health care-related goods, and health care financing. Private sector involvement in the provision of health care encompasses a complex range of activities carried out by various non-state actors. These actors may include (multi)national companies, nongovernmental organizations, and nonprofit entities. It is important to address private actors' involvement in light of the aim to achieve UHC. For example, private actors may not always have the incentives to deal with externalities that affect the availability, accessibility, acceptability, and quality (AAAQ) of health care services; they may not be in a position to provide "public goods"; or they may operate under imperfect information. In this article, we take a neutral approach toward this phenomenon, meaning that we assume that private sector involvement is a reality that needs to be addressed as appropriately as possible.

Drawing on existing research and evidence, we first discuss some facts and trends regarding the role of private actors in the health sector. Subsequently, we explore the normative overlaps between UHC and the right to health. We then address the tripartite relationship between UHC, private sector involvement, and the right to health. We explain that based on international human rights law, states are free to choose any mix of public and private involvement in the health sector. Nonetheless, they have a legal "obligation to protect," based on which they must protect individuals from harmful actions by non-state actors, including those in the health sector. This undertaking results in both substantive and procedural obligations for states, and

it embraces the state's duty to ensure the AAAQ criteria, regardless of whether health care services are publicly or privately provided. In relation to all of the above, we stress the importance of effective monitoring, accountability, and participatory mechanisms.

We identify a human rights impact assessment of the consequences of the (further) involvement of private actors in the health sector. While most obligations identified in this article fall on states, there are also several tentative and progressive obligations for non-state actors in the health sector. However, given that such actors do not have formal legal obligations (for human rights treaties such as the International Covenant on Economic, Social and Cultural Rights are aimed at states), an exploration of these potential obligations falls outside of the scope of this article.

Private sector involvement: Definition, trends, and challenges

Definition

Private sector participation in health care is not a new phenomenon. To the contrary, public and governmental concern in health care appears to have come to the fore only relatively recently.² This is certainly the case with respect to health care financing.³ The involvement of private actors in the provision of health care—whether as direct providers of services (e.g., physicians, pharmacies, and hospitals) or as the providers or manufacturers of materials and technologies used in health care provision—has a long history.

There is no concrete legal definition of private sector participation, and it appears that related concepts, such as public-private partnerships and privatization, are used inconsistently.⁴ It is therefore somewhat challenging to precisely *define* private sector involvement in health care. Given that it is not a passive concept but an actual state of affairs, it seems more reasonable to describe what private sector participation in health care may *entail*. Such involvement encompasses participation in the health care sector and would thus cover a

complex range of activities performed by various types of non-state actors in the health sector.⁵ These actors include (multi)national corporations, non-governmental organizations, private institutions (including charitable bodies and other nonprofit entities), and private individuals, such as general practitioners and consultants. Their roles and activities may include the direct provision of health care, the management of health care institutions, the manufacturing of health care goods and services (e.g., medicines, pharmaceutical products, and rehabilitation), and the financing of health care products and services. These roles and activities may also be carried out within a publicly run health care system. This is the case in the United Kingdom, where private actors have a role in nursing homes for persons with disabilities under the National Health System.⁶ They may also take place through public-private partnerships, or in privatized contexts (as discussed below).⁷

Given the multitude of potential roles and players in the health care sector, this article will focus on only a few of them—the ones we consider to pose relevant challenges with respect to the realization and implementation of the right to health. Thus, our focus will be on the role of (multi)national companies, nongovernmental organizations, and nonprofit entities involved in the direct provision of health care, the supply of health care related goods, and health care financing (see Table 1). These roles may be the result of historical developments (e.g., private actors already operating in health care provision prior to the introduction of a public health care system), privatization, or an increased reliance on public-private relationships. Here it is also important to acknowledge the role of nongovernmental organizations, such as *Médecins Sans Frontières* and religious organizations, in providing health care services within the development or humanitarian contexts in situations in which states are incapable of or unwilling to provide those services. Due to space constraints, however, we will not discuss those contexts here.

For this article, we consider privatization to entail the transfer of the direct provision of health

care services or health care financing from public authorities to private actors. This description is based on the definition of privatization provided by the Committee of Ministers of the Council of Europe, which defines it as

*i. the total or partial transfer from public ownership or control of a public undertaking so that it ceases to be a public undertaking; ii. the transfer to a private person of an activity previously carried on by a public undertaking or public authority, whether or not accompanied by a transfer of property.*⁸

There are mixed experiences with privatization from the perspective of the realization of the right to health. In the Netherlands, where a single compulsory health insurance scheme has replaced the dual system of public and private insurance, the now private health insurance companies are obligated to accept every resident in their area of activity and to provide a basic health insurance package that has been designed by the government.⁹ While this transition has been moderately positive, in other countries the experience is less so. China, for example, has had to overcome difficulties as a result of its transition to a market economy. In 1984, it reduced the government's role in the health sector, which caused many health care professionals to lose their public subsidies, while the government exerted little control over the behavior of health care organizations.¹⁰ Many health care workers became "private entrepreneurs," and the vast majority of the population remained uninsured. Because of these problems, in 2009 the government decided to abandon a market-led health care system and launched a new round of health care reform.¹¹ By 2011, a government-subsidized insurance system provided modest health coverage to 95% of the population, and an effort to create a primary care system was introduced.¹²

Public-private partnerships in health care, which are distinct from privatization, are another way in which private sector participation can take place. As with privatization, there is no single legal definition of public-private partnerships. The World Health Organization (WHO) and its Legal Counsel

describe these partnerships as covering a “wide variety of ventures involving a diversity of arrangements, varying with regard to participants, legal status, governance, management, policy-setting prerogatives, contributions, and operational roles.”²³

Trends and challenges

Given that private sector participation in health care takes many shapes and involves various kinds of actors, the academic literature on the subject is not conclusive as to whether this participation has a positive or negative impact.¹⁴ There seems to be an increasing reliance on private actors to provide, finance, and supply health care goods and services. In Africa, for example, the International Finance Corporation has found that “the private sector already delivers about half of Africa’s health products and services.”¹⁵ There are various reasons for this: the perceived lack of efficiency and quality in the provision of public health care, increased costs and reduced budgets for health care due to the 2007–2008 financial crisis, and encouragement by international financial institutions to rely on private actors to decrease the burden on national budgets.¹⁶

Some recent studies suggest positive outcomes in terms of private sector participation. For example, with respect to access to health care facilities for childbirth and the treatment of acute respiratory illness, private sector participation in a number of sub-Saharan African countries appears to have led to improved performance in terms of access and equity.¹⁷ However, that particular study notes that its findings were limited since it was unable to measure two very relevant aspects related to health care and the right to health: how much did individuals have to pay to access these facilities, and what was the quality of the care provided?¹⁸ Other studies are more cautious and cannot find overwhelming evidence in favor of or against increased private sector participation.¹⁹ Nonetheless, in health care,²⁰ there is no consistent manner for measuring the contribution of private actors. In some cases, private sector participation has led to increased costs for patients—for example, through higher out-of-pocket expenses when governments do not cover

these costs through subsidies or taxes, or through public insurance coverage—and not necessarily to a more efficient provision of health care.²¹ Weak regulatory frameworks appear to be an important problem in this regard.²²

In terms of the private sector’s involvement in promoting UHC, there is a lot of discussion on what precisely this sector can contribute, given the varying functions it can perform.²³ On the one hand, we should recognize that the private sector may be better placed than the government to deliver certain services and that it is able to make a contribution to health financing. On the other, there is an urgency to uphold the state’s ultimate responsibility for the health of its citizens. Our human rights analysis below offers some suggestions in this regard.

Conceptual overlap between universal health coverage and the right to health

The goal of UHC is to “ensure that all people obtain the health services they need without suffering financial hardship when paying for them.”²⁴ According to WHO, UHC is a “practical expression of the concern for health equity and the right to health.”²⁵ This leads us to ask how UHC and the right to health are connected. An identification of the various components of UHC, on the one hand, and the right-to-health framework, on the other, reveals many dense connections between the two.²⁶ For example, while affordability is a key component of the right to health, it also underpins UHC.²⁷ In addition, the inclusion of a specific target related to UHC in the Sustainable Development Goals, which emphasizes the provision of quality UHC that is also financially accessible, reinforces the link between UHC and the right to health.²⁸ Table 2 maps a number of key components of UHC and shows their connection to the right-to-health framework.

Private sector involvement and the right to health

The state’s “obligation to protect” and the AAAQ

Based on the right to health as framed under international and domestic law, states are obliged to

ensure timely access to good-quality care for their residents.³⁰ Governments, as the primary duty bearers, have a responsibility to ensure that health care services (even if privately provided) are available, accessible, acceptable, and of good quality. They must ensure that mechanisms are in place for patients to seek legal redress if they have received inadequate or untimely care. These obligations do not necessarily mean that the state must be the actual provider of health care or that it must maintain a public health system. General Comment No.

3 of the United Nations Committee on Economic, Social and Cultural Rights, adopted in 1990, states that “the undertaking ‘to take steps ... by all appropriate means including particularly the adoption of legislative measures’ *neither requires nor precludes any particular form of government or economic system*” (emphasis added).³¹ And it concludes that “*the Covenant is neutral* and ... the rights recognized in the Covenant are susceptible of realization within the context of a *wide variety of economic and political systems*” (emphasis added).³² This indicates

TABLE 1. Forms of private sector involvement

Type of involvement	Actors
Payers or financers	Private health insurance companies Charities
Providers	Private hospitals and clinics Private doctors and nurses Civil society organizations Charities
Suppliers	Pharmaceutical companies Suppliers of medical equipment

TABLE 2. Normative overlaps between universal health coverage and the right to health

Universal health coverage: Factors that must be in place ²⁹	Obligations of the right to health (General Comment No. 14)
A strong, efficient, well-run health system that meets priority health needs through people-centered integrated care, implying the following:	Adoption and implementation of a national public health strategy and plan of action as a core obligation (General Comment No. 14, para. 43(f))
Informing and encouraging people to stay healthy and prevent illness	Information accessibility (General Comment No. 14, para. 12)
Detecting health conditions early	Prevention (International Covenant on Economic, Social and Cultural Rights, arts. 12(2)(b) and (c))
Having the capacity to treat disease	Treatment (International Covenant on Economic, Social and Cultural Rights, arts. 12(2)(c) and (d))
Helping patients with rehabilitation	
A system for financing health services so people do not suffer financial hardship when using them	Affordability (“financial accessibility”) (General Comment No. 14, para. 12)
Access to essential medicines and technologies to diagnose and treat medical problems	Access to essential medicines as a core obligation (General Comment No. 14, para. 43)
A sufficient capacity of well-trained, motivated health workers who can provide the services based on the best available evidence	Training of health personnel as a core obligation (General Comment No. 14, para. 44(e))
Coverage of all components of the health system: service delivery systems, workforce, facilities and communication networks, technologies, information systems, quality assurance mechanisms, governance, and legislation	Availability, accessibility, and high quality of health services (General Comment No. 14, para. 12)
A progressive expansion of coverage of health services and financial risk protection as more resources become available	Progressive realization (International Covenant on Economic, Social and Cultural Rights, art. 2(1); General Comment No. 3)
Not necessarily free coverage for all possible health interventions	The right to health is “not a right to be healthy” (General Comment No. 14, para. 8); affordability means making health services financially accessible, not free of charge (General Comment No. 14, para. 12)
Steps toward equity, development priorities, social inclusion, and cohesion	Importance of the underlying determinants of health (General Comment No. 14, para. 4)

that based on the right-to-health framework, governments are free to choose any mix of public and private involvement in the health sector that they consider suitable.

According to the World Bank's 2004 *World Development Report*, governments may not necessarily play the role of direct provider of health care services; however, the possibility of market failure calls for governments to play a role in financing, regulation, and information dissemination.³³ In this light, it is necessary to identify the most relevant legal obligations pertaining to the right to health as they relate to the involvement of the private sector. These obligations apply to states regardless of the type or organization of their health care system, and they mean that states must ensure that all actors in the health sector, whether public or private, respect the right to health.³⁴

Human rights treaties impose three levels of legal obligations on states: the obligations to *respect*, to *protect*, and to *fulfill*. The obligation to respect requires states to refrain from interfering directly or indirectly with the enjoyment of the right to health; the obligation to protect requires states to take measures that prevent third parties from interfering with guarantees under the right to health; and the obligation to fulfill requires states to adopt appropriate measures toward the full realization of the right to health.³⁵ The obligation to *protect* is of particular significance in this context since it requires active monitoring of the activities of third parties. When certain services fall into private hands, there is a shift from the state "respecting" and "fulfilling" the right to a state's obligation to "protect."³⁶ The state is no longer the provider of the service, but now needs to oversee third parties to ensure that they provide this service in an adequate fashion in conformity with the AAAQ framework.

The obligation to protect has also been emphasized by international courts. For example, the Inter-American Court of Human Rights singled it out in *Ximenes-Lopes v. Brazil*, which concerned the regulation of a private psychiatric clinic in Brazil that participated in the public health scheme set up by the government.³⁷ The court asserted that under the American Convention on Human Rights,

international liability comprises acts performed by private entities acting in a state capacity. In this context, the court referred to the Brazilian Constitution, which recognizes that health care is open to private actors but also identifies the state's duty to regulate, supervise, and control health programs and services, whether carried out directly or through third parties.³⁸ The court found that

*States must regulate and supervise all activities related to the health care given to the individuals under the jurisdiction thereof, as a special duty to protect life and personal integrity, regardless of the public or private nature of the entity giving such health care.*³⁹ (emphasis added)

The obligation to protect falls into a number of interlinked duties on the part of the state.⁴⁰ It entails four key components: the obligation to *regulate* all actors in the health sector through the adoption of legislation, regulations, and policies; the obligation to *monitor*, through independent mechanisms, the behavior of these actors; the obligation to ensure that there is *accountability* for violations committed by public and private actors; and the obligation to ensure the population's *participation* in health care decision-making.⁴¹

As observed above, the state's obligation to protect is closely connected to regulation and the AAAQ criteria. As stated in General Comment No. 14, this obligation requires the state to guarantee that private actor involvement in the health sector (referred to as "privatization") does not negatively affect the AAAQ:

*[T]o ensure that privatization of the health sector does not constitute a threat to the availability, accessibility, acceptability and quality of health facilities, goods and services ... States should also ensure that third parties do not limit people's access to health-related information and services.*⁴²

When it comes to private actor involvement, the question must be addressed whether this involvement negatively affects enjoyment of the AAAQ. For example, in terms of geographic accessibility, the operation of private hospitals should not mean

that health services are available only in affluent areas. Table 3 defines a set of questions that can be asked when determining how private actors might be affecting the AAAQ criteria (which also apply to all public actors in the health sector):

Regulation of the private sector as an element of the obligation to protect

As mentioned, regulation is a key tool for dealing with the conduct of actors operating in the health care arena, and it may take various forms, depending on the desired goals.⁴³ One author's definition of regulation, which we like due to its resemblance to what the obligation to protect requires in the context of UHC, describes it as "the sustained and focused attempt to alter the behavior of others according to defined standards or purposes with the intention of producing a broadly identified outcome or outcomes, which may involve mechanisms of standard-setting, information gathering and behavior modification."⁴⁴ According to the literature on the subject, many of the rationales for regulation can be ascribed to instances of "market failure"⁴⁵—that is, situations in which "[m]arket imperfections make it impossible for market forces to achieve an efficient

allocation of resources."⁴⁶ Since regulation is adopted for various reasons, including compensating for market failure, for the purposes of this article, we will briefly mention two general types of regulation: economic regulation and social regulation.⁴⁷ Economic regulation deals with the regulation of monopoly and competition. Social regulation, on the other hand, is concerned with the promotion of social objectives. Christopher Foster provides some examples of objectives that may be served by social regulation, including achieving fairness between various interest groups, redistributing income, and providing a service deemed important by the government, such as health care.⁴⁸ For our purposes, it is precisely social regulation that may be of interest in relation to the human rights obligation to protect in the context of health care.

As stated in the definition above, regulation encompasses a "sustained and focused attempt to alter the behavior of others." Arguably, a proper realization of the obligation to protect also requires a sustained effort by the state to alter or guide the behavior of private entities involved in the health care sector in order to protect human rights, which is one of the main outcomes of social regulation.

TABLE 3. The AAAQ and the role of the private sector in health care

Availability	
Is the availability of goods, services, and personnel ensured in the health system, despite the involvement of private actors?	
Accessibility	
Non-discrimination	Are sufficient health services available to secure the needs of vulnerable populations? Do private actors provide the services in such a manner that they are equally accessible, taking into account the needs of vulnerable populations?
Physical accessibility	Does the involvement of private actors affect the geographic accessibility of health care services?
Affordability	Does private sector involvement make the health care more expensive, either when paid with public funding or by citizens? Does private sector involvement lead to increased out-of-pocket expenditures?
Informational accessibility	Does private actor involvement affect patients' ability to make informed choices? Are patients sufficiently informed about the quality and conditions of their private care?
Acceptability	
Is the private care respectful of medical ethics and culturally appropriate (respectful of the cultures of individuals, minorities, peoples, and communities)?	
Is the private care sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned?	
Does the private health insurance accept all patients, or does it select them on the basis of their health or financial status?	
Quality	
Do private health facilities guarantee a certain quality of care?	
Do practitioners who work in private health clinics receive proper training?	

This requires the fulfillment of certain substantive, institutional, and procedural elements to make social regulation usable as a tool for the implementation of the right to health.⁴⁹

Substantive elements of regulation

Regulatory measures that aim to steer or alter the behavior of private actors operating in this sector should embody the AAAQ framework (see Table 3 above). Thus, with respect to availability, if the state is going to increasingly rely on private actors to provide health care services, regulations should ensure that there are sufficient numbers of providers in the geographical areas where they operate. Regulations should also ensure that private actors do not retreat from particular areas just because they are not, or no longer, financially rewarding.

With regard to accessibility, regulations must guarantee non-discriminating access to private health care facilities. They must further ensure that health care is physically accessible—in other words, that health care facilities are within safe physical reach for all sections of the population. Financial accessibility is also a matter that should be subjected to regulation—for example (and this is related to the issue of financing), by ensuring that private insurance companies offer affordable policies or by providing subsidies to people who would otherwise be unable to obtain indispensable treatment that may be offered by private clinics. When it comes to substantive regulation of the private health insurance market, for example, Neelam Sekhri et al. mention the need for a robust regulatory framework, especially in developing countries where private coverage may be the only form of financial protection available to the population.⁵⁰ The authors refer to some countries' practice of conscripting private insurance to serve the public goal of equitable access.⁵¹ However, they also stress that regulation should not be so restrictive that it "strangle[s] the market."⁵²

Substantive regulation also plays a role in securing the acceptability and quality of health care services provided by private actors. Regulations dealing with medical ethics should be present for both private and public health care providers. Regu-

lations should also require private actors to provide services that are mindful of the different cultures of their patients. National regulatory measures must also aim to ensure that private and public health care providers alike abide by the necessary quality requirements and that their personnel have the required training and certificates.

Arguably, these concerns about substantive regulation also apply to nonprofit organizations. Nongovernmental organizations have increasingly been involved in the delivery of health care, especially in developing countries. Lucy Gilson et al. argue that there should be a strong government presence in coordinating and regulating health care provision by these actors.⁵³

Institutional and procedural elements of regulation

Institutional and procedural regulation entail regulatory bodies and procedural rules that allow the state to control and monitor the activities of private actors in the health care sector, thus helping it alter their conduct. This type of regulation requires the establishment of independent regulatory bodies and a venue where those affected by the conduct of health care providers can seek redress.⁵⁴ The latter usually includes courts of law, where victims can bring claims against the providers. Given that human rights obligations, as they currently stand, do not directly apply to non-state actors, having an effective avenue for seeking redress for the harmful effects of conduct committed by private entities is of great importance.

Insofar as these regulatory efforts relate to the provision and financing of health care, as well as the manufacturing of health care goods, they must strike a balance between, on the one hand, ensuring the economic efficiency of services and the production of these goods and, on the other, ensuring the protection of the right to health.⁵⁵ A World Bank study has identified a number of institutional criteria based on the findings of several studies in order to assess the effectiveness of regulation and regulators for privatized infrastructure and essential services.⁵⁶ Arguably, the same approach can be used for the institutional and procedural regulation

of private sector participation in health care. First, regulation must be coherent, entailing agreement between the different laws guiding regulation and the elimination of inconsistencies. Coherence with regard to regulators aims at ensuring that the latter have clearly defined responsibilities, and it should require them to publish their goals and reasons for adopting decisions.

Second, effective institutional and procedural regulation requires the regulatory body to be free from political influence; this can be achieved, for example, by establishing a statutory basis for the regulator, free from any ministerial control. It also requires the appointment of regulatory bodies on the basis of professional criteria through open processes involving the participation of key stakeholders, such as health care consumers and patients. Additionally, in order to maintain a regulatory body's independence, the central government should not be able to easily overturn its decisions. Equally, private sector entities involved should not be able to influence the regulator or its decisions. Third, the regulator must be accountable. Stakeholders should be able to question the reasoning behind the regulator's decisions, and the latter should be subject to review by courts and other independent, nonpolitical bodies. Inspiration for the creation of independent regulatory bodies in the health care sector could be drawn from the Paris Principles on national human rights institutions.⁵⁷

Obliging the regulator to publish an annual report documenting its activities can also contribute to its accountability, help monitor its efficiency, and guard against corruption. Fourth, transparency is essential for the effective work of the regulator. Its regulatory rules and decisions need to be made public and accessible to all actors with a vested interest: health care providers, financiers, the producers of health care goods, and patients. Fifth, the regulator needs to be predictable. This means following the rule of law and basing its decisions on durable rules and procedures. Finally, the regulatory body should be endowed with sufficient financial resources, and its personnel must have relevant expertise.⁵⁸ Having stated this, it is important to recognize the difficulties in establishing a proper

regulatory framework in practice. Low-income countries with varying degrees of development and respect for the rule of law may face challenges in coming up with proper independent and effective regulatory bodies and procedural regulations. The following section dedicates more attention to the operationalization of such regulation.

Operationalizing the obligation to protect through monitoring, accountability, and participation

Monitoring, which is closely connected to institutional regulation and accountability, means consistently analyzing and overseeing the process of realizing health-related rights. Monitoring can be done both by the state (through independent regulatory bodies and health care inspectorates) and by civil society organizations. The aim of monitoring is to obtain the information that governments need to track their progress toward health-related targets. Quite often, governments and civil society organizations use indicators to measure this progress.⁵⁹

Given the connection between monitoring and institutional regulation, some observations and developments are worth mentioning. A recent trend under international human rights law involves the creation of mandatory national bodies designed to monitor the implementation of human rights treaty obligations. One example includes the national preventive mechanisms (NPMs) that states must establish under the Optional Protocol to the Convention against Torture. These mechanisms are charged with conducting inspections of detention facilities, including psychiatric institutions and hospital wards in which persons are deprived of their liberty. Another example can be seen in the national framework mechanisms that states have to establish under the Convention on the Rights of Persons with Disabilities, which are of great interest to our discussion: states must maintain, strengthen, designate, or establish "a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation" of the disabilities convention.⁶⁰ These bodies, whether already existing or newly created, are charged with monitoring how states abide by their

obligations under this treaty. Arguably, they can fulfill a role in monitoring the conduct of private sector participants in health care.

Again, it is important to acknowledge the difficulty of guaranteeing independent, transparent, and effective regulatory bodies, particularly in low-income countries. At the same time, there are ways to strengthen and improve states' institutional frameworks to face these challenges. For example, the United Nations Subcommittee on the Prevention of Torture, the international supervisory body established under the Optional Protocol to the Convention against Torture to complement the work of the NPMs, has taken upon itself to help improve NPMs' mandates, working methods, and awareness of the importance of independence and transparency by offering consultations, cooperation, and advice.⁶¹

Accountability has also been described as "the process which requires government to show, explain and justify how it has discharged its obligations regarding the right to the highest attainable standard of health."⁶² While the accountability process, to some extent, is about monitoring and evaluating the state's own actions, the responsibility to provide health care is partly in the hands of other actors, such as private health care providers, private insurance companies, and pharmaceutical companies. In such cases, the state must oversee

the actions of these actors. Given the complexity of health systems, a wide variety of accountability mechanisms is required to ensure that the right to health is properly overseen. Based on a comprehensive overview by Potts, Table 4 distinguishes between five different accountability mechanisms and provides examples of ones that can be adopted for ensuring health sector accountability.⁶³

The state's obligations to protect and fulfill in relation to public and private health care financing

As observed above, the private sector can also play an important role with respect to the financing of health care. According to a WHO study, financing plays a threefold role: (i) raising the required resources for health and health care, (ii) removing financial barriers to health care and minimizing the financial risks implied by illness, and (iii) making better use of resources.⁷² Although the financing of health care takes place primarily through taxation, private actors also have a role to play. For example, with regard to the first task, private companies or charities can provide financial support to help run the health care system. With respect to the second, private insurance companies can be engaged by the state to facilitate or complement existing public insurance systems. At the same time, however, they

TABLE 4. Five types of accountability

Nature	Type	Examples
Judicial	Judicial review by domestic and international courts, constitutional redress, public interest litigation	Ximena Lopez v. Brazil, a case before the Inter-American Court of Human Rights concerning the regulation of private actors The Treatment Action Campaign case and other right-to-health case law from the South African Constitutional Court ⁶⁴
Quasi-judicial	Hospital complaint boards, national human rights institutions, national ombudsmen, regional and international human rights treaty bodies	Alyne da Silva Pimentel v. Brazil, a case before the CEDAW Committee concerning discrimination against women ⁶⁵ A public inquiry on reproductive health violations initiated by the Kenya National Commission on Human Rights ⁶⁶ ERRC v. Bulgaria and other case law from the European Committee of Social Rights of the Council of Europe concerning the right to the protection of health in the (Revised) European Social Charter ⁶⁷
Administrative	Human rights impact assessment by a governmental or independent body	Equality and human rights impact assessment carried out by Aberdeen City Council ⁶⁸
Political	Parliamentary committee review of budgetary allocations, health councils and committees	Australia's Human Rights (Parliamentary Scrutiny) Act 2011 ⁶⁹
Social	Domestic and international nongovernmental organizations, the media, public hearings, social audits	Social audits in Andhra Pradesh, India ⁷⁰ Inclusive public participation in China's new health care reform ⁷¹

could also be an obstacle to this aim if, for example, their insurance premiums are far above what low-income families can afford or if their coverage is insufficient for reducing the financial burdens incurred by persons using the insurance. Here, the obligation to protect plays an important role through the duty to regulate the conduct of private actors involved in or hindering the proper financing of health care systems.

While our focus is on the state's duty to regulate private actors in the health sector, closely related to this is governments' responsibility to secure sufficient (public) funding in order to remove financial risks and barriers to access.⁷³ Financing is also arguably an element of the state's positive obligation to fulfill in terms of a duty to facilitate the enjoyment of the right to health. The obligation to fulfill is further operationalized when governmental financing is used to directly aid individuals who are unable to enjoy the right themselves due to economic circumstances. Here, for example, one of the state's roles is to minimize high out-of-pocket payments to public and private providers (which are regarded as an important reason for the lack of proper access to health care) by establishing pre-paid and pooling systems of financing.⁷⁴ This would also enhance UHC, which, according to WHO, is most closely achieved through "current pooled funds."⁷⁵ Of course, this may depend on an efficient taxation system that helps bolster public finances to feed these funds. A failure to provide adequate financing to health care would imply a violation of the right to health under the International Covenant on Economic, Social and Cultural Rights.

A right-to-health impact assessment for private sector involvement in the health sector

How can the state ensure that private actors in the health sector take the AAAQ framework into account? Several authors have suggested that states should conduct human rights impact assessments prior to the introduction of private sector involvement.⁷⁶ These assessments enable states and international and national organizations to assess

the possible human rights implications of a certain policy, trend, or development. They are increasingly being used in the context of privatization, new business plans, and trade agreements.⁷⁷ For example, Paul Hunt, the former United Nations Special Rapporteur on the right to health, has suggested undertaking a human rights impact assessment of trade-related policies. He argues that such assessments should be conducted at both the international and national level.⁷⁸ With regard to health care privatization, he notes that it "should be preceded by an independent, objective and publicly available assessment of the impact on the respective right."⁷⁹

Drawing from Simon Walker's study on human rights impact assessments for trade agreements, which in turn is partially inspired by Hunt's work, we recommend the following steps in order to assess the impact of private sector involvement on the right to health in a given country:⁸⁰

- *Step 1* – Identify the relevant legal, economic, social, and regulatory contexts with regard to the right to health; identify the people who will most likely be affected by private sector involvement in health care provision, health care financing, or UHC (e.g., patients in general, vulnerable groups, doctors, medical researchers, providers of ambulance services); and inventory the available goods and services within the health system, including those provided by the private sector.
- *Step 2* – Narrow down the various manifestations of private sector involvement in health care and UHC that could have the most significant impact on the enjoyment of the right to health care in terms of availability, accessibility, acceptability, and quality.
- *Step 3* – Determine the scope of the assessment by identifying different/future scenarios of private sector participation in the measures to be assessed, and identify the relevant indicators and stakeholders to be consulted.⁸¹ In the context of low-income countries, seek international assistance to address the scope of the assessment and the identification of indicators and stakeholders to be consulted.

- *Step 4* – Collect and analyze data to verify the potential impact of private sector involvement in health care and UHC; evaluate the results and determine which of the already identified stakeholders are the most likely to be affected by it; determine whether the accessibility of health care is compromised (Does private sector involvement private sector involvement result in discrimination? Do they maintain a certain affordability in health care?).
- *Step 5* – Recommend measures that would lead to or enhance the positive impacts of private sector participation, as well as measures to reduce, ameliorate, or eliminate negative impacts, taking care to consider the acceptability and quality elements of the AAAQ framework.
- *Step 6* – Evaluate the general assessment to see if the objectives of the assessment have been met and to examine the extent to which the stakeholders have been consulted. According to Walker,⁸² at this stage, a monitoring plan should be adopted in consultation with those stakeholders to keep an eye on actual impacts once the measures regarding private sector involvement in health care, financing, and UHC have been adopted. Arguably, this monitoring plan should consider the AAAQ framework.
- *Step 7* – Compile and adopt a report of the assessment that includes an overview of the preceding steps.

Conclusion

The aim of UHC—which is closely connected to the right to health—is for everyone to have access to a full range of good-quality and affordable health services. Countries around the globe have had mixed experiences with regard to private actor involvement in the health sector. The consequences of such involvement should be monitored very carefully.

Human rights law does not interfere with the state's choice of its health care system—that is, whether it is public, private, or mixed. However, it provides an authoritative set of legal tools for assess-

ing the consequences of private sector involvement. Based on human rights law, governments have an obligation “to protect” the right to health. This means a duty to adopt regulations and other measures to regulate all actors in the health sector. Such regulation should reflect the state's duty to ensure that health services are available, accessible, acceptable, and of good quality. As we have suggested in this article, governments can be encouraged to conduct human rights impact assessments to assess the consequences of privatization prior to its introduction. We have also briefly asserted that states' duty to fulfill entails, among other things, an obligation to secure the financing of their health system, such as through taxation and in collaboration with the private sector.

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Case Study of an Aboriginal Community-Controlled Health Service in Australia: Universal, Rights-Based, Publicly Funded Comprehensive Primary Health Care in Action

TOBY FREEMAN, FRAN BAUM, ANGELA LAWLESS, RONALD LABONTÉ, DAVID SANDERS, JOHN BOFFA, TAHNIA EDWARDS, AND SARA JAVANPARAST

Abstract

Universal health coverage provides a framework to achieve health services coverage but does not articulate the model of care desired. Comprehensive primary health care includes promotive, preventive, curative, and rehabilitative interventions and health equity and health as a human right as central goals. In Australia, Aboriginal community-controlled health services have pioneered comprehensive primary health care since their inception in the early 1970s. Our five-year project on comprehensive primary health care in Australia partnered with six services, including one Aboriginal community-controlled health service, the Central Australian Aboriginal Congress. Our findings revealed more impressive outcomes in several areas—multidisciplinary work, community participation, cultural respect and accessibility strategies, preventive and promotive work, and advocacy and intersectoral collaboration on social determinants of health—at the Aboriginal community-controlled health service compared to the other participating South Australian services (state-managed and nongovernmental ones). Because of these strengths, the Central Australian Aboriginal Congress's community-controlled model of comprehensive primary health care deserves attention as a promising form of implementation of universal health coverage by articulating a model of care based on health as a human right that pursues the goal of health equity.

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Competing interests: None declared.

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Introduction

Universal health coverage (UHC) is “access to key promotive, preventive, curative and rehabilitative health interventions for all at an affordable cost.”¹ UHC is seen as critical to the health and well-being of populations, and a contributor to reducing poverty.² Achieving UHC is one of the Sustainable Development Goals in the 2030 Agenda for Sustainable Development.³ However, UHC is but one part of the conception of health as a human right, which also strives for equity in the social determinants of health and in health outcomes.⁴ Depending on how UHC is pursued, it can either support health as a human right or undermine it.⁵ There is a risk that a focus on UHC could emphasize access to health care over other measures to equitably improve health—for example, the remainder of measures needed to realize health as a human right.⁶ There is also debate over whether UHC should strive for universal health *care*, which would require realized access to health services, or universal health *coverage*, which focuses on the necessary, but not sufficient, affordability element of access.⁷

The definition of UHC leaves open to interpretation exactly what model would realize equitable access.⁸ In addition, UHC focuses predominantly on access to primary medical care and does not distinguish between modes of financing or delivery (e.g., whether publicly or privately financed), which could lead to profit-taking by private insurers or providers, representing opportunity costs to UHC systems.⁹

In the 1978 Alma-Ata Declaration, the World Health Organization detailed a comprehensive approach to health system development.¹⁰ The declaration calls for the integration of promotive, preventive, curative, and rehabilitative activities; a holistic and rights-based approach to health; community participation in health care; universal accessibility; and intersectoral action on the social determinants of health. This was swiftly challenged by a selective, technical approach to primary health care (PHC) targeting the prevention of key diseases.¹¹ As a result of this resistance, and despite the World Health Organization’s renewed call for a more comprehensive PHC vision, comprehensive

PHC implementation internationally has been patchy, with few strong national programs.¹² Ronald Labonté et al. argue that with the focus in international dialogue shifting to issues of financing and UHC, articulating the necessity of comprehensive PHC is as important as ever.¹³ While not explicitly named, strong PHC is essential to achieving many of the Sustainable Development Goals.¹⁴ A publicly funded comprehensive PHC approach to UHC would promote health, prevent ill health, allow affordable curative and rehabilitative interventions, and emphasize health as a human right.

In Australia, Medicare is the primary vehicle for UHC. Introduced in 1975 (as Medibank) by the Labor government of the time, Medicare allows citizens and permanent residents to access primary medical care through fee-for-service private general practitioners at little or no cost. Medicare includes preventive medicine (within a biomedical framework), but little that could be classified as promotive services. General practitioners are free to charge a higher fee than Medicare will reimburse, in which case the patient pays out of pocket for any fee gap. The pharmaceutical benefits scheme also subsidizes medications, improving affordability. As in other countries, recent austerity and negative perceptions of health care costs have brought UHC under threat.¹⁵ Since 2013, the conservative government has sought to increase primary medical care user fees and public health care costs, and remove subsidies from services such as pathology, threatening the affordability and accessibility of PHC. Fear of the government privatizing Medicare was a key theme in the 2016 election, which was seen to contribute to the government’s greatly reduced majority and highlights Australian public support for the universality of Medicare.¹⁶

In Australia, in 2011 there were 669,900 Aboriginal and Torres Strait Islander people, comprising 3% of the population.¹⁷ In the Northern Territory, where this case study is situated, the proportion is much higher, at 30%.¹⁸ Aboriginal and Torres Strait Islander people are more likely to live outside major city areas (65% versus 29% of non-Indigenous people), with 44% living in regional areas and over 20% living in remote or very remote areas.¹⁹

Australia lags behind other colonial nations in achieving Indigenous health equity.²⁰ Aboriginal and Torres Strait Islander peoples experience inequities in health (with a life expectancy 10.6 and 9.5 years lower than non-Indigenous males and females, respectively), and in social determinants, including employment (65% employment versus 79% for non-Indigenous Australians), income (2.5 times more likely to be in the lowest income bracket), and increased rates of incarceration (comprising over 25% of prisoners).²¹ Racism and other intersecting forms of discrimination continue to be reported in health services, with up to 42% of Aboriginal and Torres Strait Islander peoples reporting racism in health services.²² Regular experience of racism in other daily life also has significant detrimental effects on health.²³

Aboriginal community-controlled health services pioneered comprehensive PHC in Australia, predating the World Health Organization's Alma-Ata Declaration. First established in the 1970s as a response to poor access to services and discriminatory practices in mainstream health care, these services present a radically different model of primary care to Medicare-financed general practice.²⁴ The first Aboriginal community-controlled health services, including the Central Australian Aboriginal Congress (hereinafter referred to as Congress), were established as a result of public meetings of local Aboriginal people seeking collective advocacy and action to support their rights, including their right to health. In 2016, over 150 Aboriginal community-controlled health services served between a third to a half of the Aboriginal and Torres Strait Islander population.²⁵ In current-day Australia, where the self-determination-centered policies of the 1980s and early 1990s have been replaced by an approach characterized by paternalistic interventionism and a deficit model of Aboriginal and Torres Strait Islander health and well-being, Aboriginal community-controlled organizations play a vital role in providing voice and control to local Aboriginal and Torres Strait Islander communities.²⁶ If UHC is to be pursued in a way that embraces health as a human right, particularly in the context of Indigenous peoples' rights, then

Aboriginal community-controlled organizations provide an illuminating case study of one way to achieve its vision.²⁷

This study is a reflection on findings from a five-year research project on the implementation of comprehensive PHC that partnered with six PHC services: five in South Australia and one Aboriginal community-controlled organization in the Northern Territory, the Central Australian Aboriginal Congress Aboriginal Corporation. Three of the South Australian sites (anonymized as Services, A, C, and E) were longstanding services which arose from a national Community Health Program in 1973 that established community health centers led by community boards and that provided comprehensive social health services; medical services, meanwhile, were largely provided in parallel by private general practitioners. The program was discontinued after three years, but in South Australia and some other states, the services were maintained with state funding. The two remaining South Australian services were an Aboriginal health team (Service D) and a nongovernmental sexual health organization, SHine SA. While we found that the South Australian services moved away from implementation of the comprehensive PHC vision, we found that Congress maintained a comprehensive view of health as a human right, potentially providing a strong basis for UHC.²⁸ In this paper, we explore two questions: What were the strengths of the Aboriginal community-controlled service as a comprehensive PHC model for UHC compared to state-funded and state-managed PHC services? And what threats did the Aboriginal community-controlled service face in achieving a comprehensive PHC model for UHC?

Method

The six PHC services were selected to maximize diversity and because of their existing relationships with the research team that would make participation in a five-year research project (2009–2014) feasible. All services strove to be universally accessible (with the Aboriginal services striving to reach the full local Aboriginal and Torres Strait

Islander population) and affordable (only the non-governmental organization charged fees, and these were minimal and negotiable). However, in reality, the South Australian services were mostly small in scale and residual (available only to those unable to afford private services); they provided timely care only to those individuals and families who qualified as disadvantaged, and their care generally centered only on physical chronic diseases. Congress placed no access criteria on its target Aboriginal population.

For each service, we developed a program logic model in conjunction with service staff to capture in a diagram how the service worked, its suite of activities, its intended outcomes, and the influence of contextual factors.²⁹ At Congress, we did this through two iterative workshops with senior staff and board members in March and August 2010. We employed a range of evaluation methods to measure the services' performance against the service qualities and outcomes in the logic models, including the following:

1. Two rounds of staff interviews: one in 2009–2010 with 68 employees, managers, and regional and central health executives, including 14 interviews with Congress staff and board members, and one in 2013–2014 with 63 employees, managers, and executives, including 15 interviews with Congress staff and board members.³⁰ The first round explored the services' implementation of comprehensive PHC principles, while the second round focused on how this had changed in the intervening four years.
2. An online survey of 130 service employees in 2012–2013, including 59 responses from Congress covering the implementation of comprehensive PHC principles in its work.³¹ This survey aimed for breadth to complement the depth of the interviews.
3. Workshops at each service with community members, including three workshops at Congress with a total of 13 community members.³² Community members were asked to rate the services' achievement of nine different PHC service qualities and to provide reasons for those ratings.
4. For each service, a case study of intersectoral action on a social determinant of health.³³ For Congress, its contribution to collaborative

advocacy work on alcohol supply restrictions in Alice Springs was documented through the collection of reports and media releases, and interviews with two Congress employees, three employees from partner organizations, and one community member.

Each service provided six monthly reports on changes in service provision, partnerships, budgets, staffing, and other relevant factors for the duration of the project.

Congress board members and senior executive staff were informed of each stage of research, and the board approved Congress's participation in the project. Two Congress staff members served as associate investigators for the grant proposal, on which they provided input. Ethical approval for each research stage was received from the relevant Flinders University and South Australian Health research ethics committees, as well as the Aboriginal Health Research Ethics Committee in South Australia.

Findings

Summary and context history of service

The Central Australian Aboriginal Congress was formed at a public meeting in Alice Springs (a remote township of approximately 28,000 people) in June 1973, which was attended by over 100 Aboriginal people from across Central Australia.³⁴ Established as an advocacy organization to provide a voice for Aboriginal people, its first service was a "tent program" to provide shelter to Aboriginal people living in town. In 1974, Congress founders called for a comprehensive approach to health that included addressing access to economic opportunities and nutrition, as well as health care. They lobbied the minister for Aboriginal affairs and minister for health to establish a multidisciplinary health service that would be "comprehensive, not selective" and that would incorporate preventive and curative approaches and be controlled by the Aboriginal community.³⁵ A medical service was established with a doctor, and later, in 1975, two Aboriginal people were trained and employed as health workers. In the late 1970s, Congress's

services expanded to include a dental clinic, a pharmacy, and welfare services. In the 1980s, they were further expanded to include an alcohol rehabilitation center, a child care facility, a women's health and maternity service, family support services, and outreach health promotion programs in remote areas. A social and emotional well-being service was set up in the 1990s, followed by a male health service.³⁶ Congress also provides PHC services in partnership with other remote Northern Territory Aboriginal communities in Central Australia. By the time our research program began in 2009, Congress employed approximately 300 staff.

The project started two years after the controversial Northern Territory Emergency Response began in the Northern Territory. Known as "the intervention," it was prompted by the release of a report on child sexual abuse.³⁷ During this intervention, the Australian government suspended the Racial Discrimination Act in order to instigate a range of health and social measures in the territory, including alcohol restrictions, compulsory income management, child health checks, and a ban on pornography.³⁸ The intervention is widely regarded as a racist and paternalistic exercise, with considerable negative health impacts.³⁹ However, it was a source of significant additional funding for Congress PHC services.

The study took place one year after the Australian prime minister's apology to Australia's Indigenous peoples in 2008, and the Closing the Gap national partnership agreements, which committed resources against Aboriginal and Torres Strait Islander health inequality reduction targets. In 2009, Congress had an annual budget of \$27m. The Alice Springs Transformation Plan, a Commonwealth-funded collaboration between the Federal and Northern Territory Governments, was established in 2009 with the aim of expanding social support services and reducing homelessness in the town. Congress staff reported that the initiative improved intersectoral collaboration and dialogue on social determinants of health, and funded some of the service's programs, such as the Safe and Sober alcohol treatment program and the Targeted Family Support Service.

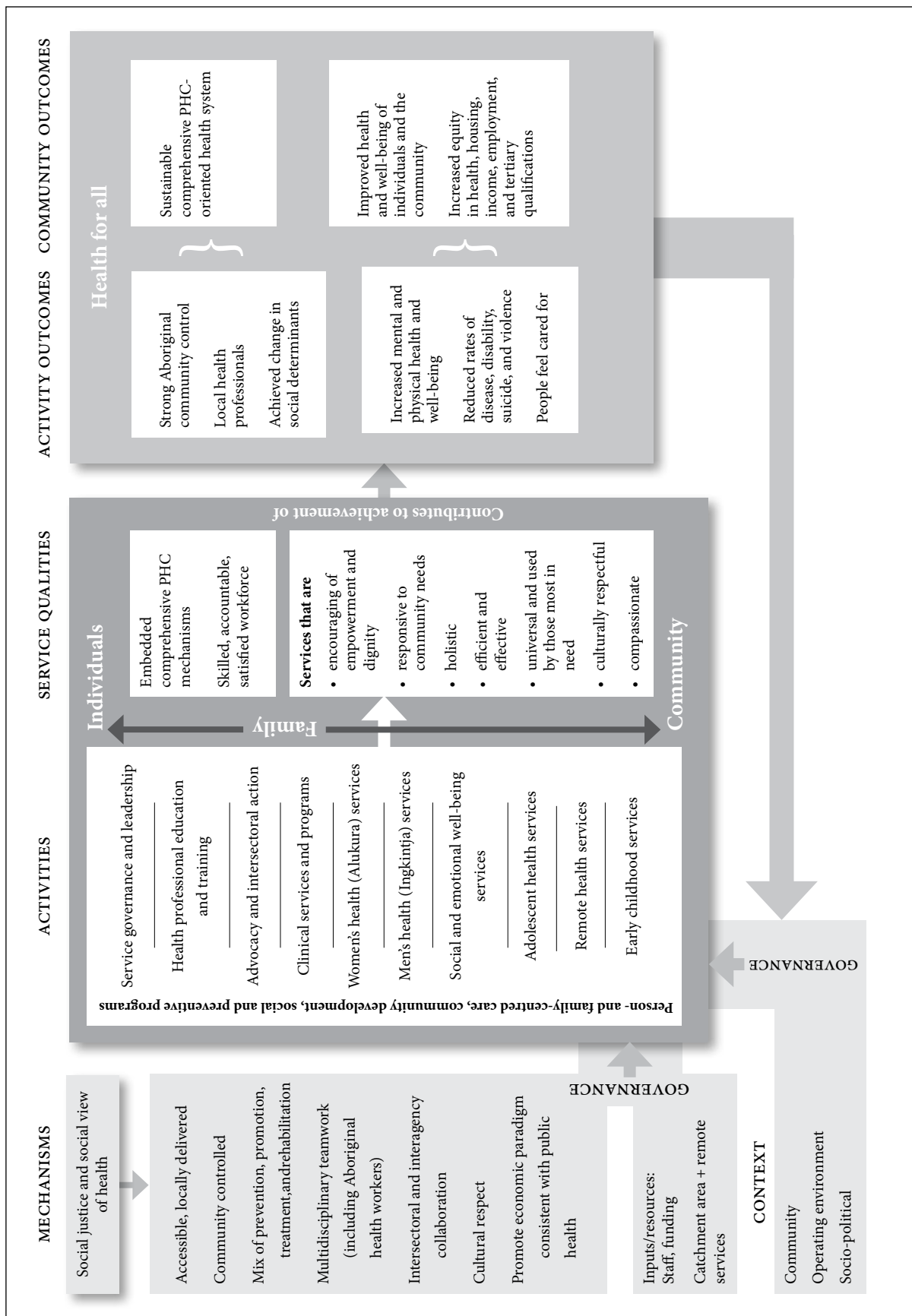
In 2011, there were further modest increases in funding to Congress programs, including its Pre-school Readiness Program, a trachoma program, and the Indigenous Chronic Disease Program. In 2012, it hired a renal PHC team and launched an Intensive and Targeted Family Support Service. There were few programs or positions lost over this period—one sexual offender program ceased, with responsibility transferred to the jail; two positions were lost when a regional center's funding was cut; and a youth psychology service ceased.

In 2012, Congress leadership underwent significant changes, including a change of chief executive officer. Also that same year, Congress held an annual general meeting, where the community voted to make changes to Congress's constitution and to register the service under the Corporations (Aboriginal and Torres Strait Islander) Act 2006. Our findings suggest that while such high-level changes—particularly the transition of chief executive officer—had the potential to be disruptive, Congress's day-to-day operations and its community control and comprehensiveness remained largely unaffected.

Program logic model

A simplified version of the program logic model developed in 2010 in collaboration with Congress staff is presented in Figure 1.⁴⁰ The model captures the goals of the health service and the values that underpin it, and articulates the logic of the activities and strategies used to reach those goals. The elements on the left and bottom cover the primary mechanisms of comprehensive PHC that Congress sought to implement, as well as the service's context and operating environment. These combined to inform, through the filter of governance, the service's "space for action" to implement comprehensive PHC, including the activities that Congress undertook and the comprehensive PHC service qualities that it sought to enact in all its programs. These activities, conducted in accordance with the service qualities, in turn seek to contribute to activity outcomes, such as reduced rates of diseases and improved local social determinants of health. These activity outcomes

FIGURE 1. Program logic model for Congress (simplified, full model available from the authors)



fed into the aspirational goals of improving the health and well-being of individuals and the community, improving equity in health and other arenas for Aboriginal people, and having a sustainable and comprehensive PHC-oriented health system.

The key definitional elements of UHC—universal affordable access to promotive, preventive, and curative services—are clearly present in this model, even though the focus was on comprehensive PHC and even though UHC was not explicitly raised in the design of the model. The model also highlights the critical elements of advocacy and action on social determinants in order to improve health equity, thus addressing Harald Schmidt et al.'s concerns about a narrow focus on UHC.⁴¹ Again, while the logic models for the other partner services contained these same UHC elements, Congress demonstrated the most extensive implementation of these ideals. Table 1 shows the characteristics of all six services, as well as a comparison of their accessibility, treatment, prevention, and promotion work; community participation; and advocacy and intersectoral action. Congress exhibited a number of strengths over the other service models. These are presented below.

1. *A more comprehensive multidisciplinary service*

One question the World Health Organization includes in its consideration of UHC is “Which services are covered?”⁴² Moreover, the World Bank report on UHC highlights that integration is vital to quality of care.⁴³ Part of the necessity for a comprehensive PHC approach to UHC is the need for coverage to access a wide range of disciplines to support the health and well-being of individuals and the community. Universal coverage for only a narrow set of services is likely to have a reduced ability to address health inequities. Congress is an exemplar of such a free, multidisciplinary service. In addition to providing primary medical care with salaried general practitioners, Congress offers transportation services and employs a wide range of disciplines that provide many programs and services (see Table 2). This represents a far greater breadth of disciplines than those employed in the smaller South Australian services, allowing

Congress to offer a more comprehensive, holistic response to the community's health and well-being.

2. *Multiple avenues of community participation*

Of all the services studied, Congress enacted the widest range of strategies to ensure community participation. This is unsurprising given that Congress is community controlled and comes from a social movement emphasizing self-determination. The service's board was the only example of structural participation in our research—that is, participation driven and controlled by the community, where the community can define the scope and agenda of its participation.⁴⁴ A number of other community participation strategies were documented at Congress, including taking community members to external forums to provide a voice for the local community, consulting community members about new programs, employing local Aboriginal health practitioners, and having cultural advisory committees which provided advice and guidance on cultural protocols. Staff felt that this community participation provided community members with a sense of ownership over the service.⁴⁵ Community participation is a critical element of a rights-based approach to health, including through the politics of solidarity and civil society movements, and is hence valuable for framing UHC in terms of health as a human right.⁴⁶

Engaging in community participation is rarely unproblematic, and Congress faced barriers to successful community participation in service planning. In particular, challenges were reported in balancing community desires with evidence-based medicine and with program requirements accompanying vertical funding sources, and in ensuring that views from both the town community and the geographically widespread, remote, and often very impoverished town camps were gathered.⁴⁷

3. *Greater scope of cultural respect and accessibility strategies*

Congress demonstrated the greatest scope of strategies to address the accessibility of its services, including culturally respectful service delivery.⁴⁸ It addressed the following elements:

TABLE 1. Characteristics of case study PHC services as of 2013 and a comparison of the comprehensiveness of their PHC models

Service	Annual budget (AUD)	Governance	Staff (full-time equivalent)	Activities and services provided	Service accessibility	Treatment, prevention, promotion	Community participation	Advocacy, intersectoral action
A	\$0.5m*	State managed	10 (8.1)	Early childhood care	Free; in area of disadvantage; limited crèche; no transportation support; priority system/residual service only for those who cannot afford private care	Treatment only	Nil	Nil
C	\$1.6m	State managed	25 (15.3)	Chronic condition self-management; early childhood care; mental health care; family violence services	Free; some crèche; no transportation support; priority system/residual service only for those who cannot afford private care	Treatment only	Active complaints system	Some intersectoral action with supported residential facilities
D	\$0.5m	State managed	9 (8.8)	Medical clinic; Aboriginal clinical health workers; adult learning center	Aboriginal-specific service; free; transportation support for those with chronic conditions	Mainly treatment; some prevention and health checks; promotion through learning center; community lunches	Little consultation	Learning center that collaborates with education sector
E	\$1.7m	State managed	21 (16.6)	Early childhood care; chronic disease self-management; mental health care; antenatal and postnatal support	Free; some crèche; no transportation support; priority system/residual service only for those who cannot afford private care	Treatment only	Nil	Nil

* Approximate; the budget was combined with another site. The budget for two sites was \$1.1m.

TABLE 1. *continued.* Characteristics of case study PHC services as of 2013 and a comparison of the comprehensiveness of their PHC models

Service	Annual budget (AUD)	Governance	Staff (full-time equivalent)	Activities and services provided	Service accessibility	Treatment, prevention, promotion	Community participation	Advocacy, intersectoral action
Congress	\$30m	Aboriginal community-controlled board	310 (204.5)	Medical clinic; allied health care; child health care; chronic disease management; women's health care; men's health care; social and emotional well-being services; pharmaceutical services; dental care; health promotion	Free services and pharmacy; mix of drop-in and appointments; outreach; home visitation; transportation service; free phone service	Mix of treatment, rehabilitation, prevention, and promotion work	Board; cultural advisory committees; forums; consultations; local Aboriginal staff	Advocacy on Aboriginal community control and PHC; intersectoral action (e.g., housing, alcohol, employment)
SFine SA	\$5.8m	Nongovernmental with governing council	68 (50.7)	Sexual health capacity building for health professionals and teachers; sexual health school curriculum; sexual health services; counselling	Low or no-cost services; clinics in areas of disadvantage; drop-in service for young people	Individual treatment and prevention (e.g., STIs, Pap smears); promotion through school curriculum; capacity building; online resources	Consultations; advisory/reference committees	Intersectoral collaboration with schools for curriculum development

- *Availability* through the provision of a free transportation service to all its service areas; outreach; home visitation; and a hybrid appointment system that allowed for walk-ins.
- *Affordability* through the provision of all services and medicines free of charge.
- *Acceptability* through the design of spaces to make the service welcoming and culturally respectful, the employment of local Aboriginal staff, and a consideration of cultural protocols.
- *Engagement* through interactions with the local community, including campaigns, awareness raising, and informal community development activities (such as cultural days that acted as entry points into the service).⁴⁹

As explained above, strong community participation also promoted a sense of ownership that facilitated access. As a result of these accessibility initiatives, a senior staff member of Congress noted that a demographer had told him, “We are the only health service I’ve ever seen that could honestly say we are seeing 100% of the population every year.”⁵⁰ Congress’s success implies the importance of a comprehensive approach to accessibility (the specifics of which would vary by context) if the UHC goal of equity in access at an affordable cost is to be achieved.⁵¹

4. Health promotion and disease prevention

Congress participated in a wide range of disease prevention and health promotion activities in addition to providing treatment and rehabilitative

services that included a medical clinic, a dental clinic, and mental health and addiction therapy (all of which also incorporate prevention and health promotion). Congress’s prevention and health promotion activities included early childhood and youth programs (e.g., antenatal care and birthing classes, immunizations, day care, a preschool readiness program, and youth outreach), adult health check-ups, healthy lifestyle groups, exercise groups, community health education (e.g., on young women’s and men’s sexual health), and mental health promotion (including for young people and the community at large).⁵²

While the state-funded services in the study were stripped of their health promotion funding and mandate, Congress—like SHine SA, the other nongovernmental service in our study—was able to continue its health promotion work with strong organizational support due to the fact that it was not managed by the government and had a board committed to comprehensive PHC.⁵³ However, Congress did feel pressure on its prevention and health promotion work in light of the need to balance this work with the need to meet an immediate and high ongoing demand for curative services for a “very sick” population.⁵⁴ Congress thus exhibited a comprehensive PHC approach to the spectrum of “treatment, prevention, and promotion” activities embedded in the definition of UHC. In its service reports, Congress estimated spending 70% of its time and resources on individual-level treatment, prevention, and promotion work, 10% on group work, and 20% on community health promotion,

Table 2. Examples of Congress’s services and personnel

Congress’s services	Personnel
Medical clinic	General practitioners, nurses, Aboriginal health practitioners
Allied health team	Podiatrists, nutritionists, diabetes nurse educators
Child health team	Child health nurses, Aboriginal liaison officers, Aboriginal health practitioners
Chronic disease team	Nurse coordinator; diabetes, renal, and cardiovascular nurses
Women’s health section (Alukura)	Female general practitioners, nurses, midwives, trainee midwives, Aboriginal liaison officers, Aboriginal health practitioners, sexual health community educators
Male health section (Ingkintja)	Male nurses, Aboriginal liaison officers
Social and emotional well-being branch	Psychologists, counselors, youth workers, alcohol and other drug therapists, Aboriginal liaison officers
Pharmacy	Pharmacists and pharmacy assistants
Dental services	Dentists, dental assistants

with an estimated 33% of its budget allocated to prevention and promotion work.

5. *Advocacy and intersectoral collaboration on social determinants*

Congress engaged in more efforts than the other services to address local social determinants; these efforts included an anti-violence campaign, participation in a local government-led “transformation plan” for the town, attention to housing issues, and advocacy around comprehensive PHC in multiple forums.⁵⁵ The service’s employment of Aboriginal staff was also seen as a way to directly affect social determinants and thus improve population health. In addition, we documented Congress’s involvement in a community coalition that lobbied for alcohol supply restrictions in collaboration with community organizations and other sectors. This case study highlighted potential threats to successful advocacy, with some of the changes that the coalition had lobbied for implemented and then subsequently dismantled by a successive government, despite emerging evidence of the reduction in alcohol-related harm.⁵⁶ However, the major change of increasing the minimum unit price of alcohol has been sustained. Additionally, as Congress staff were aware, many social determinants of the community’s health were not local in origin and were largely outside the health service’s area of influence.⁵⁷

Table 3 summarizes how these characteristics relate to the implementation of health as a human right within Congress’ model of care.⁵⁸

Discussion

Translating comprehensive PHC from ideal to practice raises many political and practical challenges. Nonetheless, it provides a potentially valuable model of accessible UHC that maintains a focus on health as a human right and on the reduction of health inequities, including through action on the social determinants of health. Congress implemented the most comprehensive approach to PHC among the services in our study. It was able to maintain its commitment to accessibility,

community participation, disease prevention, health promotion, and action on social determinants, while the services in South Australia were unable to do so. Congress is located in a different jurisdiction (Northern Territory), with most of its funding coming from Commonwealth sources for Aboriginal community-controlled services. The policies of the Australian federal government are supportive of the need for comprehensive PHC within Aboriginal health services although less so within non-Indigenous services.⁵⁹ The withdrawal from comprehensive PHC in South Australia was driven by the state government’s desire to reduce health care expenditures, cost-shift PHC to federally funded regional PHC organizations, and treat chronic physical conditions in out-of-hospital services. While the sexual health nongovernmental organization in this state (SHine SA) was less affected than the state-managed services, its prescriptive service agreement nevertheless constrained its comprehensive PHC practice. Congress and SHine SA maintained their conception of health as a human right, while this approach was no longer evident at the state-managed services. These two services’ nongovernmental nature seems to have protected them somewhat from changes in state government budgets and priorities.

One critical supportive factor is Congress’s public funding of approximately \$30 million per year, an amount much higher than that enjoyed by the South Australian services. This has allowed Congress to implement a wide range of programs and overcome the access challenges faced by community members and the geographic challenges of such a remote setting. However, this funding alone does not explain Congress’s commitment to comprehensive PHC, as the service’s history indicates a dedication to human rights, comprehensive PHC, and universal access for Aboriginal and Torres Strait Islander peoples.⁶⁰ Indeed, Congress implemented health and social programs during a long period of hostile and underfunded circumstances. The period of sufficient public funding is relatively recent and has enabled Congress to more fully implement its long-held commitment to comprehensive PHC.

Our research utilized a case study design with six partner services to provide an in-depth examination of local context and the practice of comprehensive PHC. We included one case study of an Aboriginal community-controlled service—the Central Australian Aboriginal Congress—whereas there are 150 other such community-controlled health services in Australia that vary in size, resources, staffing, and ability to implement comprehensive PHC. However, the Congress model is illustrative of what Aboriginal community-controlled services can accomplish and provides insight into the contextual factors that can support the implementation of comprehensive PHC; these factors include the provision of adequate public funding that allows for comprehensive service provision, being a nongovernmental organization with local community governance that enables advocacy, and policy support for a comprehensive PHC approach. While this may suggest that Congress is a “best case” of an Aboriginal community-controlled PHC, it is unlikely to be unique. Although we do not have comparable data from this research, other Aboriginal community-controlled health services—including the Aboriginal Medical Service Redfern (New South Wales), Rumbalara Aboriginal Cooperative (Victoria), and Winnunga Nimmityjah Aboriginal Health Services (Austra-

lian Capital Territory)—are equally highly regarded and demonstrate a comprehensive, rights-based model of PHC.

Action and advocacy on social determinants is particularly important when considering the ongoing colonization of Aboriginal and Torres Strait Islander peoples in Australia, as well as other Indigenous peoples worldwide, due to unequal power and voice, discrimination, and racism.⁶¹ In order to maintain health equity as the overarching goal, and UHC as the means to this end, the health-promotion aspect of UHC needs to include advocacy and action on social determinants.⁶² Furthermore, health sector actions need to be complemented by whole-of-government approaches to address social determinants—particularly for determinants that are nationally or internationally influenced, such as through trade and investment agreements and economic policies that affect wealth and income equity.⁶³ Such efforts are integral to health as a human right.⁶⁴

Our study did not gather comparative health outcome data that could yield further insight into the strengths and weaknesses of different PHC models and build the evidence base for effective, comprehensive PHC. Other Australian research has found that Aboriginal community-controlled health services achieve similar clinical outcomes as general practices despite having a more com-

TABLE 3. Implementation of health as a human right within Congress’s Aboriginal community-controlled model of care

Health as a human right element*	Implementation in Congress
Availability: availability of public health and health care facilities, including availability of underlying determinants of health	Comprehensive PHC and community-controlled services that are available to the community; advocacy and intersectoral action that address the social determinants of the community’s health
Accessibility: health facilities and services are accessible to everyone (non-discrimination, physical accessibility, economic accessibility, information accessibility)	A range of strategies implemented to support physical, economic, and information accessibility (e.g., transportation, outreach, home visitation, and free services, programs, and pharmacy); community forums and knowledge exchange; culturally safe, community-controlled service with anti-racism advocacy
Acceptability: health services are respectful and culturally appropriate	Culturally safe, community-controlled service, with local Aboriginal staff; recognition and consideration of clients’ social circumstances and determinants of health
Quality: health services are scientifically and medically appropriate and of good quality	Efficient and effective treatment, rehabilitation, prevention, and promotion services and programs
Participation: population participates in the provision of preventive and curative health services (article 12.2d)	Community participation through board, cultural advisory committees, forums, consultations, and employment of local staff

* United Nations, *Substantive issues arising in the implementation of the international covenant on economic, social, and cultural rights* (Geneva: Committee on Economic, Social, and Cultural Rights, 2000).

plex and disadvantaged caseload.⁶⁵ The transfer of health services to Aboriginal community control has been associated with better access to doctors and Aboriginal health practitioners, more culturally respectful services, and a greater focus on population health.⁶⁶

There is also Canadian evidence for community-controlled PHC. In one study, First Nation community health services that transitioned from government control to community control achieved a 30% reduction in hospital utilization rates compared to the non-community-controlled services, which the authors attributed to the positive health benefits of self-determination.⁶⁷ A survey of over 200 community health centers in Canada serving non-Indigenous populations found that community-governed centers were more likely than non-community-governed centers to undertake work on social determinants and health equity, such as programs and advocacy on food security, homelessness and housing, poverty and income security, and refugee health services.⁶⁸ While these associations may be correlational—with community governance, social determinants, and health equity ideals all stemming from a comprehensive PHC vision—these findings together suggest that community-controlled PHC services may lead to better health outcomes because of the ability of the service to assume responsibility for the health and well-being of its community, carve out space to take action on social determinants, and increase the community's voice in decision making. This further highlights the community-controlled model as a potentially beneficial pathway to achieve UHC with a focus on health as a human right. While Aboriginal and Torres Strait Islander services target a specific population group, they indicate how UHC could be achieved with a comprehensive and rights-based approach if the comprehensive community-controlled model were employed for the wider population.

Conclusion

Our research highlighted the strengths of a well-funded Aboriginal community-controlled

model in achieving UHC, based on a comprehensive PHC approach that covered treatment, prevention, and promotion activities and that was rooted in a commitment to health as a human right. The community-controlled model emerged as a promising form for the implementation of the UHC vision, which stresses health equity. The model suggests a range of benefits for population health over and above what a purely primary-medical-care or private-health-insurance-driven vision of UHC may have to offer, and it is worthy of serious attention and consideration in debates as countries strive to achieve the UHC Sustainable Development Goal.

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Ethics approvals

Social and Behavioural Research Ethics Committee, Flinders University 4433.

Aboriginal Health Research Ethics Committee, South Australia 04-09-281; 04-12-438; 04-12-429; 04-12-447; 04-10-377; 04-13-504.

Southern Adelaide Health Service / Flinders University
Human Research Ethics Committee 020.11.

Southern Adelaide Clinical Human Research Ethics
Committee 131.12; 499.11; 235.12; 150.13.

South Australian Health Human Research Ethics
Committee 429/01/2014; 486/11/2014; HREC/12/SAH/15;
509/03/2015.

Interpreting the International Right to Health in a Human Rights-Based Approach to Health

PAUL HUNT

Abstract

This article tracks the shifting place of the international right to health, and human rights-based approaches to health, in the scholarly literature and United Nations (UN). From 1993 to 1994, the focus began to move from the right to health toward human rights-based approaches to health, including human rights guidance adopted by UN agencies in relation to specific health issues. There is a compelling case for a human rights-based approach to health, but it runs the risk of playing down the right to health, as evidenced by an examination of some UN human rights guidance. The right to health has important and distinctive qualities that are not provided by other rights—consequently, playing down the right to health can diminish rights-based approaches to health, as well as the right to health itself. Because general comments, the reports of UN Special Rapporteurs, and UN agencies' guidance are exercises in interpretation, I discuss methods of legal interpretation. I suggest that the International Covenant on Economic, Social and Cultural Rights permits distinctive interpretative methods within the boundaries established by the Vienna Convention on the Law of Treaties. I call for the right to health to be placed explicitly at the center of a rights-based approach and interpreted in accordance with public international law and international human rights law.

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Competing interests: None declared.

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Introduction

Among the dynamics that have shaped the recent development of the international right to health are a drive toward its “real-life” implementation for the benefit of individuals, communities, and populations, and a movement from short, general, abstract, legal treaty provisions toward specific, practical human rights guidance. These two trends are closely interrelated.

For example, the general comments of United Nations (UN) human rights treaty bodies have added flesh to the bare bones of human rights treaty provisions. Since 2002, UN Special Rapporteurs on the right to health have endeavored to apply the treaties and general comments to many themes, states, and other duty-bearers. When rapporteurs have encountered specific issues on which the existing jurisprudence gives no or scant guidance, they have offered their interpretations of the international right to health. UN agencies have adopted increasingly detailed guidance on how to operationalize human rights, for example, in relation to HIV/AIDS, tuberculosis, maternal mortality, under-five mortality, contraceptive information and services, and clinical management of female genital mutilation.¹ This has required agencies to interpret and apply treaties, general comments, and other jurisprudence, sometimes weighing the available evidence as part of their interpretative process. None of these initiatives is above criticism but, at least, as John Harrington and Maria Stuttaford put it, a “beginning has been made” to provide treaty provisions with detailed normative and operational content.²

Although very welcome, these important developments give rise to numerous complex issues. Alicia Yamin and Rebecca Cantor identify some of the formidable challenges, dilemmas, and contradictions generated by attempts to operationalize human-rights based approaches to health. For example, human rights are understood “as universal, deontological principles”—yet, in operationalizing them through rights-based approaches, “trade-offs and deeply contextualized political realities necessarily enter the equation.”³

This article aims to supplement Yamin and Cantor’s analysis by addressing two questions that

bear closely on contemporary discussions about health and human rights. First, what is the role of the right to health in human rights-based approaches to health? Second, since general comments, rapporteurs’ reports, and agencies’ guidance are exercises in legal interpretation, what is the legal methodology for the interpretation of the international right to health?

Although there is not yet a universally agreed definition of a rights-based approach to health, a good starting point is the account provided by the World Health Organization (WHO) and Office of the United Nations High Commissioner for Human Rights (OHCHR).⁴ This definition is considered by Flavia Bustreo, Paul Hunt, Sofia Gruskin, and others in *Women’s and Children’s Health: Evidence of Impact of Human Rights*.⁵ However, for the purposes of the present discussion, it is not necessary to favor one definition of a human rights-based approach to health. The important point here is that all these definitions encompass all relevant human rights, including the rights to life, information, privacy, participation, association, equality, non-discrimination, and the prohibition of torture and inhuman and degrading treatment. One of the key aims of this article is to explore the place of the international right to health in human rights-based approaches to health.

However, it is important to emphasize that there is merit in applying a rights-based approach to health rather than confining the analytical and operational “lens” to the right to health. Although the right to health is extensive, it is narrower than a human rights-based approach, and the wider “lens” may help devise a more comprehensive and effective strategy. Deploying several human rights may strengthen the human rights case by, for example, securing protection from a wider range of national and international laws and also by generating support from a broader coalition of groups and interests. Also, some duty-bearers still harbor ideological or other objections to the right to health, and they may be quicker to accept the relevance of civil and political rights, such as the right to life. Indeed, it might be possible to “smuggle” the right to health into a rights-based approach without trig-

gering ideological objections, although this article does not favor such a tactic. It is accepted that there will sometimes be advantages in adopting a human rights-based approach rather than relying only on the right to health.

The problem identified and addressed in this article is that rights-based approaches to health, however they are defined, run the risk of playing down, and sometimes obscuring, the central role of the international right to health. For example, when I served as UN Special Rapporteur on the right to health and, more recently, when I participated in a statutory human rights inquiry into Northern Ireland's emergency health care, it was sometimes suggested by those in authority that they were *implicitly* including the right to health in policy-making or a rights-based approach to health. This is problematic because, in such a situation, only they know whether the right to health is present and, if it is, how it is interpreted and applied. Such arbitrariness is inconsistent with the *raison d'être* of human rights. One never hears an argument for a rights-based approach to fair trials. But a rights-based approach to fair trials which only *implicitly* includes the right to a fair trial is inconceivable. If there were a rights-based approach to fair trials, the explicit right to a fair trial would have to be at its center. Of course the parallel is not exact, but a rights-based approach to health that only *implicitly* includes the right to health lacks credibility and legitimacy. After all, the right to health is in the Constitution of the World Health Organization, all states have ratified one or more treaties which include the right, and it has been recognized by the UN on innumerable occasions.⁶

Playing down the right to health may not matter if other human rights within a rights-based approach possess all the features enjoyed by the right to health, but they do not. The right to health has distinctive characteristics which are indispensable for the effective implementation of a rights-based approach to health. Adopting a rights-based approach, and muting the right to health within it, runs the risk of diminishing both the approach and the right to health. Also, it may perpetuate what Yamin and Cantor refer to

as "an erroneous conception of human rights that is limited to a narrow sphere of civil and political rights."⁷ All of this points to the importance of legal interpretive methodology: if the right to health has distinctive features, their interpretation (i.e., establishing the contours and content of these distinctive characteristics) becomes crucially important.

In this article, I trace the shifting place of the international right to health, and human rights-based approaches to health, in the scholarly literature and United Nations. Second, I explore evidence that the international right to health is played down within a rights-based approach to health. Third, I analyze the degree to which the international right to health has qualities not possessed by other rights that form part of a rights-based approach to health. Because of the importance of these distinctive qualities, I then explore legal methodology for the interpretation of the international right to health. After critiquing the methodology that John Tobin uses to interpret the international right to health, I suggest that the "special character" of human rights treaties permits distinctive methods of treaty interpretation, while remaining within the interpretative boundaries established by the Vienna Convention on the Law of Treaties. I argue that the international right to health, as part of the rights-based approach to health, should be interpreted by way of these distinctive methods of treaty interpretation. In conclusion, I favor a rights-based approach to health which explicitly and consistently includes the international right to health.

It is helpful to distinguish (1) the international right to health, (2) human rights-based approaches to health, and (3) the national right to health; this article focuses on the relationship between (1) and (2), especially within the UN. However, the discussion also bears upon the right to health and human rights-based approaches to health within regions and countries. I use the "right to health" as a shorthand for the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health," as enshrined in article 12 International Covenant on Economic, Social and Cultural Rights (ICESCR).⁸ "UN agencies" includes UN agencies, funds, programs, and similar

UN organizations. “General comments” includes general comments and general recommendations of UN human rights treaty bodies. The discussion focuses on specific developments in relation to health and human rights; however, it builds on generic initiatives in relation to economic, social, and cultural rights, such as the Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights.⁹

Trends in the scholarly literature

The following survey focuses on monographs that examine either the right to health or human rights and health. In particular, it considers monographs that are scholarly, broadly understood; for example, it includes those from the meetings of scholars and policy makers, but excludes the campaigning material of civil society organizations. The focus is on key trends among monographs that give significant attention to international human rights standards.

Although the international right to health found its place in the UN in 1946, it was not subject to academic treatment until more than 30 years later. WHO’s first director-general, Brock Chisholm, was an energetic proponent of the right to health, and it was partly thanks to his leadership that the right was firmly established in the International Bill of Rights.¹⁰ But it was only in 1978—30 years after the Universal Declaration of Human Rights and 12 years after the ICESCR were adopted by the General Assembly—that eminent scholars, policy makers, and others explored the right to health in a three-day workshop organized by the Hague Academy of International Law and United Nations University. The proceedings were published in 1979 as *The Right to Health as a Human Right*.¹¹

In 1985, the University of Sherbrooke, Quebec, hosted a similar event which was followed by papers on the right to health in the *Revue Québécoise de Droit International*.¹² Four years later, the Pan American Health Organization published a voluminous study, *The Right to Health in the Americas*.¹³ Although mainly a comparative examination of constitutions from the region, the study has content on international law and was partly a response

to the 1978 Declaration of Alma-Ata, which affirms health as “a fundamental human right.”¹⁴

During 1992–1993, the American Association for the Advancement of Science held four day-long consultations on “the right to health care,” with a focus on the United States, which contributed to Audrey Chapman’s *Exploring a Human Rights Approach to Health Care Reform* and an edited collection of papers on the same theme.¹⁵ One striking feature of these publications is that they give considerable attention to both the international right to health, or health care, and a human rights approach. Given resistance in the United States to the right to health, it was considered strategic to place this right within a human rights approach.

In 1993, there were two other significant meetings on the right to health. In September, the Human Rights Program at Harvard Law School and the François-Xavier Bagnoud Center for Health and Human Rights at Harvard School of Public Health brought together a small group of people, mainly academics, for a one-day discussion on economic, social, and cultural rights, with a particular focus on the right to health. Formal papers were not presented, but a record of the discussions was published in 1995.¹⁶ Second, in December 1993, the UN Committee on Economic, Social and Cultural Rights held a public “Day of General Discussion on the Right to Health” which focused on the meaning to be attributed to article 12 of ICESCR. When presenting a working paper to his colleagues, committee member Alvarez Vita remarked that “although there was an abundant bibliography on health, very little of it related to health as a human right.”¹⁷

The groundbreaking *Health and Human Rights: An International Journal* was launched by the François-Xavier Bagnoud Center for Health and Human Rights in 1994. The first issue’s main article, “Health and Human Rights,” one of the most seminal in the field, mentions the right to health only twice: once in relation to the preamble of WHO’s Constitution and again when the article refers to “the specific health-related responsibilities of states listed in Article 12 of the ICESCR,” a choice of words that avoids “right to health responsibilities.”¹⁸ However, the issue’s second article is an

important piece on the international right to health in which Virginia Leary underscores that “there have been few serious efforts by international organizations or scholars to consider the scope of the right to health.”¹⁹

In summary, the emphasis of the relevant literature changed around 1993–1994. Beforehand, the relatively spare literature focused on the right to health; in 1993–1994, it began to lean toward human rights and health. This shift in emphasis is reinforced in the context of HIV/AIDS—for example, the *International Guidelines on HIV/AIDS and Human Rights*, adopted in 1996, refer to a “human rights approach” and “rights-based response,” and the 1997 book *Human Rights and Public Health in the AIDS Pandemic*, by Lawrence Gostin and Zita Lazzarini, focuses on a human rights approach.²⁰

A brief word is needed about the contribution of WHO. Health and human rights, including the right to health, was on WHO’s agenda until 1953, when a change of leadership effectively suspended for many years its serious and sustained consideration within the organization.²¹ In 1993, WHO published Rebecca Cook’s *Human Rights in Relation to Women’s Health*, which raised issues that contributed not only to the World Conference on Human Rights (1993), for which it was written, but also to the International Conference on Population and Development (1994) and Fourth World Conference on Women (1995).²² Four years later, WHO held a two-day informal consultation on health and human rights which the chairperson described as “the first meeting at WHO to be convened specifically to address health and human rights.”²³ In one of the meeting’s key papers, Julia Häusermann presented a conceptual framework for the right to health.²⁴

In 1999, Brigit Toebe wrote the first single-author book on the international right to health.²⁵ Here, for the first time, was a detailed, coherent, critical examination of the international right to health that looked at its historical origins, legal content, and international supervision and justiciability; it also appended a draft general comment on article 12 of the ICESCR. This pioneering book was published about fifty years after the right to health was first discussed in the United Nations.

Toebe’s analysis has limits: for example, it provides neither a philosophical justification for the right to health nor a clear interpretative methodology.²⁶ Nonetheless, it is an exceptional contribution to the literature, and the following year, after extensive consultations, research, and discussions, the Committee on Economic, Social and Cultural Rights adopted General Comment No. 14 on the right to health. Although the committee did not adopt Toebe’s draft general comment, her scholarship and draft emboldened the committee, informed its thinking, and contributed to its work.

There was another shift in the literature around 1999–2000. Before that time, the quantity of literature on either the right to health or human rights and health was limited. But in the seventeen years since the turn of the century, there has been a steady stream of academic books, articles, reports, and other publications on human rights and health, including the right to health. The contrast between the two periods—before and after 1999–2000—is dramatic.

The post-2000 scholarly monographs on human rights and health, including the right to health, display a number of features. First, a minority of them focus on the right to health.²⁷ Second, most of the monographs base themselves on phrases like “human rights framework(s),” “rights-based approaches,” “health rights,” and “human rights.”²⁸ Third, there are small clusters of monographs (on the right to health or one of the other formulations) around certain topics—for example, medicines, sexual and reproductive health, poverty, and neglected diseases. Other topics include health care, litigation, mental health, international assistance and cooperation, women’s and children’s health, public health, global health, Europe, and neoliberalism. Fourth, several collections include contributions on a wide range of issues, beginning with *Health and Human Rights: A Reader*, edited by Jonathan Mann, Sofia Gruskin, and colleagues; also notable is *Health and Human Rights: Basic International Documents*, which runs over 550 pages.²⁹

In a different group are philosophical books that examine the foundations of health and human rights, such as Jennifer Ruger’s *Health and Social*

Justice and Sridhar Venkatapuram's *Health Justice*.³⁰ In 2015, Benedict Rumbold, in his survey of conceptions of the "moral right to health," observed that "since 2012 alone there has been a cluster of work on the right to health" and found that there is "increasing recognition of both the philosophical questions engendered by the idea of a human right to health and the potential of philosophical analysis to help in the formulation of better policy."³¹

In conclusion, prior to 1993–1994, a few conferences and publications examined the right to health, rather than a human rights-based approach (or similar formulation). They gave the international right to health a degree of respectability and began the long process of placing it on academic and policy agendas.³² After 1993–1994, the focus began to shift from the right to health toward a human rights-based approach. Finally, after 1999–2000, there was a dramatic increase in the amount of scholarship on both human rights-based approaches to health and the right to health.

It is beyond the scope of this article to examine in detail why this sea change occurred around 1999–2000. However, drawing from Colleen Flood and Aeyal Gross, reasons include the reduced ideological divide between civil and political rights, on the one hand, and economic, social, and cultural rights, on the other, after the Cold War; the recognition by many in the human rights movement that their relevance and credibility required them to take social rights more seriously; the recognition by those working on HIV/AIDS and on women's health of the potential of human rights to fortify their campaigns (e.g., the demand for universal access to antiretroviral therapies was grounded in the idea of health as a human right); transformative constitutionalism, especially in Latin America and South Africa, that included new constitutions often encompassing an explicitly justiciable right to health (which has generated a huge amount of case law in some countries); and the perception of human rights as a way to challenge the detrimental impact of neoliberal economic policies on health-related services.³³ These interrelated factors also contributed to developments within the UN, to which I now turn.

Key developments in the United Nations

In addition to the growing scholarly literature since 1999–2000, there have been significant health and human rights developments in the UN. There is considerable crossover between the literature and UN developments. For present purposes, the post 1999–2000 UN developments may be divided into two groups: those that focus on the right to health and those with wider formulations, such as human rights-based approaches to health, which include the right to health.

Right to health

The key right-to-health developments include the adoption of general comments by human rights treaty bodies. Among the most important of these general comments are General Recommendation 24 of the Committee on the Elimination of Discrimination against Women (1999), General Comments No. 14 (2000) and No. 22 (2016) of the Committee on Economic, Social and Cultural Rights, and General Comment No. 15 of the Committee on the Rights of the Child (2015), all of which focus on either the right to health or parts of the right to health, such as sexual and reproductive health rights.³⁴

The developments also include the reports of UN Special Rapporteurs on the right to health: myself (2002–2008), Anand Grover (2008–2014), and Dainius Puras (2014–to date). In brief, they have written thematic and mission reports, as well as reports on the "communications" or complaints they have taken up, with summaries of any replies received. The appendix to this article lists all the rapporteurs' thematic and mission reports to date. Also, it signals the themes reported on, such as neglected diseases, maternal mortality, medicines, mental health, noncommunicable diseases, and adolescent health, as well as the issues considered in each mission report. To date, the rapporteurs have written 32 thematic reports and 23 mission reports on the right to health.

Although this article does not aim to provide an overview or analysis of these reports, a few brief points are in order.³⁵ First, broadly speaking, the reports endeavor to interpret and apply the

international right to health, drawing from general comments, international and national case law, and academic and other literature. Second, where there are gaps in the jurisprudence, the reports suggest the way forward. For example, in 2007 the Human Rights Council asked the Special Rapporteur to prepare a report on health systems and the right to health. At that time, there was scarce guidance from the treaty bodies or elsewhere on this topic, and so the rapporteur turned to basic principles, analogous practice, and extensive consultations and began to fill this jurisprudential gap.³⁶ Third, the rapporteurs consult, discuss, and research widely before writing their reports. Fourth, their more than 50 thematic and mission reports provide a unique cache of insights into the interpretation and application of the international right to health. Lastly, although, as befits their UN mandate, rapporteurs focus on the international right to health, sometimes they refer to human rights-based approaches.³⁷

Human rights-based approaches

As discussed, one of the purposes of treaty bodies' general comments is to provide a bridge between short, legalistic treaty provisions and practice. However, it is a long way from one side of the river to the other. While general comments get some of the way, they cannot span the gap alone. The rapporteurs' thematic and mission reports may provide another arch to the bridge, but they, too, are unlikely to be sufficiently detailed, specific, and practical to reach the other side. Often drawing from *A Human Rights-Based Approach to Health*, adopted by WHO and OHCHR, some UN agencies have risen to the challenge by preparing further guidance on how to operationalize human rights in relation to range of health issues.³⁸ The guidance varies in several ways, such as provenance, specificity, and practicality. However, how high is the profile of the international right to health in this guidance? By way of illustration, three different forms of guidance are briefly considered. First, however, it is necessary to confirm some of the key features of the international right to health.

In 2009, Sofia Gruskin, Dina Bogecho, and Laura Ferguson conducted a review of scholarly and

other literature to identify the common elements of a rights-based approach, especially in the context of health.³⁹ In light of this survey, they propose a framework for assessing “institutional articulations” of rights-based approaches to health.⁴⁰ Their framework includes a “minimal list” of “specific norms and standards” to “facilitate operation” of a rights-based approach: availability, accessibility, acceptability, and quality (collectively known as AAAQ), participation, non-discrimination, transparency, and accountability. Participation, non-discrimination, transparency, and accountability are commonly associated with a range of human rights—that is, they are crucial elements of, but not distinctive to, the right to health. On the other hand, the AAAQ derive from the Committee on Economic, Social and Cultural Rights' General Comment No. 14—in other words, they are closely associated with the right to health.

As Gruskin and colleagues observe, their list is “minimal.” If the list is to capture the influence of the right to health, at least three more elements are needed: progressive realization, maximum available resources, and international assistance and cooperation.⁴¹ Thus, when examining the following guidance, I pay particular attention to AAAQ, progressive realization, maximum available resources, and international assistance and cooperation.

First, under the rubric of “Guidelines for Social Mobilization,” *A Human Rights Approach to Tuberculosis* was published by WHO in 2001, not long after the Committee on Economic, Social and Cultural Rights' adoption of General Comment No. 14 in mid-2000.⁴² The heart of the guidelines consists of a section entitled “What are human rights?” and another called “TB and human rights.” The former refers generally to the right to health, progressive realization, and maximum available resources, and makes an oblique reference to international assistance and cooperation. The latter has several subsections on TB and poverty, children, women, and similar groups and issues. Most of these subsections end with a few lines on the relevance of human rights to the issue under discussion—for example, the only human rights content in the subsection on poverty is a quote from article 25 of the

Universal Declaration of Human Rights.⁴³ Scattered throughout the guidelines are occasional references to the right to health and General Comment No. 14, including two of the elements of AAAQ (availability and accessibility). Importantly, the guidelines are not intended to be comprehensive and are one of the earliest attempts within the UN to apply human rights to a health condition.⁴⁴ Nonetheless, from today's vantage point, they appear weak. The right to health, and some of its key elements, are evident, but marginal.

Second, *Ensuring Human Rights in the Provision of Contraceptive Information and Services: Guidance and Recommendations* was published by WHO in 2014.⁴⁵ Twenty-four specific and practical recommendations, clustered under concepts such as privacy, participation, accountability, and AAAQ, arose from an impressive combination of health-related evidence, human rights norms, and good process. The guidance is a measure of how far health and human rights have traveled since the TB guidelines thirteen years earlier. As for the place of the right to health, AAAQ form a key part of the structure of the guidance, but international assistance and cooperation is mentioned only once, while progressive realization and maximum available resources are barely visible.⁴⁶ The guidance considers "human rights standards as they are directly or indirectly applicable to contraceptive information and services" and its annex D provides a list of 14 relevant human rights, including the right to health. The guidance mentions the right to health on a few occasions.⁴⁷ However, despite the prominence given to AAAQ, overall the right to health has a fairly low profile.

Third, in 2011 the Human Rights Council asked OHCHR to prepare *Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Mortality and Morbidity*.⁴⁸ The guidance was presented to, and adopted by, the council in 2012.⁴⁹ Perhaps because of its origins, this guidance has a different tenor than the other two illustrations. Predictably, its human rights content is much stronger than in the TB guidelines and its evidence base is weaker

than the guidance on contraception. Overall, the maternal mortality guidance gives significantly higher visibility to the right to health through a combination of references to the right, AAAQ, progressive realization, maximum available resources, and international assistance and cooperation. For example, it devotes a chapter to international assistance and cooperation.⁵⁰

In conclusion, it is unrealistic to expect health policy makers or practitioners to read either a treaty provision or its corresponding general comment and then grasp how they are to operationalize the right to health. More detailed, specific, and practical human rights guidance is essential. By way of illustration, this section has looked at three examples: two in which the right to health has a marginal or low profile and one in which the profile is significantly higher. Firm conclusions cannot be drawn from this small sample, but it does highlight some important questions—for example, does it matter whether the right to health is absent, marginal, or prominent? To answer that question, it is necessary to clarify the distinctive contribution of the right to health to a rights-based approach.

The distinctive contribution of the right to health

Drawing from Gruskin and colleagues, the previous section provided a checklist of key right-to-health features, such as progressive realization, maximum available resources, and so on. However, more substantively, what is the distinctive contribution of the right to health to a rights-based approach? What does it contribute that other rights, which usually form part of such an approach, do not?

Most health policies, programs, and interventions cannot be implemented overnight; they take time, often years. Also, they usually require extensive resources. In the case of low- and middle-income countries, these resources include development assistance. For these reasons, the international right to health encompasses progressive realization, maximum available resources, and international assistance and cooperation.⁵¹ These concepts do not enfeeble the right to health. On the contrary, they ensure that the right to health has

the conceptual and operational potential to make a sustained contribution to the implementation of complex and costly health interventions that inevitably take years to put in place and will usually be ongoing. Also, as discussed, general comments have increased the usefulness of the right to health by interpreting it as including AAAQ.⁵²

Most of the other international human rights that are part of a human rights-based approach to health, such as the rights to life, privacy, and the prohibition against torture and inhuman and degrading treatment, do not have progressive realization and these other features. Of course, these other rights have a vital role to play in human rights-based approaches. But, for the most part, they do not have the qualities that give the right to health an indispensable role in relation to many health interventions, such as the construction of a quality health system for all, the establishment of a program for contraceptive information and services, or the establishment of harm reduction strategies for intravenous drug users. With few exceptions, civil, political, economic, social, and cultural rights place both negative and positive obligations on duty-bearers. However, the law and practice of economic, social, and cultural rights provide a more refined and extensive treatment of positive rights (i.e., the duty to fulfill and aspects of the duty to protect) than is provided by civil and political rights. In short, the right to health is equipped to make a crucial and *distinctive* contribution to a human rights-based approach to health.

My argument is that the right to health has the conceptual and operational *potential* to make an indispensable and distinctive contribution, especially in relation to the implementation of complex, costly, and long-term health interventions. However, this potential is not yet fully realized. Building on recent progress, more work is needed to develop concepts and practices that will make the right to health more effective and useful to policy makers, practitioners, and others. For example, in the context of finite budgets, how can policy makers prioritize among health interventions in a manner that is respectful of the international right to health? In recent years, progress has been made

toward answering this question, but the issues are complex and invite additional consideration.⁵³ Further advancing the conceptual and operational development of the international right to health will require multidisciplinary collaboration.

In conclusion, according to Sofia Gruskin, Edward Mills, and Daniel Tarantola, “the right to health forms the basis for much of the present work in health and human rights.”⁵⁴ Paul O’Connell agrees: “a consensus has emerged on the centrality of health as a basic human right.”⁵⁵ While Thérèse Murphy tends to the same view—“the rights to health and to have access to health care can be at the centre”—she adds an important rider with which I concur: “but other rights need to be present too.”⁵⁶

The conceptual and operational contours and content of the right to health are becoming clearer, and there is a strong case that the right to health makes a contribution to human rights-based approaches by way of its distinctive features, such as AAAQ, progressive realization, maximum available resources, and international assistance and cooperation. However, this valuable contribution is unlikely to be realized unless the right to health, including its distinctive features, are explicitly recognized and consistently applied. As we have seen, there is some preliminary evidence that this is not happening in relation to some rights-based approaches to health. This is partly a failure of legal interpretation.

If the right-to-health provisions of a treaty are relevant, then, according to article 31 of the Vienna Convention on the Law of Treaties, they have to be “interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its objects and purpose.”⁵⁷ In other words, the distinctive features of the right to health cannot be ignored or applied on some occasions but not on others; they have to be interpreted and applied in “good faith,” in accordance with their “ordinary meaning” and “context,” and in light of the treaty’s “objects and purpose.” This does not mean that the drafters of human rights-based approaches to health must become international lawyers. But it does mean they are required to have regard to the interpreta-

tion (i.e., the meaning) of the international right to health, and its distinctive features. So I now turn to the issue of legal interpretation.

Legal interpretative methods

In 2009, Fons Coomans and colleagues complained that “scholarship in the field of human rights is often lacking in attention to methodology.”⁵⁸ In recent years, attention to human rights method has grown, including in relation to health. For example, a new interest in measuring the evidence of impact of human rights on the health and well-being of individuals and communities has led to consideration of multidisciplinary research and evaluation methods.⁵⁹ The increasing attention to human rights method may arise from two interrelated factors: a deepening interest in the practical operationalization of human rights and the growing multidisciplinary of human rights studies. Both factors are especially acute in relation to economic, social, and cultural rights.

The growing interest in human rights method extends to human rights *legal* method. Murphy regrets that human rights legal method has been “a non-topic ... more disregarded than studied.”⁶⁰ In *Health and Human Rights*, she argues that “engagement with human rights legal method is essential” and she puts it “at centre stage.”⁶¹

In *The Right to Health in International Law*, after helpful chapters on the history of the right to health and its conceptual foundations, Tobin devotes a chapter to a legal methodology for interpreting the international right to health.⁶² His methodology illustrates major issues concerning the legal interpretation of the international right to health, as well as economic, social, and cultural rights more generally. It highlights issues that arise when treaty bodies, special rapporteurs, and agencies endeavor to interpret and apply the international right to health. Thus, Tobin’s proposed interpretative methodology warrants examination.

In summary, Tobin argues that the act of interpretation “is an attempt to persuade the relevant interpretative community that a particular

interpretation of the right to health is the most appropriate meaning to adopt.”⁶³ The “interpretative community” includes a “much wider range of stakeholders” whose “interests and insights must be taken into account in the interpretative exercise—a process described as constructive engagement.”⁶⁴ By “interpretative community,” Tobin refers to states, health professionals, international organizations, nongovernmental organizations, religious groups, multinational corporations, and “members of the general community who may be affected by the reallocation of resources to realize the right to health.”⁶⁵ General community members appear to be included to ensure, for example, that the health budget is not privileged over those of education or housing. At the beginning of his discussion, Tobin says that states form “a core part” of his interpretative community and then later describes them as “the central actors.”⁶⁶ He explains that, to be persuasive, the interpretation must satisfy four criteria—“it must be principled, practical, coherent, and context sensitive”—each of which he discusses in some detail.⁶⁷ Tobin favors an approach that “accepts the need to entertain a certain level of deference to the varied and often potentially conflicting interests within the relevant interpretative community.”⁶⁸

Claire Lougarre is troubled by Tobin’s interpretative methodology for three reasons. First, she doubts whether “consensus” among his interpretative community “should be the way we define human rights law” and observes the existence of “dangers that appeals to consensus might create.”⁶⁹ Katharine Young also argues that “the consensualist approach to the interpretation of economic and social rights is beset with several limitations.”⁷⁰ The approach fails “because it makes legitimate only the lowest common denominator of international protection.”⁷¹ If Tobin were to object that he is not arguing in favor of consensus, Young also points out that replacing unanimity with what she calls “majority consensus” is also problematic “because of the inevitable tendency to prejudice the minority articulation of rights.”⁷² She reminds us that “the claims of minorities ... are a main reason for the

existence of rights” and concludes that “focusing on consensus alone thwarts the definition of economic and social rights.”⁷³

Lougarre’s second difficulty with Tobin’s interpretative methodology is that it does not provide a solution to resolve conflicting views within the interpretative community.⁷⁴ Third, she doubts that his interpretative methodology “offers legal certainty to rights-holders and duty-bearers.”⁷⁵

In my view, there are several additional difficulties with Tobin’s interpretative methodology. For example, he begins by saying his aim is to devise a methodology that produces a meaning, or interpretation, of the right to health, but later he says the “aim ... is to contribute to a dialogue with the interpretative community whereby an understanding *as to the practical implementation of the right to health* will be developed through consultation and negotiation” (emphasis added).⁷⁶ Of course, interpretation and implementation are (or should be) closely related. Nonetheless, they remain distinct exercises. Interpretation focuses on clarifying the contours and content of the right to health—in other words, what the right means. On the other hand, implementation may be understood as diverse practical measures—laws, policies, practices, interventions, and so on—designed to ensure its realization.⁷⁷ Put simply, one needs a method to interpret the right to health (e.g., article 12 of the ICESCR) and also a process to work out how to implement it in the context of a particular state party (e.g., taking into account article 2(1) of the ICESCR). Implementation measures are bound to vary from one state to another, not least because all countries are at different stages of progressive realization and have different resource capacities. Although the overarching meaning of the right to health is not static, it will be much more constant, across both countries and time, than its implementation measures. In short, Tobin’s interpretative methodology would be more coherent and credible if it more clearly distinguished between interpretation and implementation.

However, his methodology has a more serious defect. At no point does Tobin mention the

rights-holders for whom article 12 is of particular importance: those living in poverty. Of course, article 12 has universal application, extending to everyone in a state’s jurisdiction. But, like ICESCR in general, article 12 has special relevance to the impoverished. The better-off, through their superior financial and other resources, including what Pierre Bourdieu calls “social capital,” are in a much stronger position to enjoy the right to health than those living in poverty.⁷⁸ Accordingly, any interpretative methodology of article 12 that fails to even acknowledge those living in poverty is deeply flawed for two reasons. First, it will have failed to put in place effective arrangements within the interpretative (or implementation) process that permit the active and informed participation of those living in poverty. Second, it is unlikely to identify and address the substantive health issues that are priorities for the impoverished. In short, Tobin’s “interpretative community,” which includes states, multinational corporations, and religious groups, excludes the individuals and communities who should be at the procedural and substantive center of the interpretative exercise. Tobin includes “NGOs that invoke the language of the right to health” in his “interpretative community,” but this could mean organizations that are far removed from the realities or insights of those living in poverty.

Of course, it is challenging to ensure the active and informed participation of those living in poverty in either an interpretative or implementation process. Certainly, elites and their allies will cavil and resist. Nonetheless, there is a wealth of theory and practice from which to draw.⁷⁹ In *Localising Human Rights*, for example, Koen de Feyter outlines four links in a chain: community-based organizations, local human rights nongovernmental organizations, international nongovernmental organizations, and allies in governmental and intergovernmental institutions.⁸⁰ The essential starting point is to ensure that the impoverished are visible and, by one means or another, have space to speak. Regrettably, Tobin’s methodology provides for neither, which casts a long shadow over the rest of his analysis.

Distinctive methods for the interpretation of ICESCR

Tobin's methodology points to juridical issues concerning the legal interpretation of international economic, social, and cultural rights, including the right to health in the context of rights-based approaches.

International policy makers and international human rights bodies have only recently begun to routinely apply and interpret economic, social, and cultural rights. There are exceptions, such as the International Labour Organization and its adjudicative bodies. Also, the Committee on Economic, Social and Cultural Rights has been interpreting and applying economic, social, and cultural rights since the late 1980s. Now that the Optional Protocol to the ICESCR has entered into force, the committee will have new opportunities to deepen its jurisprudence. Numerous UN Special Rapporteurs have interpreted and applied a range of economic, social, and cultural rights in relation to many themes and duty-bearers. Guidelines on international economic, social, and cultural rights are increasing.⁸¹ Nonetheless, on the whole, the international interpretation and application of these human rights is a relatively recent enterprise. As international economic, social, and cultural rights, including the right to health, gain currency, methodologies for their interpretation will have to address the relationship between public international law and international human rights law.

International human rights law is almost universally understood as a distinct subdiscipline of the broader, more general public international law.⁸² However, the relationship between the two domains "is a complex narrative of tension, evolution and juxtaposition."⁸³ While public international law is "traditionally considered as the rules and processes created by sovereign states to govern their interactions with each other," international human rights law is essentially concerned with placing entitlements on individuals and correlative obligations on states—in other words, the "constraint of state or public power."⁸⁴ As Scott Sheeran puts it, the origins of public international law are "inter-state,"

and the main focus of international human rights law is "intra-state."⁸⁵

Usually, international treaties reflect a contractual paradigm characterized by reciprocity between states—that is, an "exchange of obligations" between states in relation to peace, disarmament, trade, and other international matters.⁸⁶ However, international human rights treaties do not conform to this paradigm because, as expressed by the UN Human Rights Committee, they "are for the benefit of persons within [the state's] jurisdiction."⁸⁷ According to Matthew Craven, "it does seem that the overriding 'contractual' paradigm is largely (if not wholly) inappropriate in the case of human rights treaties."⁸⁸

As already discussed, article 31 of the Vienna Convention on the Law of Treaties provides general rules of interpretation for all treaties, including human rights treaties.⁸⁹ Broadly speaking, there are three schools of thought—or "doctrinal divisions"—for treaty interpretation: the "textual," "intentions," and "teleological" approaches. Clapham observes that article 31 manages to combine all three.⁹⁰ Article 32 provides the "supplementary means of interpretation"—for example, the preparatory work of a treaty, or *travaux préparatoires*.

A further important rule of interpretation is *lex specialis derogat legi generali*: whenever two or more norms deal with the same subject matter, priority should be given to the norm that is more specific.⁹¹ Sheeran remarks that this maxim is relevant with respect to competing rules *between* public international law and international human rights law, and also *within* international human rights law.⁹² While the application of the rule of *lex specialis* needs considerable care, it may have relevance in the context of international human rights law and international economic, social, and cultural rights.

International human rights and other bodies have considered these challenging issues of interpretation.⁹³ Here, it is neither possible nor necessary to analyze these contributions. However, three judicial pronouncements are especially instructive. The Inter-American Court of Human Rights has confirmed that human rights treaties do not con-

form to the traditional paradigm of an exchange of obligations between states:

*In concluding these human rights treaties, the States can be deemed to submit themselves to a legal order within which they, for the common good, assume various obligations, not in relation to other States, but towards all individuals within their jurisdiction.*⁹⁴

The European Court of Human Rights provides more specific interpretative guidance:

*In interpreting the Convention regard must be had to its special character as a treaty for the collective enforcement of human rights and fundamental freedoms Thus, the object and purpose of the Convention as an instrument for the protection of individual human beings require that its provisions be interpreted and applied so as to make its safeguards practical and effective. ... In addition, any interpretation of the rights and freedoms guaranteed must be consistent with the "general spirit of the Convention, an instrument designed to maintain and promote the ideals and values of a democratic society."*⁹⁵

In its Advisory Opinion on the Genocide Convention, the International Court of Justice not only alludes to the convention's distinctive character and the inapplicability of the traditional contractual paradigm but also emphasizes the importance of the "high ideals" underpinning the treaty:

*Consequently, in a convention of this type one cannot speak of individual advantages and disadvantages to States, or of the maintenance of a perfect contractual balance between rights and duties. The high ideals which inspired the Convention provide, by virtue of the common will of the parties, the foundation and measure of all its provisions.*⁹⁶

In summary, there is a credible argument that the distinctive features (or "special character") of human rights treaties permit distinctive methods of interpretation, while remaining within the interpretative boundaries established by the Vienna Convention on the Law of Treaties. If that is correct, what are these distinctive methods?

Briefly, Sheeran advises that the "*corpus juris* of human rights features a dominant dynamic or teleological method of interpretation, which considers treaties as 'living' instruments, rather than tied to the original intent of states parties."⁹⁷ This *corpus* has developed without much reference to international economic, social, and cultural rights because, as discussed, it is only recently that international policy makers and international human rights bodies have begun to routinely apply and interpret international economic, social, and cultural rights. However, if the prevailing human rights interpretative method tends to favor a teleological approach, this tendency is likely to be even more pronounced in relation to international economic, social, and cultural rights. Article 2(1) of the ICESCR requires states to take steps "with a view to achieving progressively the full realization of the rights recognized in the present Covenant."⁹⁸ Thus, with its explicit focus on progression toward a goal, both the text and the apparent intentions of the parties point toward a teleological method of interpretation in relation to international economic, social, and cultural rights, including the right to health.

Apart from their different catalogues of rights, what are the major differences between the International Covenant on Civil and Political Rights (ICCPR) and ICESCR that have interpretative implications? Here, I confine myself to two. First, as is well known, the key textual provisions in the ICCPR and ICESCR establishing the overarching legal obligations of state parties are substantively different. For example, while article 2(1) of the ICCPR uses the language of "respect and ensure," article 2(1) of the ICESCR, as already discussed, requires states "to take steps, individually and through international assistance and cooperation ... to the maximum of [their] available resources, with a view to achieving progressively the full realization" of the enumerated rights. It should not be overlooked, however, that article 2(2) of the ICCPR requires states "to take the necessary steps ... as may be necessary to give effect to" the enumerated rights, a formulation with similarities (i.e., taking steps) to article 2(1) of the ICESCR.

Second, while the object and purpose of the two treaties have much in common, there is an argument that their objects and purposes are also different; if that is correct, article 31 of the Vienna Convention on the Law of Treaties requires those interpreting the treaties to give due weight to this difference. Looking at the ICESCR as a whole, it can be argued that the object and purpose animating the covenant is the reduction and elimination of poverty, what President Roosevelt called “freedom from want.”⁹⁹ Although a closer examination of the object and purpose of the covenant is needed, the tenor of the Committee on Economic, Social and Cultural Rights’ statement on poverty tends to support this argument.¹⁰⁰ Of course, it is important that those living in poverty enjoy the full range of civil and political rights, as well as economic, social, and cultural rights. Nonetheless, the ICESCR is arguably shaped by the object and purpose of reducing and eliminating poverty, while the ICCPR is not. If so, the Vienna Convention on the Law of Treaties calls for the two treaties to be interpreted in a different manner, quite apart from their obvious textual differences.¹⁰¹

In summary, there is considerable support for the proposition that the distinctive features of human rights treaties permit distinct methods of interpretation. In addition, if the ICESCR’s object and purpose is to reduce and eliminate poverty, that treaty may be interpreted differently from the ICCPR. As the ICESCR is increasingly applied, international policy makers and human rights bodies will need to pay close attention to the distinctive legal interpretation of this covenant, including the right to health in the context of rights-based approaches to health.

Conclusion

This article has argued that in relation to human rights and health, the current trend is from theory to practice and the general to specific—hence the recent practical guidelines on specific health issues, such as contraception, maternal mortality, and under-five mortality. It has also shown that, since about 1993–1994, there has been a trend in

the scholarly literature away from consideration of the right to health by itself and toward looking at health and human rights generally—that is, human rights-based approaches to health. On the whole, these trends are welcome; for example, there are some advantages in moving from a right to health toward a rights-based approach. However, this article has also argued, and demonstrated by way of preliminary evidence, that there are risks associated with the adoption of a rights-based approach to health.

In the context of health policies, programs, and interventions, the human right of most central relevance will usually be the international right to health. The right has some features which make it especially well equipped to contribute to the effective implementation of health policies and interventions, over the medium and long term, in countries with different resource capacities. A risk arising from a human rights-based approach is that the right to health may become marginal within such an approach. Indeed, there is some preliminary evidence that this is happening. This might occur because the international right to health is not well understood. Also, in some quarters, there is ideological resistance to the right to health, in which case it may be convenient to “bury” the right within a human rights-based approach. For whatever reason, if the right to health does not explicitly play a central role in a rights-based approach, this is likely to weaken such an approach, diminish the right, and reinforce misconceptions about, and the marginalization of, economic, social, and cultural rights generally.

Thus, the preferred strategy is a rights-based approach to health that consistently and explicitly includes the international right to health. Certainly, giving the international right to health an explicit and central role within a rights-based approach will complicate some discussions. For example, it will become necessary to (1) distinguish between those human rights that are, and are not, subject to progressive realization; (2) explain that the right to health places more demanding obligations on high-income than low-income countries, except there are some “core obligations” that apply uni-

formly to all countries (e.g., non-discrimination, equitable access, and the adoption of an effective, participatory health strategy that gives particular attention to the disadvantaged); (3) confirm that states and others “in a position to assist” have a responsibility to provide international assistance and cooperation in health, especially to low-income countries; (4) explain that duty-bearers are accountable for their right-to-health obligations, including optimal progressivity, just as they are their obligations under the right to a fair trial; and (5) acknowledge that while effective health monitoring is important, it is not the same as accountability.¹⁰²

In this way, however, myths may be dispelled and rights-holders and duty-bearers may better grasp that the international right to health is not just exhortatory or rhetorical; on the contrary, it can help to improve the health and well-being of individuals, communities, and populations.¹⁰³ But this is unlikely to happen if the international right to health is placed on the fringes of a human rights-based approach, only implicitly present or “smuggled” in without discussion.

This is why legal interpretation is important. If the international right to health is to be applied, it needs to be explicitly placed in the center of a rights-based approach and interpreted in accordance with public international, and international human rights, law. The meaning of article 2(1) of the ICESCR—including the concepts of progressive realization, resource availability, and international assistance and cooperation, as well as AAAQ—needs careful discussion, interpretation, and application. These phrases and concepts are not yellow post-its: they have substantive content. Also, consistent with the Vienna Convention on the Law of Treaties, attention must be given to the ICESCR’s object and purpose, which probably include the reduction and elimination of poverty. Of course, such an interpretative exercise will be challenging because neither the meaning of the right to health nor the methods for its interpretation are settled. However, it is only by explicitly putting the right to health at the center of rights-based approaches to health, and by discussing its interpretation and application, including discussions with those living in

poverty, that the right can mature and consolidate its place in the international code of human rights.

Acknowledgments

I am very grateful to Danilo Curcic, Rebecca Wallace, Eibe Riedel, Thérèse Murphy, Rajat Khosla, Giulia Giannuzzi, Sabine Michalowski, and anonymous reviewers. However, the views in the article are mine, and any mistakes are my responsibility.

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APPENDIX

Thematic and mission reports prepared by UN Special Rapporteurs on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

PAUL HUNT, 2002-2008

Thematic reports

The right to health: sources, contours, and content. The mandate holder's key objectives, themes, and specific issues.	Report to the Commission on Human Rights, February 13, 2003 (E/CN.4/2003/5)
Right-to-health indicators. Good practices. HIV/AIDS. Neglected diseases (and leprosy). Optional Protocol to the Covenant on Economic, Social and Cultural Rights.	Report to the General Assembly, October 10, 2003 (A/58/427)
Sexual and reproductive health. Poverty (and Niger's Poverty Reduction Strategy). Neglected diseases. Violence prevention.	Report to the Commission on Human Rights, February 16, 2004 (E/CN.4/2004/49)
Millennium Development Goals. Indigenous peoples. Child survival and indicators.	Report to the General Assembly, October 8, 2004 (A/59/422)
Mental disability.	Report to the Commission on Human Rights, February 11, 2005 (E/CN.4/2005/51)
Commission on Social Determinants of Health. Health professionals and human rights education. The skills drain: migration of health professionals.	Report to the General Assembly, September 12, 2005 (A/60/348)
Right to an effective, integrated health system accessible for all. Human rights-based approach to health indicators.	Report to the Commission on Human Rights, March 3, 2006 (E/CN.4/2006/48)
Maternal mortality. Access to medicines (responsibilities of states and pharmaceutical companies).	Report to the General Assembly, September 13, 2006 (A/61/338)
Health and human rights movement. Cases on the right to health and other health-related rights.	Report to the Human Rights Council, January 17, 2007 (A/HRC/4/28)

Prioritization. Impact assessments. Water and sanitation.	Report to the General Assembly, August 8, 2007 (A/62/214)
Health systems and the right to health.	Report to the Human Rights Council, January 31, 2008 (A/HRC/7/11)
Accountability. Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines.	Report to the General Assembly, August 11, 2008 (A/63/263)

Mission reports

Intellectual property and access to medicines. Trade in services and the General Agreement on Trade in Services. Impact assessments. Gender and trade. Technical assistance. Trade Policy Review Mechanism. Accessing countries to World Trade Organization.	Report to the Commission on Human Rights on Mission to World Trade Organization, March 1, 2004 (E/CN.4/2004/49/Add.1)
Poverty. Prevention, treatment, and control of diseases. Women's and children's health. Health-related policy frameworks (poverty reduction and non-discrimination). Availability, accessibility, and acceptability of health care. Health professionals. Water and sanitation. Availability of resources.	Report to the Commission on Human Rights on Mission to Mozambique, January 4, 2005 (E/CN.4/2005/51/Add.2)
Poverty, discrimination, inequality, and the right to health. Role of international community, civil society, and health professionals. Trade agreements. Environment. Mental health. Sexual and reproductive health. Ethnicity and culture (indigenous peoples).	Report to the Commission on Human Rights on Mission to Peru, February 4, 2005 (E/CN.4/2005/51/Add.3)
Participation, access to information, accountability, and health professionals. Health system financing. Corruption. Sexual and reproductive health. HIV/AIDS. Tuberculosis. Mental health. Environment. Roma.	Report to the Commission on Human Rights on Mission to Romania, February 21, 2005 (E/CN.4/2005/51/Add.4)
Neglected diseases.	Report to the Commission on Human Rights on Mission to Uganda, January 19, 2006 (E/CN.4/2006/48/Add.2)
Detention. Mental health. Ethical obligations of health professionals. Force-feeding.	Report to the Commission on Human Rights on the situation of detainees at Guantanamo Bay, February 27, 2006 (E/CN.4/2006/120)
Protection of civilians during and after the conflict of 2006, and the right to health.	Report to the Human Rights Council on Lebanon/Israel conflict of August 2006, October 2, 2006 (A/HRC/2/7)
Integration of the right to health into domestic laws and policies. Access to appropriate health care. Mental health. The Sami. Harm-reduction for drug users. Human rights education and health professionals. Asylum-seekers and undocumented foreign nationals. International obligations in relation to the right to health and development. Health indicators. Disaggregation of data. Impact assessment.	Report to the Human Rights Council on Mission to Sweden, February 28, 2007 (A/HRC/4/28/Add.2)
Sweden's obligations of international assistance and cooperation in relation to the right to health. Sweden's role in Uganda, the World Bank, and International Monetary Fund. ³	Report to the Human Rights Council on Missions to Uganda, the World Bank, and the International Monetary Fund, March 5, 2008 (A/HRC/7/11/Add.2)
The government of Ecuador invited the rapporteur to appraise Colombia's aerial spraying of glyphosate along the Colombia-Ecuador border. The Rapporteur visited Ecuador (May 2007) and Colombia (September 2007).	The Rapporteur publicly presented his preliminary conclusions and recommendations at the end of both visits. ⁴ Subsequently, Ecuador issued proceedings against Colombia before the International Court of Justice. In these circumstances, the Rapporteur did not submit a full report to the UN Human Rights Council.
Access to medicines. Human rights responsibilities of pharmaceutical companies. Affordability of medicines. Effects of patents and licensing on access to medicines. Research and development: neglected diseases and pediatric formulations.	Report to the Human Rights Council on Mission to GlaxoSmithKline, May 5, 2009 (A/HRC/11/12/Add.2) ⁵
Maternal mortality.	Report to the Human Rights Council on Mission to India, April 15, 2010 (A/HRC/14/20/Add.2)

ANAND GROVER, 2008–2014

Thematic reports

Access to medicines. Impact of intellectual property rights on access to medicines.	Report to the Human Rights Council, March 31, 2009 (A/HRC/11/12)
Informed consent.	Report to the General Assembly, August 10, 2009 (A/64/272)
Same-sex conduct, sexual orientation and gender identity. Sex work. HIV transmission. Effects of criminalization on the right to health.	Report to the Human Rights Council, April 27, 2010 (A/HRC/14/20)
Impact of drug control on the right to health. Compulsory treatment for drug dependence. Access to controlled medicines. Human rights-based approach to drug control.	Report to the General Assembly, August 6, 2010 (A/65/255)
Access to medicines.	Report to the Human Rights Council, March 16, 2011 (A/HRC/17/43) 5
Development. Convergence of development, human rights and the right to health. Human rights-based approaches to development.	Report to the Human Rights Council, April 12, 2011 (A/HRC/17/2)
Right to health of older persons.	Report to the Human Rights Council, July 4, 2011 (A/HRC/18/37)
Impact of criminalization on sexual and reproductive health. Family planning. Education and information.	Report to the General Assembly, August 3, 2011 (A/66/254)
Occupational health.	Report to the Human Rights Council, April 10, 2012 (A/HRC/20/15)
Health financing and the right to health.	Report to the General Assembly, August 13, 2012 (A/67/302)
Access to medicines.	Report to the Human Rights Council, May 1, 2013 (A/HRC/23/42)
Right to health of migrant workers.	Report to the Human Rights Council, May 15, 2013 (A/HRC/23/41)
States and non-state actors' obligations toward persons affected by or involved in conflict situations.	Report to the General Assembly, August 9, 2013 (A/68/297)
Unhealthy foods and diet-related non communicable diseases.	Report to the Human Rights Council, April 1, 2014 (A/HRC/26/31)
Effective and full implementation of the right-to-health framework. Justiciability. Progressive realization and the enforcement of the right to health. Transnational corporations. International investment agreements. Investor-state dispute settlement.	Report to the General Assembly, August 11, 2014 (A/69/299)

Mission reports

Sexual and reproductive health. Harm reduction policies for drug users. Harm reduction policies and HIV/AIDS.	Report to the Human Rights Council on Mission to Poland, May 20, 2010 (A/HRC/14/20/Add.3)
Right to health of indigenous peoples. Detention.	Report to the Human Rights Council on Mission to Australia, June 3, 2010 (A/HRC/14/20/Add.4)
Inequalities and discrimination. Indigenous peoples. Women's right to health. Sexual and reproductive health. Violence against women. Access to medicines.	Report to the Human Rights Council on Mission to Guatemala, March 16, 2011 (A/HRC/17/25/Add.2)
Women's and children's health. Gender-based and family violence. Right to health of stateless persons and refugees. Detention.	Report to the Human Rights Council on Syrian Arab Republic, March 21, 2011 (A/HRC/17/25/Add.3)
Mental health. Maternal health. Malaria. Environment. Occupational health.	Report to the Human Rights Council on Mission to Ghana, April 10, 2012 (A/HRC/20/15/Add.1)
Access to medicines. HIV/AIDS. Criminalization of sex work and the use of drugs. Detention.	Report to the Human Rights Council on Mission to Vietnam, June 4, 2012 (A/HRC/20/15/Add.2)
Tuberculosis. Mental health. Domestic violence.	Report to the Human Rights Council on Mission to Tajikistan, May 2, 2013 (A/HRC/23/41/Add.2)
Tuberculosis. Detention.	Report to the Human Rights Council on Mission to Azerbaijan, May 3, 2013 (A/HRC/23/41/Add.1)
Right to health and nuclear disaster management.	Report to the Human Rights Council on Mission to Japan, July 31, 2013 (A/HRC/23/41/Add.3)

DAINIUS PŪRAS, 2014–CURRENT

Thematic reports

Overview of the mandate. Priorities in future work.	Report to the Human Rights Council, April 2, 2015 (A/HRC/29/33)
Child survival. Early childhood development.	Report to the General Assembly, July 30, 2015 (A/70/213)
Right to health of adolescents.	Report to the Human Rights Council, April 4, 2016 (A/HRC/32/32)
Sports and healthy lifestyles. Non-state actors' obligations. Good-practice approaches.	Report to the Human Rights Council, April 4, 2016 (A/HRC/32/33)
Sustainable development goals.	Report to the General Assembly, August 5, 2016 (A/71/304)

Mission reports

Health system financing. Vulnerable groups.	Report to the Human Rights Council on Mission to Malaysia, May 1, 2015 (A/HRC/29/33/Add.1)
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International Human Rights and the Mistreatment of Women During Childbirth

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Abstract

International human rights bodies have played a critical role in codifying, setting standards, and monitoring human rights violations in the context of sexual and reproductive health and rights. In recent years, these institutions have developed and applied human rights standards in the more particular context of maternal mortality and morbidity, and have increasingly recognized a critical human rights issue in the provision and experience of care during and after pregnancy, including during childbirth. However, the international human rights standards on mistreatment during facility-based childbirth remain, in an early stage of development, focused largely on a discrete subset of experiences, such as forced sterilization and lack of access to emergency obstetric care. As a consequence, the range of mistreatment that women may experience has not been adequately addressed or analyzed under international human rights law. Identifying human rights norms and standards related to the full range of documented mistreatment is thus a first step towards addressing violations of human rights during facility-based childbirth, ensuring respectful and humane treatment, and developing a program of work to improve the overall quality of maternal care. This article reviews international human rights standards related to the mistreatment of women during childbirth in facility settings under regional and international human rights law and lays out an agenda for further research and action.

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Competing interests: None declared.

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Introduction

International human rights bodies have played a critical role in codifying, setting standards, and monitoring human rights violations in the context of sexual and reproductive health and rights.¹ In recent years, these institutions have developed and applied human rights standards in the more particular context of maternal mortality and morbidity, and have increasingly recognized a critical human rights issue in the provision and experience of care during and after pregnancy, including during the time of childbirth.^{2,3} However, the international human rights standards on mistreatment during facility-based childbirth remain in an early stage of development, focused largely on a discrete subset of issues such as forced or coerced sterilization and denied or neglected access to emergency obstetric care. A recent systematic review of the scientific literature documented an extensive range of mistreatment to which women are subjected during childbirth, including forms of physical, verbal, and sexual abuse; experiences of discrimination and neglect; and denials of privacy, confidentiality, and high-quality care.⁴ However, many forms of mistreatment remain unaddressed or inadequately analyzed under international human rights law.

The World Health Organization (WHO) addressed this gap in a 2014 statement on mistreatment during childbirth and its associated human rights violations, calling for greater action, dialogue, research, and advocacy on this global problem.⁵ The statement, endorsed by more than 90 international, civil society, and health professional organizations, affirms that “every woman has the right to the highest attainable standard of health, which includes the right to dignified, respectful health care throughout pregnancy and childbirth.”⁶ This right was further highlighted in 2015, as UN and regional human rights experts, the rapporteur on the rights of women of the Inter-American Commission on Human Rights, and the special rapporteurs on the rights of women and human rights defenders of the African Commission on Human and Peoples’ Rights issued a joint statement explicitly calling on states to address “acts of obstetric and institutional violence.”⁷

Identifying human rights norms and standards related to the full range of documented mistreatment is thus a first step towards addressing violations of human rights during facility-based childbirth, ensuring respectful and humane treatment, and developing a program of work to improve the overall quality of maternal care. A qualitative evidence synthesis found that mistreatment during childbirth is a potent disincentive for women to attend facilities in low- and middle-income countries.⁸ Hence, efforts to improve maternity care could also encourage more women to use facilities during pregnancy and childbirth.

Based in international and regional treaty law, human rights standards are developed through authoritative interpretations by a diverse set of institutions, including treaty-monitoring bodies, the Human Rights Council and special rapporteurs, and regional courts and commissions, all of which have been addressing different aspects of treatment of pregnant women in health care settings in their different reports over the years. Any one form of mistreatment may implicate multiple human rights and result in their violations, reflected in Table 1.

This article reviews existing international human rights standards related to the mistreatment of women during childbirth in facility settings under regional and international human rights law. While this article acknowledges the critical role of national legal systems in developing human rights standards, its objective is to identify and articulate human rights standards in international law.

Methods

The starting point of this review of human rights standards was a mixed-methods systematic review published by Bohren and colleagues which identified several forms of mistreatment women experience during childbirth in health facilities: physical, sexual, and verbal abuse; stigma and discrimination; care that falls short of professional standards; and poor rapport with providers. The review also identified health system factors contributing to these occurrences and proposed a typology of the identified forms of mistreatment.⁹

This typology, presented in Table 1, is organized by common attributes of specific events or instances of mistreatment during childbirth in facilities.

The review of human rights standards was conducted in two stages. First, a review was undertaken of reports, concluding observations, and general comments of the UN Human Rights Council, treaty monitoring bodies, and special rapporteur reports. Four databases were searched: the OHCHR Universal Human Rights Index; Bayefsky.com; the University of Minnesota Human Rights Library; and the Universal Periodic Review (UPR). Findings included results from documents of the Committee against Torture (CAT); Committee on the Elimination of Discrimination against Women (CEDAW); Committee on the Rights of the Child (CRC); Committee on Economic, Social and Cultural Rights (CESCR); Human Rights Committee (HRC); the special rapporteur on the right to health; and the special rapporteur on torture. Relevant findings of the UN Human Rights Council, other treaty monitoring bodies, and special rapporteurs (including reports, concluding observations, and general comments) were also reviewed. Second, a regional review was undertaken. This included a review of resolutions and decisions of regional human rights bodies: Inter-American Commission of Human Rights (IACHR/CIDH) (including the Organization of American States (OAS)); the African Commission of Human and Peoples' Rights (including the African Union); and the European Court of Human Rights (ECHR) (including the Council of Europe). All recovered documents were critically reviewed in relation to normative developments regarding mistreatment of women during childbirth.

For both stages of review, search terms were variations on the following concepts: childbirth, informed consent, discrimination, accountability, abuse in childbirth, mistreatment during childbirth, sterilization, stigma, harmful practices during childbirth, sexual and reproductive health and rights, respect and disrespect, and reproductive choice. The review included findings covering 2000 to 2015 (general comments issued in 2016 were also reviewed). Searches were done for documents written in English, and also in Spanish for IACHR/CIDH, in-

cluding the OAS and national judgments. We elected to begin the search with findings from 2000, when the UN Committee on Economic, Social and Cultural Rights issued General Comment No. 14, which set down a common framework for the development of human rights standards in health.¹⁰

The search covered all findings (including concluding observations, general comments, and recommendations) where international or regional human rights bodies had made explicit observations on mistreatment during childbirth, as well as those that dealt with the issue implicitly. Based on this initial search, data was extracted and organized according to human rights norms and standards that explicitly address events of mistreatment during childbirth (as referenced in the typology). Human rights standards that address more generally the treatment of women in the provision of reproductive health care were also included, on the assumption that such care includes childbirth. Findings without a specific focus on issues related to childbirth, or on mistreatment occurring during childbirth, were excluded.

Results

This section provides an overview of the international and regional human rights standards related to the mistreatment of women during childbirth in facility settings organized by the third-order themes presented in the Bohren et al. typology (Table 1). Acknowledging the indivisibility and interconnectedness of human rights, any one form of mistreatment may implicate multiple human rights, as reflected in the overlap of rights shown in Table 1.

Violence (physical, sexual, and verbal abuse)

Manifestations of violence against women during childbirth in facility settings are varied. Women have reported physical and verbal abuse, such as beatings, hitting, slapping, kicking, and pinching.¹¹ The use of mouth gags and bed restraints, such as shackles and ropes, during labor is also documented.¹² Health care professionals (including obstetricians) have been reported for sexually

assaulting their patients.¹³ There is extensive documentation of demeaning and degrading verbal abuse by maternity care providers.¹⁴ These include the use of abusive, harsh, or rude language, threats to withhold treatment or of poor outcomes, as well as judgmental, accusatory remarks.¹⁵ Women from marginalized communities, such as racial and ethnic minorities, refugees, unmarried women, and adolescents, may be more vulnerable to this abuse.¹⁶

International and regional human rights experts have also noted the severity of obstetric violence faced by women giving birth while in detention facilities. In a joint statement, a group of special rapporteurs noted: “We are deeply disturbed by reports of women being shackled to their hospital beds whilst giving birth in prison.”¹⁷ Other human rights bodies have reiterated this concern. The UN Committee Against Torture has also expressed concern over “the treatment of detained women,” including “incidents of shackling of women detainees during childbirth.”¹⁸ The committee recommended that state parties “should adopt all appropriate measures to ensure that women in detention are treated in conformity with international standards.”¹⁹

Such abuse impinges on women’s human right to be free from gender-based violence, defined as “acts that inflict physical, mental or sexual harm or suffering, threats of such acts, coercion, and other deprivations of liberty.” These acts impair or nullify women’s fundamental rights, including the rights to health and privacy.²⁰ The right to live free from violence is based in norms of physical, sexual, and psychological integrity, and extends to both the public and private spheres.²¹

Acts of violence during childbirth may also constitute violations of the right to be free from torture, or cruel, inhuman, or degrading treatment, which is protected by numerous international and regional treaties.²² Cruel, inhuman, and degrading treatment is not restricted to acts that cause physical pain, but also encompasses acts that result in mental suffering.²³ Treatment withheld during pregnancy that causes the patient emotional distress, for example, has been interpreted as inhuman

and degrading treatment.²⁴ The special rapporteur on torture recently called attention to the ways health care professionals may inflict physical and psychological suffering, amounting to cruel, inhuman, and degrading treatment and torture, on women before, during, and after childbirth.²⁵

Stigma and discrimination

International human rights law guarantees the right to be free from discrimination on the basis of sex, race, health status, sexual orientation, economic or social status, gender, disability, age, and other statuses.²⁶

The mistreatment of women during facility-based childbirth raises concerns of sex and gender discrimination because it exclusively impinges upon the health and rights of women and limits their enjoyment of equality in access to health care.²⁷ International human rights law recognizes, too, the particular vulnerability of pregnant women, including during childbirth and for a reasonable period before and after, which may render them at greater risk of mistreatment in health care settings.²⁸

Such mistreatment can result from negative gender stereotyping, for example, about women’s lack of decision-making capacity, or their deservedness of suffering or punishment.²⁹ The African Commission on Human and People’s Rights has addressed the need to eliminate gender stereotyping in reproductive health care settings, emphasizing that efforts should “be especially made to address patriarchal attitudes, as well as the prejudices of health care providers.”³⁰

Women who belong to marginalized groups may also be vulnerable to mistreatment during childbirth due to their age, race/ethnicity, socio-economic, migration, and/or health status, sexual orientation/gender expression, and/or location.³¹ The enhanced risk of human rights abuses in the context of reproductive health care, based on sex and/or gender and such intersecting factors is well documented, and is often referred to as intersectional or multiple discrimination.³² The HRC and CRC, for example, have both recognized the vulnerability of girls to denials of reproductive health

services and information on the basis of age.³³ The CEDAW Committee attributed poor quality of care in a case on maternal mortality to the intersecting vulnerabilities of gender, race, and socio-economic status.³⁴ Other forms of mistreatment that violate the right to be free from discrimination include segregation within maternity hospitals on the basis of race and/or ethnic origin, as experienced by Roma women in Europe, and the detention of women in maternity hospitals following childbirth because of their inability to pay (economic status).^{35,36}

Refusal of care is another form of economic discrimination. The CEDAW Committee, for example, raised concern under the right to non-discrimination in access to health care services for the “many women [who] are at risk of death or disability from pregnancy-related causes because they lack the funds to obtain or access the necessary services, which include antenatal, maternity and post-natal services.”³⁷

Committees have also drawn attention to stigma and discrimination against poor women, manifested in the form of post-delivery detention of women within health facilities for non-payment of fees. The UN Committee against Torture (CAT) has recognized such detention as a deprivation of liberty and called for an end to the practice. Such practices are condemned in other human rights treaties. CEDAW obligates States Parties to ensure women receive appropriate services in connection with pregnancy, confinement, and the post-natal period, including free services where necessary.³⁸ In interpreting this provision, the CEDAW Committee addressed the economic vulnerability of women in the context of childbirth.³⁹ Part of the state obligation to ensure women’s right to safe motherhood thus includes state provision of services to the maximum extent of available resources.⁴⁰

International human rights institutions have developed strong standards on coercive sterilization, including during labor and delivery, against HIV-positive women, Roma and indigenous women, and women with disabilities, which address, in particular, claimed medical justification for the practice.⁴¹ The UN special rapporteur on torture, for example, acknowledged that “the administra-

tion of non-consensual medication or involuntary sterilization is often claimed as being a necessary treatment for the so-called best interest of the person concerned.”⁴² In setting a human rights standard against this practice, he referenced the ethical guidelines of the International Federation of Gynecology and Obstetrics, which state: “sterilization for the prevention of future pregnancy cannot be ethically justified on grounds of medical emergency.”⁴³

In the context of individual cases, the CEDAW Committee and the ECHR have each developed human rights standards on coercive sterilization where professional standards of care, including informed consent standards, were not met.⁴⁴ The ECHR, in a case against Slovakia in 2012, highlighted that in failing to secure a woman’s informed consent, they had acted with “gross disregard for her right to autonomy and choice as a patient” —regardless of the fact that the medical staff involved did not intend to mistreat the patient. The Court described the actions of the hospital staff as “paternalistic, since, in practice, the applicant [patient] was not offered any option but to agree to the procedure which the doctors considered appropriate.”⁴⁵ Such treatment caused the patient “feelings of fear, anguish and inferiority and to entail lasting suffering.”⁴⁶ Imposing medical treatment without informed consent, the Court concluded, is “incompatible with the requirement of respect for human freedom and dignity, one of the fundamental principles on which the [European] Convention [on Human Rights] is based.”⁴⁷ The African Commission on Human and People’s Rights’ resolution on sterilization places particular emphasis on the involuntary sterilization of HIV-positive women.⁴⁸

Failure to meet professional standards of care

Mistreatment of women in the reproductive health context, including mistreatment during childbirth, often occurs in the context of overall failures to meet professional standards of care. Painful and unnecessary exams, refusals to provide pain relief, neglect, abandonment and long delays, breaches of confidentiality, and the lack of informed consent, including

in the context of sterilization, as discussed above, are documented examples of such failures.⁴⁹

The CEDAW Committee, in the context of women's health generally, has called on governments to monitor the quality of health services, and to ensure that professional standards of care are met and health services are "delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives."⁵⁰

Sexual and reproductive health, including during childbirth, involves many sensitive and personal matters that patients may wish to keep private within families or communities, but that they entrust to health care workers. Confidentiality includes the duty of providers to protect an individual's privacy, and thus not to share patient information with third parties, including the woman's spouse, parents, or other family members or friends, without the patient's full and informed consent.⁵¹

This duty of medical confidentiality is important in the provision of health care during childbirth because many women are vulnerable to personal harm or discrimination when it is breached.⁵² Fear of disclosure of private information, such as HIV status, has also deterred women from attending facilities for childbirth.⁵³

The ECHR has recognized the necessity of ensuring confidentiality and informed consent during facility-based childbirth. In a case involving a group of medical students observing a woman during childbirth without her consent, the Court noted that the patient only learned of the presence of the medical students while in a state of extreme stress and fatigue, between two sessions of drug-induced sleep, and during prolonged contractions. Given these circumstances, the Court questioned whether the patient actually had a choice regarding the students' participation, and whether she was capable of making an intelligible, informed decision. In finding a violation of the right to respect for private life, the Court emphasized the lack of adequate notice, the patient's vulnerable condition during childbirth, and the lack of alternative arrangements to ensure the patient has a meaningful opportunity to refuse observation.⁵⁴

Failure to meet professional standards of care is sometimes attributed to power dynamics in health care settings, especially between health care providers, who hold medical knowledge, and patients, who are dependent upon the health system to obtain information and care. The UN special rapporteur on the right to health has recognized this power dynamic, describing the right to autonomy over medical decision-making as a counterweight to "the imbalance of power, experience and trust inherently present in the doctor-patient relationship."⁵⁵ This imbalance is reflected in the abuse of the doctrine of medical necessity to justify mistreatment. The UN special rapporteur on torture has recognized that "the doctrine of medical necessity continues to be an obstacle to protection from arbitrary abuses in health-care settings" and has acknowledged reports of "health providers withholding care or performing treatments that intentionally or negligently inflict severe pain or suffering for no legitimate medical purpose."⁵⁶ Medical care that causes severe suffering for no justifiable reason can be considered "cruel, inhuman or degrading treatment or punishment."⁵⁷

The CEDAW Committee has noted, for example, unnecessary and non-medically indicated interventions during childbirth, and has called for adequate safeguards to ensure that medical procedures during childbirth are subject to objective assessments of need, and are conducted with respect for women's autonomy and informed consent.⁵⁸ In addressing the historical practice of symphysiotomies conducted during childbirth, the Human Rights Committee called for the investigation, prosecution, and punishment of perpetrators, and for reparations to victims.⁵⁹

Poor rapport between women and providers

Autonomy, often captured by the concept of informed decision-making, is a critical human rights component of reproductive health. Yet women commonly describe communication failures with health workers during facility-based childbirth, which leave them "feeling in the dark" about the state of their health (for example, with labor complications) and the nature of proposed care

(benefits, risks, and alternatives).⁶⁰ These failures sometimes stem from language or other interpretation barriers, but women also report that health workers withhold or rush through information in an effort to secure patient compliance.

Under the European Convention of Human Rights, the right of a pregnant woman to obtain available information about her health is protected under the right to respect for private life.⁶¹ The ECHR affirms: “In the context of pregnancy, effective access to relevant information on the mother’s and foetus’ health ... is directly relevant for the exercise of personal autonomy.”⁶² To ensure equality in access to health care services, CEDAW likewise guarantees women the right “to be fully informed, by properly trained personnel, of their options in agreeing to treatment ... including likely benefits and potential adverse effects of proposed procedures and available alternatives.”⁶³ Critical to the full scope of this right is the timing and manner of information provision. For example, in a case involving the coercive sterilization of a Roma woman during an emergency Caesarean section, the CEDAW Committee emphasized that the patient “did not understand the Latin term for sterilization that was used on the barely legible consent note that had been handwritten by the doctor ... [She was not given] information in a way in which she was able to understand it.”⁶⁴ In finding the State Party in violation of its human rights obligations, the Committee referred to the medical records that revealed the patient was in a very poor state of health, even shock, when she was informed about the procedure and her consent obtained.

Human rights standards routinely link informed decision-making to values of both autonomy and dignity.⁶⁵ Under the right to health, acceptable services are defined as those “delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives.”⁶⁶ Women commonly report not being respected, supported, or cared for by health workers during facility-based childbirth.⁶⁷ Though technically sound, care that is lacking in compassion, attentiveness, and concern for wom-

en’s needs and perspectives leaves the patients feeling disempowered, frightened, and alone.⁶⁸ In the aforementioned case involving non-consensual medical student observation of childbirth, the ECHR reaffirmed its longstanding position that the intimate nature of any medical intervention on the human body, however minor, implicates the right to respect for private life.⁶⁹ In another case, a woman was denied access to prenatal diagnostic care, and the Court found a State Party in violation of the right to be free from inhuman and degrading treatment.⁷⁰ The Court again recognized the vulnerability of pregnant women seeking information and care, especially those concerned with the healthy development of their pregnancies. The woman had endured weeks of painful uncertainty about her own and her family’s future because health workers failed to acknowledge and address her concerns.⁷⁰ Moreover, the Court found that health workers had deliberately withheld treatment in an effort to frustrate the patient’s exercise of autonomy in the management of her pregnancy.⁷³

UN treaty monitoring bodies and regional mechanisms have also drawn attention to the serious harms of removing newborns from the care of their mothers, against the mothers’ will, and without a compelling health-related justification.⁷³ Such practices exploit the vulnerability of women in childbirth, reducing them to dependent and passive patients.

Health system conditions and constraints

Broader health system constraints and limitations can contribute, directly or indirectly, to women’s negative experiences during childbirth. Overworked or undertrained providers, overcrowded or unsanitary facilities, or a lack of medical supplies make it challenging for health care providers to provide respectful, woman-centered care.⁷⁴ Under CESC, the availability and quality of health facilities, goods, and services is an essential component of the right to health, as is the adequate training of obstetric care professionals.⁷⁵

The Protocol on the Rights of Women in Africa (Maputo Protocol) more specifically obligates State Parties to “establish and strengthen existing

pre-natal, delivery and post-natal health and nutritional services for women during pregnancy and while they are breast-feeding,” and requires that provider training include not only technical aspects of care, but quality of care issues such as “non-discrimination, confidentiality, respect for autonomy and free and informed consent.”⁷⁶ In a case involving a poor woman who died as a result of obstetric complications while seeking care in multiple health facilities, the CEDAW Committee found the State Party in violation of the rights to life, health, and non-discrimination.⁷⁶ These violations, as well as the CEDAW Committee’s recommendations for redress, reached system-level factors of neglect, including the inadequate resources and ineffective implementation of existing state policies.⁷⁸ The Committee also affirmed that “the State is directly responsible for the action of private institutions when it outsources its medical services, and that furthermore, the State always maintains the duty to regulate and monitor private health-care institutions.”⁷⁹

Human rights standards, including the right to health, the right to privacy, the right to be free from torture and other ill-treatment, and the right to an effective remedy, among other rights, require the adoption of clear legal and procedural frameworks to ensure the effective delivery of and access to health services. While health system constraints, including lack of resources or services, may create conditions for mistreatment in facility-based childbirth, they cannot be used to justify these actions.⁸⁰ Rather, the UN special rapporteur on torture identifies states obligation to redress abuse within health systems by establishing adequate redress and accountability mechanisms, reforming regulation of the system, and promoting a culture of respect for human integrity and dignity within health settings.⁸⁰ CESCR requires states to “ensure that all individuals have access to justice and to a meaningful and effective remedy in instances where the right to sexual and reproductive health is violated.”⁸² As interpreted in the maternal health context, the United Nations

Human Rights Council obligates states to ensure accountability at the professional and institutional levels of the health system.⁸³

Conclusion

Human rights standards are an important accountability tool for recognizing and protecting the human rights of women during childbirth in facilities, and for supporting health system reform to prevent mistreatment in the future. Human rights standards assist health care practitioners and policy makers to define what constitutes mistreatment during childbirth and to develop effective interventions and policies to address this mistreatment in all its forms. This review of existing human rights standards thus suggests two areas for action. First, there is a call for continued human rights monitoring and documentation to deepen our understandings of the nature of violations, their causes and effects, and the development of more comprehensive human rights standards to guide remedy and redress measures.⁸⁴ Meaningful human rights accountability is not possible without systematic monitoring and other initiatives to gather information about the conditions of service access and delivery, to identify where and why patient-provider relations break down, and to thereby identify concrete actions the state can take to fulfill women’s human rights. Second, there is a need to develop innovative human rights accountability measures to enforce standards both for individual remedy and redress for victims of mistreatment, but also for constructive accountability within health systems to prevent future violations. These are measures that can effectively and sustainably transform health systems to shape and change the experience of service provision and access. This includes measures taken to ensure that hospital environments and staff are sufficiently trained and empowered to meet women’s emotional, physical, and medical needs and guarantee that human rights are respected. Supporting institutional arrange-

TABLE 1. Typology of mistreatment of women during facility-based childbirth⁸⁵ and relevant human rights

Third order	Second order	First order	Relevant human rights
Physical abuse	Use of force	Beaten, slapped, kicked, and pinched during delivery	<ul style="list-style-type: none"> • Right to be free from violence • Right to be free from torture and other ill-treatment
	Physical restraint	Physically restrained to the bed or gagged during delivery	
Sexual abuse	Sexual abuse	Sexual abuse or rape	<ul style="list-style-type: none"> • Right to non-discrimination • Right to health
Verbal abuse	Harsh language	Harsh or rude language	<ul style="list-style-type: none"> • Right to privacy (including physical and mental integrity) • Right to be free from practices that harm women and girls • Right to information • Right to decide the number, spacing, and timing of children
		Judgmental and accusatory comments	
	Threats and blaming	Threats of withholding treatment or poor outcomes Blaming for poor outcomes	
Stigma and discrimination	Discrimination based on socio-demographic characteristics	Discrimination based on sex and/or gender	<ul style="list-style-type: none"> • Right to non-discrimination • Right to be free from torture and other ill-treatment • Right to health • Right to decide the number, spacing, and timing of children • Right to information
		Discrimination based on ethnicity/race/religion	
		Discrimination based on age	
	Discrimination based on socio-economic status		
	Discrimination based on medical conditions	Discrimination based on HIV status	
Failure to meet professional standards of care	Lack of informed consent and confidentiality	Lack of informed consent process	<ul style="list-style-type: none"> • Right to privacy • Right to health • Right to non-discrimination • Right to be free from violence • Right to information • Right to decide the number, spacing, and timing of children • Right to be free from torture and other-ill treatment
		Breaches of confidentiality	
	Physical examinations and procedures	Painful vaginal exams	
		Refusal to provide pain relief	
		Performance of unconsented surgical operations	
	Neglect and abandonment	Neglect, abandonment, and long delays	
Skilled attendant absent at time of delivery			
Poor rapport between women and providers	Ineffective communication	Poor communication	<ul style="list-style-type: none"> • Right to privacy • Right to information • Right to non-discrimination • Right to be from torture and other ill-treatment
		Dismissal of women's concerns	
		Language and interpretation issues	
		Poor staff attitudes	
	Lack of supportive care	Lack of supportive care from health workers	
		Denial or lack of birth companions	
	Loss of autonomy	Women treated as passive participants during childbirth	
		Denial of food, fluids, and mobility	
		Lack of respect for women's preferred birth positions	
		Denial of safe traditional practices	
		Objectification of women	
		Detainment in facilities	
	Health systems conditions and constraints	Lack of resources	
Staffing constraints			
Staffing shortages			
Supply constraints			
Lack of privacy			
Lack of policies		Lack of redress	
Facility culture		Bribery and extortion	
		Unclear fee structures	
		Unreasonable requests of women by health workers	

ments for the active and informed participation of women as intended beneficiaries of maternal care in all aspects of its design and implementation is critical for constructive accountability.⁸⁵ Engaging women and accounting for their experiences in health system reform is the first order of respect in a human rights approach to maternal care.⁸⁶ Lastly, further research is needed to develop effective human rights-based interventions to promote and protect women's sexual and reproductive health and rights and ensure respectful and dignified care for women during childbirth.

Acknowledgments

We would like to thank Ronita Bhattacharya for help with references.

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Europe's Shifting Response to HIV/AIDS: From Human Rights to Risk Management

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Abstract

Despite a history of championing HIV/AIDS as a human rights issue, and a rhetorical commitment to health as a human right, European states and institutions have shifted from a rights-based response to a risk management approach to HIV/AIDS since the economic recession of 2008. An interdisciplinary perspective is applied to analyze health policy changes at the national, regional, and global levels by drawing on data from key informant interviews, and institutional and civil society documents. It is demonstrated that, in the context of austerity measures, member states such as the UK and Greece reduced commitments to rights associated with HIV/AIDS; at the regional level, the EU failed to develop rights-based approaches to address the vulnerabilities and health care needs of key populations affected by HIV/AIDS, particularly migrants and sex workers; and at the global level, the EU backtracked on commitments to global health and is prioritizing the intellectual property rights of pharmaceutical companies over the human rights of people living with HIV/AIDS. The focus within and from the EU is on containment, efficiency, and cost reduction. The rights of those most affected are no longer prioritized.

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Competing interests: None declared.

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Introduction

The EU and European states have in many ways been leaders in both human rights and the HIV/AIDS responses. The European Convention on Human Rights and the European Social Charter both recognize the right to health. European countries were among the first to adopt harm reduction approaches to mitigate HIV infections through injecting drug use, to champion the rights of men who have sex with men (MSM), and to lead in the formation of global health institutions to address HIV/AIDS epidemics in lower- and middle-income countries (LMICs).¹ This article asks how responses to HIV/AIDS have changed within and from Europe since the economic recession that began in 2008. While much has been written about the impact of austerity measures on health in Europe, and on the outcomes of these policies in specific states, little of it focuses explicitly on HIV/AIDS.² As the HIV/AIDS response pioneered a rights-based response to health within Europe, it presents a critical case to explore policy changes.

Despite a history of championing HIV/AIDS as a human rights issue, and a rhetorical commitment to health as a human right, European states and institutions have shifted from a rights-based response to a risk management approach since the economic recession of 2008. Ines Keygnaert et al. define a rights-based approach to HIV/AIDS as one that “considers health as a human right and assesses policies, programs and legislation accordingly, expecting them to promote health and guarantee access to health care for all independently of any

status. This approach is rooted in the overarching principle of universality.”³ While campaigns for health-related rights have shifted focus over time, the key principles of access to health care for all, support for the most vulnerable, and protection from stigma and discrimination have been key pillars of rights-based responses related to HIV/AIDS since the 1980s. In contrast, a risk management approach is defined as “the identification, assessment, and prioritization of risks followed by coordinated and economical application of resources to minimize, monitor, and control the probability and/or impact of unfortunate events or to maximize the realization of opportunities.”⁴ While not necessarily mutually exclusive, key differences between rights-based and risk management approaches relate to principles of universality versus prioritization; and a focus on equity/equality as opposed to economic efficiencies (see Table 1). There is also a notable difference between the goal of addressing a threat to protect the most vulnerable, and containing it to protect those not yet affected.

While the first section of this article describes processes in place prior to the creation and expansion of the EU, the term ‘European states’ refers to those states who are presently members. The European institutions that are discussed are those engaged in lawmaking and policy setting, including the European Parliament, European Commission, and Council of the European Union. The paper presents three levels of analysis that represent different but overlapping concepts of Europe: Europe as a group of states, Europe as a regional entity, and Europe as a global actor. The first level focuses on

TABLE 1. Comparison of rights-based and risk management approaches

Human Rights	Example	Risk Management	Example
Universality	All people, regardless of status, have access to health care	Prioritization	Only citizens or permanent residents have access to health care
Equity/equality	All people have access to medicines regardless of costs	Efficiency	Intellectual property rights ensure return on investment for pharmaceutical companies
Protecting the vulnerable	Policies developed specifically for those most at risk of infection/ ill health	Containing a threat/protecting the general population	Policies isolate or imprison those who pose a risk
Considers social marginalization	Specialized programs to address complex determinants of health	Isolates a problem	Health addressed separately from other policies

policies within European member states, facilitating discussion (through select case studies) of how health policies, which remain a national competence, have shifted. The second level is regional, considering how the European Parliament has responded to issues related to HIV/AIDS within its governance jurisdictions. Finally, the paper considers how the European Commission's engagement with the global HIV/AIDS response has changed. This multilevel analysis is crucial for two reasons. First, HIV/AIDS is a transboundary health threat that cannot be contained or addressed solely within one state or region and thus requires action across governance levels.⁵ Second, shifts from rights-based approaches to risk management approaches have occurred at all three levels, suggesting a regional shift that calls for further investigation and redress.

This topic is approached from an interdisciplinary perspective. In order to gain perspectives on more recent events that are not documented in the scarce literature on Europe and HIV/AIDS responses, the analysis draws on data from 12 key informant interviews with members of civil society organizations (7), civil servants within European institutions (2), and staff from global health institutions (3). Interviewees were selected purposefully and interviews were conducted in person or over the phone/Skype between January 2013 and May 2014. Transcripts were analyzed using iterative, inductive content analysis to identify key themes and policy processes, and the interviewees' perspectives on them. These were triangulated with secondary literature and document analysis of publications from civil society organizations, European institutions, and global health institutions. Ethical approval for this research was granted by the Ethics in Research Committee at the University of Bradford, where the author was based at the time.

Early rights-based response to HIV/AIDS

In the early 1980s, a mysterious cause of death among young adults in Europe resulted in hysteria and fear. WHO reported in retrospect, "AIDS was – and in absolute, global terms still is – a stinging challenge to the values of modernity received, for

better or worse, from Europe's Age of Enlightenment. Affluent, confident, gender-progressive, often social-democratic welfare states awoke, in the early 1980s, to an uncomfortable reminder of their human frailty."⁶ Early responses focused on containing the virus, often stigmatizing those already infected. For example, far-right French politician Jean-Marie Le Pen proposed implementing "sidatoria," which would have confined people living with HIV/AIDS (PLWHAs) in prison-like hospitals.⁷ Such proposals had counterproductive outcomes, such as reducing testing, as those at risk feared that if they knew their status they would be isolated and prosecuted. Meanwhile, public health programs focused on individual behavior. In 1987, the British government launched a major advertising campaign with the slogan "AIDS: Don't Die of Ignorance."⁸ Such approaches lacked appreciation for the sociopolitical context of the epidemic.⁹

As efforts to produce a vaccine or treatment failed, and as public health approaches bordered on blaming individuals for their positive status, PLWHAs and their allies developed an alternative response. In 1983, the Terrence Higgins Trust formed in London to support those affected by HIV/AIDS, and in 1984, Aides formed in Paris with a similar mandate.¹⁰ Over the next decade, PLWHA support groups mushroomed, providing palliative care to the sick, confidential testing to those at risk, and counseling to those affected.¹¹ Together with health professionals and human rights activists, these groups advocated for a response that recognized HIV/AIDS as an exceptional health issue requiring the empowerment of those most affected.¹²

In the absence of treatment options, public health programs increasingly adopted this human rights frame. European states, after their initial response of punishment and stigmatization, provided favorable policy environments for the realization of a rights-based response. In 1976, most had ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR), which recognized the right to health. In many European states, the feminist struggles of the 1970s had resulted in greater access to contraception, which made the promotion of condoms and other means of pre-

vention less contentious than in, for example, the American context.¹³ Many states already had policies in place to reduce risks associated with sex work and drug use, such as decriminalization and harm reduction programs. The UK started the first syringe exchange programs to prevent HIV as early as 1987.¹⁴ Most European countries also accepted access to health care as a human right by providing comprehensive public health insurance. Due to the favorable policy and social context, there was widespread adoption of rights-based prevention strategies. In 1994, 42 states joined forces with AIDS service organizations (ASOs) at the Paris AIDS Summit, signing a declaration committing to a rights-based response to the epidemic, led by those most affected.¹⁵

In response to increasing awareness of the global scale of the HIV/AIDS epidemic, European states were among those advocating for a more coordinated global response. Scandinavian countries played a key role in the formation of the United Nations Joint Program on HIV/AIDS (UNAIDS) in 1994, and the UK played a primary role in the creation of the Global Fund to Fight HIV/AIDS, Malaria and TB in 2001.¹⁶ European countries, such as France, led the formation of UNITAIDS, which aims to improve treatment access.¹⁷

Reflecting member state practices, the European Union developed its regional and neighborhood policies in line with a rights-based approach. In response to the growing epidemic in Eastern Europe, in 2004, 52 EU member states and civil society observers gathered in Dublin for a conference on “Breaking the Barriers – Partnership to fight HIV/AIDS in Europe and Central Asia.”¹⁸ The resulting declaration called for universal access to treatment, two years before the UN Declaration on Universal Access.¹⁹ The EU maintained support for Universal Access campaigns during the initial negotiations of the Doha Round of World Trade Organization (WTO), siding with PLWHAs and their allies, as opposed to the US and pharmaceutical companies.²⁰

In 2007, the European Commission announced its four-year Programme for Action to Confront HIV/AIDS, Malaria and Tuberculosis.²¹ The program asserted European leadership in the

HIV/AIDS response in general, and a commitment to a rights-based response in particular.

European states: The human costs of austerity

Risk management is generally associated with financial governance, as opposed to health governance, but the two fields inevitably overlap. Due to austerity measures, many European states have deprioritized a rights-based response to HIV/AIDS in order to mitigate financial risk. The UK and Greece provide two examples of this trend; these countries were selected as critical cases based on the breadth of the health-related austerity policies they implemented post-2008, and on their geographic location; in order to include examples from Northern and Southern Europe. While these two countries are not a representative sample, nor the findings generalizable, they present a similar policy shift in two very different European states.

The United Kingdom

In the 1990s, the UK developed one of the most progressive HIV/AIDS responses, ensuring social protection of PLWHAs. These programs recognized that in order to enjoy the right to health, PLWHAs require not only treatment, but also food security, stable living conditions, and psychosocial support. Government funding provided food aid programs and resources to support groups. Since 2008, however, the UK government has cut social spending and hollowed out this rights-based response.²²

The Welfare Reform Act of 2012 had a number of negative impacts on PLWHAs. Previously, PLWHAs who were unable to work because of their illness could apply for the Incapacity Benefit. The Reform Act initiated a reassessment process of this benefit, which aimed to move people from the Incapacity Benefits to the Employment and Support Allowance. The assessment was fraught with inconsistencies and delays, largely due to mismanagement, poor performance, and problematic assessments by Atos Healthcare, the company conducting the assessments.²³ Even without these challenges, PLWHAs faced difficulties in getting a

fair assessment of their needs. The National AIDS Trust found that, “the barriers to work experienced by people living with HIV such as severe immune deficiency, side-effects of treatment, depression, pain and fatigue are not fully taken into account by the assessment.”²⁴ Many PLWHAs had their sick benefits canceled, and others had their support reduced by up to GBP 36 per month.

In April 2013, the UK Government introduced a new benefit, Personal Independence Payment (PIP), to be rolled out between 2013 and 2017 in place of the Disability Living Allowance (DLA), which provides support for extra mobility and care costs related to living with a disability. While the rates under the new PIP remain the same as under the DLA, the assessment criteria is different, and therefore there are fears that the process will reassess PLWHAs at a lower rate, or remove their access to the benefit altogether.²⁵ The National AIDS Trust (NAT) writes:

*NAT believes that the PIP assessment will fail to pick up the needs of many people living with HIV. We also disagree with only focusing PIP payments on those with the most severe barriers—DLA currently has an important preventative impact for people living with HIV who have lower-level needs, which will now be lost.*²⁶

The trust notes that reassessment takes more than a year and is often conducted by private companies with little knowledge of HIV/AIDS; while PLWHAs can appeal the decision, they do not get support during the appeal processes, which leaves them vulnerable.²⁷ While data on PLWHAs claims are not available, nearly half of all claims for PIP benefits have been refused.²⁸

The Bedroom Tax, instituted in 2013, also negatively impacts PLWHAs on benefits, reducing assistance to those in public housing with unused bedrooms. According to an article in *the Independent* newspaper, 96% of affected people are paying the tax not because they refuse to downsize, but because they have not been able to find affordable smaller properties.²⁹ For PLWHAs, who may need caregivers to stay with them when they are unwell, the Bedroom Tax does not recognize that their particular health needs

mean a spare room increases their ability to draw on the support of family and friends.

Such cuts affect the ability of PLWHAs to meet their treatment and care needs. In 2013, the Terrence Higgins Trust National Hardship Fund for People with HIV/AIDS registered a 63% increase of those needing emergency help because their benefits had been stopped.³⁰ Corrine Squire notes, in her longitudinal research, that many PLWHAs suffer from increased food insecurity due to the cuts.³¹ Doctors report having to prescribe food supplements to PLWHAs who are otherwise unable to maintain treatment regimens, as they can no longer afford the high-protein diet essential for effective treatment. One doctor is quoted in a newspaper article explaining:

*Before the past three or four years, I never saw people coming in and saying they didn't have enough money for food. Now I've seen several people in my clinic where the fact that they've had a decrease in their income, related to benefit changes, means they can't afford regular food.*³²

Such challenges are exacerbated by cuts to support groups for PLWHAs. Cuts to psychosocial services correspond to increased levels of depression among PLWHAs.³³ In the context of social cuts, justified in relation to austerity measures, the shift within the UK's response to HIV/AIDS is subtle, but notable. It reflects an erosion of the previous rights-based response, justified by the need to reduce state costs.

Greece

As has been well documented, Greece was severely affected by the 2008 financial crisis. In order to mitigate its economic woes, and stay within the EU, it accepted a loan from the International Monetary Fund (IMF) and underwent substantial restructuring of public assets and systems. These included a restructuring of the public health system, which was admittedly suffering from poor management and corruption. However, the IMF conditionalities also included restrictions on public health spending, reducing it to less than 6% of GDP, down from approximately 10%.³⁴ As a result, many hospitals had to cut their budgets by 40%, resulting in short-

ages of staff and medical supplies. The crisis was compounded by the increased demand for public health services as patients could no longer afford private care due to widespread economic hardship.³⁵

Among the programs cut were harm reduction interventions, such as needle exchanges and opiate substitutes, which are proven to be the most effective way to prevent HIV infection among PWID.³⁶ Budget cuts in 2009 and 2010 resulted in one-third of such programs being cut.³⁷ The reduction in needle exchanges and opiate substitute programs was exacerbated by other health care cuts, which decreased access to services for PLWHAs and PWID to treat opportunistic infections, consult their doctors, and access rehabilitation services. The cancellation of harm reduction and other programs resulted in an immediate spike in HIV infections: incidence rose more than tenfold from 2009 to 2012 among PWID.³⁸ While this increase may also be due to more people resorting to the drug and sex trade because of the recession, lack of access to clean needles and opiate substitutes is recognized as a primary contributing factor.³⁹

In response to rising HIV infection rates, the Greek government “brought back into force a regulation on the transmission of infectious diseases that runs counter to all international guidelines on HIV testing and breaches human rights.”⁴⁰ Greek authorities began arresting and forcibly testing PWID and sex workers for HIV. In 2012, women suspected of being sex workers were pulled off the streets, detained by the police, tested for HIV, and then had their details, including their HIV status, published on the internet. These women were not asked to consent to the testing and felt that they were not able to refuse.⁴¹ Thirty of those found to be HIV-positive were jailed for causing intentional harm to clients.

In 2012, the Greek Ombudsman reported complaints related to the sharing of confidential medical records, the refusal of housing or employment based on HIV status, and the testing and communicating of HIV status without consent. Some employers were reportedly forcing employees to get tested for HIV prior to taking up jobs.⁴² In 2014 and 2015, Human Rights Watch documented

police harassment of PWID and sex workers, quoting one methadone recipient: “Wherever you’re coming from, wherever you’re going, without any grounds, and without provoking anyone, you are always, always going to be taken to the police station.”⁴³ Human Rights Watch also found, “Twenty-one people described situations in which police stops had a direct or indirect negative impact on their right to health, including interfering with their access to a doctor and necessary medication, as well as to services and information on HIV prevention, methadone, and other prescription drugs.”⁴⁴ Greek authorities were restricting access to health care for vulnerable groups, violating General Comment 14 of the International Covenant on Social, Economic and Cultural Rights (ICESCR), which includes the entitlement to “a system of health protection providing equality of opportunity for everyone to enjoy the highest attainable level of health” and the freedom of “the right to be free from non-consensual medical treatment . . . and to be free from degrading treatment or punishment.”⁴⁵

Managing HIV/AIDS within the EU

The right to health is recognized by the European Convention for the Protection of Human Rights and Fundamental Freedoms of the Council of Europe, and the European Social Charter. In the EU, the Charter of Fundamental Rights sets out the right of everyone to access preventive health care and to benefit from medical treatment. While health governance falls under state jurisdiction, these delineations indicate an element of regional oversight to ensure the right to health. However, the European Parliament has more often taken a risk management approach, which frames health and related issues as isolated problems to be contained. In order to demonstrate the dominance of this approach this section focuses on two key population groups: migrants and sex workers.

Migrants

The designation of migrants as a key population affected by HIV/AIDS is unique to Europe. Approximately 43% of all heterosexually transmitted

HIV infections reported in Western Europe in 2006 occurred among immigrants from high-prevalence countries, such as those in sub-Saharan Africa.⁴⁶ It is assumed, though hard to prove, that most of these infections occur in the country of origin, though higher prevalence among migrants may also be due to vulnerability upon arrival in the EU, resulting in the exchange of sex for food, shelter, or money. Migrants are also less likely to use health services, and are more at risk of other sexually transmitted infections and sexual violence than the general population, all of which increases their vulnerability to HIV.⁴⁷

In 2005, the European Court of Human Rights stated that social benefits such as health services are a property right, irrespective of work or other contributions, and that denying health care to irregular migrants may breach the right to be free from inhumane and degrading treatment.⁴⁸ Health remains a national competency, however, and each member state implements individual policies related to migrants' access to health care. Several states only allow migrants to access health care for emergencies and core benefits. Since each member state defines these terms differently, migrants who move within the EU are often unaware of what health services they can access. In some states, migrants' access to health care has decreased with austerity measures, and due to assumptions that providing quality care will encourage migration and therefore increase costs. For example, the UK removed HIV treatment from its emergency care list in 2009, abandoning free treatment for migrants.⁴⁹ Keygnaert et al. write, "While the rights-based approach of health seems to gain some momentum in international and regional frameworks, EU member states face a hiatus between these requirements and their own migration policies."⁵⁰

The EU has neglected to address contradictory approaches to HIV/AIDS treatment and the health rights of migrants, based on the argument that health is a national competence. The European Commission stated that sexual and reproductive health rights remained primarily a national competence and that the EU had no vocation to take the lead.⁵¹ In fact, the EU has taken few actions on sex-

ual and reproductive health in general, likely due to the highly political and culturally sensitive nature of such health issues. Migration is an even more highly politicized issue, and linking it to a health condition that attracts stigma and discrimination could potentially be problematic. As Richard Coker writes: "In Europe migration policy is a politically flammable issue; HIV could cause it to combust."⁵² The intersection of migration, sex, and disease means that asserting the rights of migrants to HIV prevention and treatment services has few political benefits and many pitfalls. As a result, instead of recognizing and addressing the linkages between the social vulnerabilities migrants face, barriers to access to health care, and high HIV/AIDS prevalence among this population, the European Parliament has continued to address health, migration, and related issues as separate problems. In the process, the health rights of migrants are obscured within the political discourse.

Sex workers

Migrant sex workers face particular barriers because of differing legal approaches to sex work in the EU. In many countries, such as Greece, sex workers who fear legal prosecution avoid health centers. Some countries (Austria, Hungary, and Latvia) continue mandatory HIV testing of sex workers, which violates patients' rights to voluntary testing.⁵³ In the interest of promoting a uniform approach to managing sex work, European Parliament voted in February 2014 to support the Nordic model throughout the union. Already implemented in Sweden, Norway, and Iceland, this approach criminalizes buying sex and benefiting from the profits of sex work, but does not criminalize selling sex. The argument is that the Nordic model criminalizes clients and not workers, but sex worker organizations and HIV/AIDS activists generally condemn this model as contradicting a rights-based approach to sex work and HIV/AIDS. Because the Nordic model prohibits buying sex, workers are isolated to obscure locations where their clients are not at risk of getting caught. In such places, sex workers are less able to screen potentially dangerous clients, such as those who

do not want to use condoms or who are violent. Clients are also unlikely to report abuse they may witness in brothels for fear of prosecution. Workers cannot employ bodyguards to protect themselves from unprotected and violent sex, since the Nordic model prohibits benefiting from the income of sex workers.⁵⁴ One advocate notes,

*We have seen so much evidence that the control sex workers have over their working conditions, including protecting themselves from HIV, has a huge impact on their health, and the adoption of Nordic policies in driving this wedge between sex workers and health care.*⁵⁵

Neither WHO nor UNAIDS supports the Nordic model, instead advocating for decriminalizing both buying and selling sex as the most effective way to ensure sex workers' right to health and to prevent the spread of HIV/AIDS. Similarly, Amnesty International declared its support for decriminalization of sex work in 2015.⁵⁶

In 2014, a coalition of 450 civil society organizations and 45 researchers protested the European Parliament's decision to promote the Nordic model.⁵⁷ It is too early to know exactly how the support for the Nordic model may affect sex workers, but it demonstrates a shift away from a right-based response toward strategies that isolate sex workers.⁵⁸

The treatment of key populations (those groups most at risk and affected by HIV/AIDS) within the EU is a key component to advancing a rights-based response. However, policy choices demonstrate a preference for containing the epidemic among vulnerable groups, as opposed to addressing their particular needs, which require recognizing the social determinants of health. As one key informant notes:

*Europe is really doing what we call "managing AIDS." Not ending AIDS, but managing AIDS. It is being very complacent about it; there are still many people living with HIV in Europe and you are still seeing new instances there, but since the epidemic is restricted to the key populations, nobody really thinks about it.*⁵⁹

Europe's role in the global response

Since the European Commission's Action on AIDS, TB and Malaria ended in 2011, global health policies have backtracked on human rights commitments; which is in particular contrast with increasing support for intellectual property rights that restrict access to medicines.

From HIV/AIDS to global health to inaction

When the EU's HIV/AIDS Programme ended in 2011, it was not renewed. Instead, the European Commission adopted, in 2010, a communication on the EU's Role in Global Health, which broadened the scope from focusing only on specific diseases and provided a policy framework for the EU's future actions in global health.⁶⁰ The shift from focusing solely on HIV/AIDS to working more generally toward global health reflects broader changes in development assistance for health, such as a backlash against vertical disease-specific initiatives and calls for more integrated health system strengthening.⁶¹ It also reiterates calls from civil society and HIV/AIDS activists to expand on the gains of the HIV/AIDS response and promote a rights-based response to other health issues.⁶²

The 2010 communication was never developed into a program, however, and has not been included in any work plans since.⁶³ One analysis of EU global health policy developments since 2010 finds that "the European debate [on global health] seems to have fallen largely silent."⁶³ Similarly, a key informant from a global health institution commented, "in terms of becoming instrumental on what actually that [the global health communication] will lead to, there has been dead silence."⁶⁴ The Global Health Policy Forums are the only related development, bringing together representatives from the European Commission, non-governmental organizations, industry representatives, and international organizations to discuss global health, but have produced few outcomes.⁶⁵ One of the few European Commission documents to mention global health, the Third European Health Programme 2014–2020, only refers to global health in terms of

the need to control cross-border health threats and infectious diseases. This represents a retreat from an expansion of the rights-based response, back towards vertical interventions that aim to protect the EU from external threats. Meanwhile, European Commission funding for global health has fallen from US\$520 million in 2010 to \$400 million in 2015, with HIV/AIDS funding decreasing from US\$33 million in 2010 to \$13 million in 2015.⁶⁶

The EU has also shifted away from its previous alliances with civil society-led human rights campaigns. The UN General Assembly held a High-Level Meeting on HIV/AIDS in June 2011. Prior to this meeting, UNAIDS and civil society organizations lobbied aggressively for stronger human rights language than in the previous UN resolutions and declarations, which had not specified rights for key populations, and had allowed cultural qualifications on the rights of women. States with a history of resisting human rights language, such as Egypt and Iran, pushed back—as did the EU delegation.⁶⁷ While not against the rights language, the EU delegation did not want to introduce specific targets to the declaration, without which it would lose much of its weight.⁶⁸ Civil society found it was no longer able to rely on the EU as an ally for a global rights-based response.

From human rights to property rights

The EU delegation was particularly against treatment targets. One participant recalled:

*In the beginning, just the EU was pushing for language such as “substantially increasing the number of people on treatment,” “substantially decreasing the number of people on treatment and new infections,” but they didn’t want to have figures in the political declaration, and we were working on it, so we could see the track changes on a day-to-day basis.*⁶⁹

The EU also pushed back on language related to intellectual property law flexibilities aimed to improve access to generic medications in developing countries. The statement from the EU representative only referred to access to treatment in relation to strengthening the Medicines Patent

Pool.⁷⁰ This contrasts sharply with the statement from the European Commission representative at the 2006 High-Level Plenary meeting on HIV/AIDS, which listed “affordability of new drugs, particularly through fair and tiered pricing for medicines, including the newest ones” as one of three crucial areas for future HIV/AIDS response. The changed position of European representatives was a substantial shift in EU policy, which had been previously supportive of increased access to ARVs and the ability of LMICs to access generic medications. In the end, due to extensive civil society lobbying, the EU did compromise on language related to a number of targets and intellectual property flexibilities. However, the shifting position in negotiations indicates a move away from access to medications as a human right.

The EU has continued to prioritize intellectual property rights over access to medicines in trade negotiations. In 2014, during negotiations between the EU and India, where the majority of generic HIV/AIDS medications are manufactured, the EU pushed for a data exclusivity provision that would have severely limited production of generic medications. India has refused this and other suggested provisions, but the negotiations are ongoing. For example, one proposed provision would allow EU companies to sue the Indian government for perceived threat to their profits. For example, if India overrode a medicine patent to allow for production of more affordable generic medicines (currently legal under international trade rules), a pharmaceutical company could sue the Indian government in closed-door proceedings.⁷¹ The EU is siding with pharmaceutical companies focused on profits, at the expense of those who cannot afford ARVs and will die without them.

Conclusion

While European states and institutions were once allies in campaigns to achieve the right to health, a shift is perceivable with European states cutting costs and implementing policies that threatening the health and well-being of PLWHAs and key

populations. The history of the HIV/AIDS response indicates a need for bold action and controversial policies, yet politicians and policymakers are failing to develop a regional rights-based response that will address the social determinants of vulnerability for key populations. European institutions are not only reducing action on global health generally, but also retreating from previous rights-based commitments, such as those related to access to medicines. The focus within and from the EU is on containment, reducing costs, and isolating issues. The rights of those most affected are no longer prioritized. This risk management approach to the epidemic aims to control and manage HIV/AIDS, not address it or overcome its structural drivers.

While this approach is cheaper and avoids controversial issues, there are human costs. Denying PLWHAs benefits increases their risk to opportunistic infections, and reducing support services exacerbates still-prevalent stigma. While EU politicians and policymakers may prefer to ignore key populations, such as migrants, and hide others, such as sex workers, both these groups are living within the region, which purports to respect the right to health and freedom from discrimination. The EU's reprioritization of the global response to HIV/AIDS and failure to advance its commitments to global health will impact people around the world, as will stronger intellectual property laws on pharmaceutical patents.

The history of the response to HIV/AIDS suggests that even as a short-term strategy, a risk-management approach is ineffective. The rights-based approach to health, pioneered by early European ASOs and activist groups was not only ethically sound, it was also effective in reducing HIV infection and ensuring that those affected could access care and prevent further health challenges. The tradeoff between a risk-management approach and rights-based response is perceived short-term savings and containment, versus the lasting gains of a healthier population. More importantly, the financial and political costs of a rights-based response cannot be weighed against the importance of ensuring the basic right to health to all people, as outlined

in the European Convention for the Protection of Human Rights and Fundamental Freedoms.

Acknowledgments

I am grateful to the reviewers for their helpful comments and advice. This article builds on an earlier paper prepared for the European Community Studies Association of Canada Conference in 2014.

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HIV and the Right to Health in Colombia

COREY PRACHNIAK-RINCÓN AND JIMENA VILLAR DE ONÍS

Abstract

The first Colombian to claim a judicially enforceable right to health was a gay man living with HIV, who in 1992 claimed a violation of his constitutional rights on account of being denied antiretroviral therapy. Since then, HIV activists have been at the forefront of advancing both the judicialization and social reconstruction of health as a human right. However, their role—and its implications today—has been sometimes overlooked in the study of Colombia’s right to health. Based on semi-structured interviews with key stakeholders, we evaluate the HIV movement’s effect on the progression of the right to health and resulting health care reform, and analyze the reform’s success in addressing the needs of people living with HIV. While the landmark Constitutional Court decision T-760 and resulting health care reform are not the result of any one group, the HIV movement played a significant role in these developments, and its values are largely reflected in the country’s new sociopolitical conceptualization of the right to health. However, the movement has faced division over the issue of generic medication availability and among subpopulations who have not been strongly represented or consistent beneficiaries of its successes.

Congratulations to Corey Prachniak-Rincón and Jimena Villar de Onís — this peer-reviewed full paper is a winner in the Harvard FXB Health and Human Rights Consortium Student Essay Competition 2016. The authors were both students at the Harvard T. H. Chan School of Public Health.

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Competing interests: None declared.

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Background

To a great extent, right-to-health litigation throughout the world—including in Latin America—emerged in the 1990s as a means of advancing health access for people living with HIV.¹ The courts of Costa Rica, Argentina, and Brazil have all authored notable decisions granting access to HIV-related care.² Moreover, these cases have often been a precursor to a growth in health care litigation generally, an expansion of the concept of a right to health, and sometimes (as in the case of Argentina) a degree of systemic change.³ The success of HIV activists in countries such as Brazil is directly correlated to litigation in pursuit of many other high-cost treatments that were not previously covered by government health plans; many contend that this litigation has disproportionately benefited wealthy individuals who have access to courts while damaging the financial stability of health systems.⁴ This phenomenon has been part of a larger trend in Latin America in which health care access has improved dramatically over the past half-century and yet continues to be marked by significant inequality.⁵

The HIV movement in Colombia has, to a great extent, relied on a right-to-health litigation strategy throughout its history and thus is squarely within this debate. Colombia's experience is unique, however, in the unprecedented degree to which its Constitutional Court responded to increasing health litigation by ordering widespread changes to the health care system in 2008 and forcing the government to adopt a human rights-based approach.⁶ While this decision has drawn much international attention, the HIV movement that was in many ways its catalyst has been less documented. Both the historic action of the court in 2008 and the degree to which Colombian HIV activists utilized right-to-health litigation as a central strategy make this an important story in the study of the judicialization of health. The purpose of this article is to document how, when, and with what impact the HIV movement used legal activism to advance the right to health, as well as to evaluate the relationship between the HIV movement in Colombia

and the expansion of the country's conception of the right to health.

Colombia's HIV prevalence of 0.4% is one of the highest in Latin America and equates to an estimated 120,000 adults.⁷ While this is sizeable enough to represent a significant public health and resource allocation concern, this population has remained marginalized. Furthermore, the epidemic reached Colombia during a particularly difficult time: in 1983, when the first case was diagnosed in Cartagena, the government was engulfed in conflict with left-wing guerrilla groups that emerged in the 1960s, new right-wing paramilitary organizations, and rising drug trafficking.⁸ Although significant progress has been made in achieving peace, Colombia still faces many challenges, with 28% of the population living in poverty and over six million people displaced by violence.⁹ Finally, the religious and conservative elements of Colombian society have created a difficult environment in which to address HIV given the stigma it carries with respect to sexual and cultural norms and the epidemic's disproportionate effect on sexual minorities, sex workers, and other stigmatized groups.¹⁰

At the start of the HIV epidemic, Colombia's health care system was one in which approximately 20% of the population had private health care coverage and the rest relied on the public health care system.¹¹ The current Colombian health care system was established in 1993 with the passage of Law 100, which created a universal health insurance scheme divided into contributive and subsidized packages, both managed by highly regulated but private companies.¹² The percentage of insured Colombians rose from 24% in 1993 to nearly 100% today, but the quality of care has often been criticized, particularly in the subsidized regime.¹³

Contrary to the broad epidemiological, clinical, and sociopolitical literature regarding HIV in Colombia, the study of legal and political HIV activism has been lacking.¹⁴ Furthermore, there has been much literature regarding general right-to-health litigation, particularly since the Constitutional Court's landmark T-760 decision of 2008 (outlined comprehensively by Everaldo

Lamprea in the introduction to his 2015 book), but most academic research regarding legal and political HIV activism in Colombia revolves around the Constitutional Court's impact on the health care system.¹⁵ Ana Cristina González Vélez and Juanita Durán have documented this impact on access to treatment for people living with HIV, and they and others have addressed the issues of priority setting and financing.¹⁶ This article will explain the role HIV activism has played in pursuing those changes.

This paper also seeks to record the earlier years of the HIV movement. Two notable academic works specifically address the earlier years of the HIV movement in Colombia. Luis Cañón's 1995 book documents the movement's early years in the 1980s, although it does not analyze its impact.¹⁷ Lamprea broadly details the main characteristics of the movement in the 1990s and early 2000s, exploring the role of different stakeholders in the reconstruction of the health care system.¹⁸ This article bridges the gap in detail between the different periods of litigation, from the 1980s until the late 2000s, and offers an impact analysis of the HIV movement's role in the greater right-to-health movement in Colombia.

Methods

Between January 4 and February 5, 2016, we interviewed 46 representatives from 41 organizations. Participants originated from Bogotá (n=27), Cali (n=7), Medellín (n=5), Bucaramanga (n=3), Cartagena (n=2), Ocaña (n=1), Pasto (n=1), and Popayán (n=1). In total, we interviewed 16 women and 30 men from nine different professional fields: judiciary (n=3), medical providers (n=2), research institutions (n=3), nongovernmental organizations (n=9), activists (n=7), governmental officials (n=4), academics (n=13), and media (n=1).

Two sampling methods were used. First, we conducted a literature review of written and audio sources that referred to the right to health and social movements in Colombia, which we used to generate an initial list of desired participants. Our inclusion criterion for participants was any indi-

vidual who self-identified as having participated in or researched the HIV or broader right-to-health movements. Second, we conducted exponential, non-discriminative snowball sampling in which key stakeholders provided leads to other participants directly or indirectly involved in the HIV or broader patients' movements. Snowball sampling was necessary for hard-to-reach individuals, such as activists from the earlier periods of the movement who were not presently active.

This was an exploratory qualitative study conducted with data collected through in-depth, semi-structured interviews. The interview guide was composed of a basic socio-demographic background (age, gender, profession, years active in that profession, education level, and place of origin), as well as 15 questions related to the HIV movement and their involvement in it. All interviews were audio recorded and transcribed, and we undertook coding using QSR International's NVivo 11 program for the analysis of qualitative data. We used open coding, in which we read the transcripts without having developed themes beforehand and then established a number of themes based on this reading. Subsequently, we reread all transcripts, coding with the newly established themes.

The Harvard Longwood Medical Area Institutional Review Board approved this study in the United States. In Colombia, we convened a community advisory board for ethical review and approval of the study. The board concluded that the project complied with all appropriate ethical and methodological standards for a qualitative study of this nature, that the study was culturally appropriate, and that it posed no material risk to participants. All interviews were conducted at the preferred time and location of participants, all of whom agreed to be identified in the study and offered their informed consent.

Origins of the HIV movement

The 1980s constituted the beginning of the social movement of people living with HIV. As early as 1982, through news outlets and correspondence

with LGBTQ individuals in the United States and Europe, gay men in Colombia started to receive information on what was then known as the “cancer of homosexuals.”¹⁹ Although this would change later in the epidemic, the initiatives in the 1980s were led by the LGBTQ community, specifically gay men.²⁰ What is considered the first conference on HIV in Colombia was held in Bogotá on July 28, 1983, on International Gay Pride Day.²¹ That same year, the country’s first case of HIV was officially diagnosed and reported at the University Hospital of Cartagena.

The movement’s initial organization came in the form of support groups for patients living with HIV. These groups started to organize in medical centers, where patients with HIV-related conditions met.²² The main objectives were to create a space for patients to share experiences, help patients prepare for death, and accompany them during their terminal phase.²³ One of the first groups was organized at Seguro Social, the only such center then caring for patients with HIV.²⁴ With the help of physician Bertha Gómez, who offered palliative treatments and treatments for opportunistic diseases to HIV patients, a group called El Club de la Alegría organized support meetings every fortnight. Smaller groups in Bogotá, such as El Cartel de la Vida (a play on words from the drug cartels that were operating at that time), joined the meetings at Seguro Social. As more information made its way to Colombia, the support groups began offering information on topics such as nutrition and self-care. Similar groups in other cities also emerged, such as Vivir Mejor in Cali and Compartamos in Villavicencio.²⁵ The concept of support groups came naturally to the patients, but they were also influenced by information about similar activities in the United States.²⁶

Other leading activists in the field began organizing more formally. Dr. Henry Ardila, who had been following the epidemic from the early 1980s, created the Colombian League for the Fight against AIDS in 1986 with the help of other activists and with the aim of providing assistance and information.²⁷ Nongovernmental organizations also appeared, such as Planeta Amor (then called Fundamor), which welcomed children living with HIV

with the goal of “offering a dignified death.”²⁸ Also important was Colombian Network of People Living with HIV, which offered support to and fostered connections among patients.²⁹

A key factor in the creation and cohesion of these groups was a reaction of self-preservation among their members, who were affected by deeply seeded stigma and discrimination. HIV was strongly associated with the LGBTQ community, which increased discrimination against both groups. Although in the future the LGBTQ movement and the HIV movement would mostly work separately, this gave the HIV movement an initial push, as LGBTQ organizations became involved in propelling the HIV cause during the late 1980s and early 1990s.³⁰

As these groups, organizations, and networks obtained information on treatments in the United States through personal connections and the media, and as these treatments arrived to Colombia through donations and individual purchases, the objective of the groups transitioned toward a fight for access to treatment.

Antiretroviral access through *tutelas* and the obligatory health plan

Law 100 of 1993 transformed Colombia’s health care system, which previously had a safety net comprising mostly public hospitals that provided low-income individuals with free or low-cost care.³¹ The new system was one of managed competition in which newly formed health insurance companies, known as *entidades promotoras de salud*, competed for patients under significant government regulation.³² These companies were divided into two categories: those to which beneficiaries and their employers contributed and those for minimum wage, informally employed, and unemployed people, which were subsidized.³³ The health insurance companies were required to cover only those treatments listed in the country’s obligatory health plan (Plan Obligatorio de Salud, or POS) for the contributory scheme (POS-C) or subsidized scheme (POS-S).³⁴ The POS-C was significantly more generous in its benefits than was the POS-S, and although both

excluded HIV treatment at that time, the POS-S also lacked many of the supplemental medications required by people living with HIV.³⁵

Since the antiretroviral medication AZT (azidothymidine) was not part of the POS, the only way to access it was to file a *tutela*, a device similar to a writ of protection that was introduced by article 86 of the 1991 Constitution.³⁶ A *tutela* could be filed as a simple plea, in theory by someone with no legal experience, citing a violation of a fundamental right. The claimant would then receive a response from the local court in which it was filed within 10 days. The first *tutela* to claim a violation of the right to health was T-484 of 1992, brought by a person living with HIV whose medication had been suspended by the public insurer Seguro Social de Tuluá.³⁷ The Constitutional Court held that the right to health—which was not itself considered a fundamental right—had to be protected given that it relates to the rights to life, personal integrity, and dignity: “[the right to health] can be identified as an immediate necessity to the right to life, so that to infringe upon the health of the people is equivalent to infringing upon their very right to life.”³⁸ The court therefore ordered the insurer to provide the medication. The connection between the rights to health and to life was particularly clear with respect to HIV, which at the time was marked by high mortality (particularly when untreated) and from which many patients died even while waiting the 10 days required for a *tutela*.³⁹ From that point on, HIV patients drew on the nexus between the rights to health and to life in their *tutelas*.⁴⁰ The use of courts to access ARVs was also occurring in other countries around this time.⁴¹

Support groups and organizations quickly became an incubator for the growth of *tutelas*. The very first HIV patients in Bogotá covered under Seguro Social had heard about the AZT treatment (approved by the United States’ Food and Drug Administration in 1987) and turned to patients’ organizations for help, as did a growing number of other patients.⁴² Germán Humberto Rincón Perfetti, a human rights lawyer who was volunteering for the Colombian League for the Fight against AIDS, composed the first legal strategy with patients from

Seguro Social in 1994. The strategy, which he called Operation Wasp, was to file seven HIV *tutelas* in seven different courts to occupy the dockets of seven Bogotá judges for 10 days. All seven courts ruled in their favor, ordering Seguro Social to start providing AZT regimens to its patients.⁴³ Although the groups initially used *tutelas* to access AZT treatment, they quickly started to demand their right to comprehensive treatment, including the right to diagnosis, right to CD4 count, access to diapers, and non-discrimination in the workplace.⁴⁴ *Tutelas* for the right to comprehensive treatment increased rapidly, replacing AZT-specific *tutelas*.⁴⁵ These first years were followed by a large wave of HIV-related *tutelas* filed by the Colombian League for the Fight against AIDS, which by then consisted of 30 patients’ organizations and had become known as a “*tutela* factory.”⁴⁶

The avalanche of HIV-related *tutelas* was accelerated by the movement’s shift from primarily providing social support to individuals to providing technical and legal support for right-to-health claims.⁴⁷ Lawyers and activists travelled around the country organizing workshops and providing ready-made *tutela* forms, which were being filed by patients nationwide by the late 1990s.⁴⁸ The pressure in support of AZT treatment also came from other areas of civil society. For example, in 1995, the vice president of the Pan-American Association of Infectious Diseases published an op-ed in a national newspaper on the benefits of AZT and called for the government to add it to the POS.⁴⁹ Pressure was also mounted by physicians working within Seguro Social, such as Dr. Bertha Gomez, who had been supporting patients since the beginning of the epidemic.⁵⁰

For reasons that are unclear, AZT was added to both the POS-C and POS-S in 1997.⁵¹ Most academics and activists agree that the pressure from the numerous *tutelas* and from civil society played a significant role. Financially speaking, given that courts were ordering insurance companies to provide AZT even though it was not part of the POS, the money for the medication was coming out of a government fund called the Fondo de Solidaridad y Garantía.⁵² Earlier in 1997, the Constitutional Court held that the government was responsible for “cover-

ing the costs of non-POS services ordered by judges through a writ of protection,” and with the increasing number of *tutelas*, the government’s need to reduce the use of the fund was becoming evident.⁵³ Another factor was strong political support from Minister of Health María Teresa Forero de Sade, who steadfastly supported AZT’s inclusion, allegedly after a family member was diagnosed with HIV.⁵⁴

Finally, in December 1997, Agreement Number 83 was signed into law, adding comprehensive treatment for HIV patients to the POS.⁵⁵ This meant that new antiretroviral treatments and what is known as the “cocktail” combination therapy were included in both the POS-S and POS-C, and by 2000, treatments for HIV would be virtually standardized between the two schemes. However, new treatments were not automatically included, and many non-HIV drugs needed by HIV patients remained not covered by the POS-S, forcing many patients to continue relying on *tutelas*.

The high-cost patients’ movement

During the early 1990s, HIV had been classified as a catastrophic condition, along with other diseases, such as cancer, chronic renal failure, and transplants.⁵⁶ This classification was later changed to *pacientes de alto costo* (high-cost patients), defined as a condition with “high cost, low occurrence, high complexity of treatment and low cost-effectiveness.”⁵⁷ Inspired by the HIV movement’s successful use of *tutelas*, groups representing patients with other high-cost conditions began appearing in the late 1990s.⁵⁸ These groups soon began to work together, and in the early 2000s, HIV activist Nestor Álvarez formed a group called the Association of High-Cost Patients. Rincón Perfetti, the attorney noted above, described the organization as consisting of “technical and legal experts on the right to health ... regarding everything: for cancer, for AIDS, for dialysis, for everything.”⁵⁹

By 2005, 65% of high-cost patients were receiving treatment as a result of *tutelas* (versus paying out-of-pocket or using normal POS coverage).⁶⁰ In response, the government passed Law 972 of 2005, hoping to reduce the number of *tutelas*

and improve access for patients with nine identified high-cost conditions, including HIV.⁶¹ This law forced the health insurance companies to provide comprehensive treatment to these patients even if they, for any reason, lost their affiliation to that particular insurance company, in which case the company would be reimbursed by the government fund for care not covered by the POS. However, the law did not solve the problems that some identified with the semi-privatized system created by Law 100, including fragmentation, barriers to care, and a reduction in rights (even as the 1991 Constitution theoretically expanded them).⁶²

Even as the high-cost patients’ movement was taking shape, divisions were forming around the issue of generic drug access. The pharmaceutical industry had allied with some members of the HIV movement in the late 1990s, and industry interest grew as the movement expanded beyond HIV patients to include others with high-cost conditions.⁶³ The companies saw patients’ groups as a means to broaden the market for high-cost medications and thus supported these groups with funding and pharmaceutical samples.⁶⁴ However, with the success of the *tutelas* and subsequent reforms improving access, some activists did not feel comfortable working with the pharmaceutical industry, which they saw as the reason for Colombia’s unusually high costs of care. As certain HIV and right-to-health groups started to raise the issue of pharmaceutical pricing, others quickly splintered off. Additionally, the Association of High-Cost Patients—which had merged with another patients’ group to form Pacientes Colombia in the early 2000s—survived for only two years before splitting back in two for the same reason.⁶⁵ The disunity was also driven by the opinion held by many HIV activists that HIV was actually not a “high-cost” condition and that in a properly regulated system, life-saving treatment for HIV would not be exorbitantly expensive.⁶⁶

The T-760 decision and resulting reform

By 2008, the number of annual health care *tutelas* had swelled to over 100,000, all but forcing the Con-

stitutional Court to seek a systemic resolution.⁶⁷ Juanita Durán, who worked on the case as a *magistrado auxiliar* (auxiliary magistrate, a position similar to an indefinite clerkship), said that the HIV movement was “the pioneer, the most important [actor] leading the path” to T-760.⁶⁸ Because T-760 resulted not from a single lawsuit but rather from 22 separate *tutelas* selected by the court, it cannot be said that any one group prompted the decision.⁶⁹ But in framing the right to health in the same way that the HIV movement had done for years, the court not only addressed most of the movement’s longstanding goals but also popularized its conceptualization of health as a human right.

First, T-760 and the policies that followed made the POS more generous, more equitable between the contributory and subsidized plans, and less arbitrary in determining exclusions. In keeping with the court’s orders, the government equalized the POS-C and POS-S in 2012.⁷⁰ By 2017, the POS will pivot from being a list of covered treatments that excludes anything not enumerated to a list of excluded treatments with coverage otherwise presumed.⁷¹ This reversal of defaults should mean a reduced need for advocacy around the inclusion of new HIV treatments. The court also ordered that measures be taken to prevent the arbitrary denial of covered services, including discriminatory denials against people living with HIV.⁷² Although T-760 permitted the government to reduce nonessential benefits in merging the plans, those in the subsidized plan will ultimately have greatly enhanced coverage.⁷³ This includes many treatments that, while not directly related to HIV, are required to treat conditions that are complicated by HIV. The significance of this problem for HIV patients was noted by Aquiles Arrieta, an auxiliary magistrate with the court who worked on the decision.⁷⁴

Second, the decision represents a reduction of the need to use *tutelas* for HIV treatment. In many countries, the judicialization of health rights has been criticized as exacerbating inequities because the most marginalized groups have difficulty accessing courts.⁷⁵ Many of our interviewees felt that the evidence was mixed in terms of whether *tutelas* had improved health equity, noting that *tutelas*

could be completed without the help of an attorney (unlike in many countries) but at a lower rate of success.⁷⁶ The patients’ groups may have eased inequity by providing assistance to those who were unable to file *tutelas* on their own.⁷⁷ Nonetheless, some felt the system overwhelmingly benefited the privileged.⁷⁸ Only a few interviewees felt strongly that local court access was reasonably equitable.⁷⁹ Even if this is true, those in the subsidized regime were still at a disadvantage because they had to fight more exclusions than their counterparts in the contributory scheme.⁸⁰ Additionally, it was hard to enforce *tutelas* ordering the provision of HIV medications in the POS-S pharmacies because these pharmacies often did not have such medications in stock.⁸¹ Therefore, T-760 can be seen as addressing a fundamental limitation of the *tutela* system as a means of achieving the movement’s goals.

Third, the decision led to an unprecedented public debate on health care and to a reconceptualization of health as a human right. An unexpectedly large and diverse group of patients, providers, and the general public rallied in support of the Constitutional Court and in opposition to then president Álvaro Uribe, who opposed the decision.⁸² The public essentially embraced what the HIV movement had argued for years: that health was a fundamental right that the health care system of Law 100 had systematically violated. Many of our interviewees considered this symbolic shift to be the most important direct impact of the court’s decision, especially since the long-term effects of health care reform remain to be seen.⁸³

Despite the fact that the decision addressed these three significant goals of the movement, there remains a need for *tutelas*: in recent years, 27% of people living with HIV have still claimed being denied some form of care, and the deep fragmentation that marks the system causes some to be unable to successfully navigate the care to which they are entitled.⁸⁴ Finally, the court’s ruling did not resolve two critical issues cited by activists: the fight within the movement over whether to push for increased availability of generic medications, and the degree to which the movement has not been fully inclusive of the needs of vulnerable populations.

Kaletra, pharmaceuticals, and the fight for the inclusion of generics

The division that had begun prior to 2008 over whether to fight for generic access or insist on brand-name drugs culminated with the campaign of pro-reform activists to lower the price of Kaletra, an HIV medication patented by Abbott Laboratories for patients with resistance to older HIV medications.⁸⁵

By 2010, nearly 6,000 patients were being treated with Kaletra, including 500 beneficiaries of the subsidized regime.⁸⁶ The annual per-patient cost of Kaletra was approximately US\$4,000, compared to US\$1,110–1,300 in other South American nations.⁸⁷ Four organizations—the IFARMA Foundation, the Health Mission Foundation, the Colombian Network of People Living with HIV, and the Committee of Organizations Working on HIV—contacted attorney Rincón Perfetti, who had initially led the *tutela* movement, to try to lower costs. These groups argued that the government was justified under the international compulsory licensing agreement (TRIPS) to issue a compulsory license for a generic version of Kaletra because the drug's price was hindering public health efforts.⁸⁸ The government denied the demand but nonetheless negotiated with Abbott and forced the company to reduce the price to US\$1,067 in 2009. This was seen as a partial victory, but the movement still took the matter to court. In September 2012, the Administrative Tribunal of Cundinamarca ruled against the government in a class-action suit and ordered further negotiation with Abbott, which led to a price reduction to US\$670.⁸⁹ Additional success was achieved in 2014, when the national Industry and Commerce Superintendence issued Abbott a fine of approximately US\$1 million for inflating Kaletra's price by up to 66%.⁹⁰

Although the groups never succeeded in seeing the government issue a compulsory license for HIV drugs, the HIV movement's success helped prompt the government to begin broader negotiations with the pharmaceutical industry, including the regulation of 8,600 medications in 2012, and ultimately creating a regulatory scheme to control prices.⁹¹ For the patients' movement, their initial work with price regulation gave them a special role in these

subsequent negotiations led by the government. In the future, they would be consulted on medications and generics, giving them a space in the national debates on price regulations.⁹²

However, broader organizations dedicated to medication control, such as ObservaMed, also consider the success against Abbot Laboratories as having “kaletrized” the issue.⁹³ ObservaMed contends that the HIV movement's involvement in the issue began and ended with Kaletra, rather than being a sustained effort for reform.⁹⁴ Therefore, the Kaletra issue not only finalized the split within the HIV movement but also failed to unify the pro-generics HIV groups with the pro-generics movement itself.

Activism among vulnerable populations

From the beginning, Colombian activists have strived to do more than file individual cases, instead using litigation as a strategy to build a network and produce systemic change that would benefit everyone. Most of our interviewees agreed that there have nonetheless been challenges in maintaining diversity in terms of who composes and leads the movement, as well as who benefits from its successes. Intersecting forms of discrimination and stigma have ensured that those who stand to benefit most from a human rights approach to health have, to date, benefited least.

This is perhaps most notable with respect to women. Since its early days, the HIV movement has been led mostly by men.⁹⁵ Advocates for Colombian women living with HIV began organizing separately in 1997 with the first National Meeting of Women Living with HIV, followed by the first Latin America and Caribbean Regional Seminar of Women Living with HIV in 1999.⁹⁶ They created the Sunflower Project, now the National Foundation of Positive Women, to foster women's empowerment. While many interviewees understood the concept of the feminization of HIV—that is, the global shift in which the epidemic no longer affects mostly men who have sex with men and now affects men and women equally—no interviewees could say whether the HIV movement had changed to re-

flect this demographic shift, and some suggested a need for additional study. Many interviewees raised issues faced by Colombian women living with HIV relating to the unique biases, stereotypes, and marginalization they experience, which sometimes result in different needs that have not been addressed by the movement's successes to date.⁹⁷ Heterosexual married women are generally excluded from the national HIV plan of action, further segregating efforts to end the epidemic among women from the broader HIV movement.⁹⁸ Most women receive HIV testing only if they become pregnant; even then, only two-thirds receive testing and only two-thirds of those with a positive result are given comprehensive mother-to-child transmission prevention.⁹⁹ A recent study found that 70% of Colombian women living with HIV had been surgically sterilized, which is said to discourage testing, thus nullifying for those women the gains won by the movement.¹⁰⁰

Similar to the situation with women, the LGBTQ community has a complicated history of inclusion in the movement. LGBTQ people bear a disproportionate burden of HIV, as well as stigma and discrimination, in every society.¹⁰¹ This includes Colombia, where recent progress has been made on LGBTQ rights but where many problems remain that exacerbate challenges related to HIV.¹⁰² Furthermore, the medical community has failed to demonstrate cultural competence regarding LGBTQ individuals.¹⁰³ While the movement has always been driven by gay activists, transgender people have been largely absent and their activism occurs in a separate sphere. This is partially because transgender individuals—unlike the gay men who were at the helm of the HIV movement and led its litigation strategy—have lacked the means by which to set their own community's agenda.¹⁰⁴ Instead, international donors set priorities, which are not always in line with those of the transgender community.¹⁰⁵ While internationally funded projects have made street-based rapid testing available to transgender women, these women are not connected to services that would enable them to gain insurance or enter into care.¹⁰⁶ Furthermore, transgender men lack what limited visibility that

transgender women have achieved and are not seen as at risk for HIV.¹⁰⁷

Additionally, Colombia's sex workers, many of whom exist at the intersection of gender-based and gender-identity-based marginalization, have been a notable exception to the general story of the movement told herein. Sex work is legal under certain conditions and in designated "tolerance zones" in Colombia, but a large, mainly street-based illegal market remains.¹⁰⁸ Our interviewees were not aware of sex workers playing a significant role in the movement despite their high rates of HIV. As they have with the transgender population, international donors have played a significant role in directing HIV funding for sex workers; in fact, because there is so much perceived overlap between communities of transgender women and sex workers, many programs are aimed at the combined population of both groups.¹⁰⁹ The HIV movement's success in adding treatments to the POS has not included preventive products and medication that advocates said would most benefit sex workers, who lack the bargaining power to request condoms during sex and could thus benefit more from female condoms and PrEP, which are generally unavailable through health insurance companies or otherwise.¹¹⁰ Many sex workers see HIV testing as pointless because they feel that adequate and inclusive care is out of reach, which means that the movement's gains have had a limited impact on this community.

Finally, some interviewees raised concerns that the changes brought about by the movement and T-760 have not reached incarcerated persons, who face high levels of HIV exposure due to regular sexual relations with guards and other inmates combined with limited access to condoms.¹¹¹ Many prisons have a cell block designated for people living with HIV, within which it is possible to receive some HIV-related care for those who are willing to go public with their status.¹¹² However, inmates usually need help from outside the prison in order to access HIV medications despite such access being theoretically guaranteed by T-760 and the inclusion of the drugs in the now-merged POS. Much of this is blamed on the only health insurance company that is permitted to operate in

prisons, which is allegedly ineffective and corrupt; T-760 did not change the policies on eligibility that would have allowed incarcerated persons to select another plan or to stay with the plan they had prior to incarceration.¹¹³ These issues are now being taken up primarily by those advocating for the rights of the incarcerated rather than by the movement.

Conclusion

This work outlines the history of HIV activism in Colombia—from its start with creating safe spaces for HIV patients in the 1980s, through its development of right-to-health litigation as a primary strategy for improving medication access, and to the fight over generic medication access that caused its division. The movement's success in expanding access to medications—first through *tutelas* and now through expanded health benefits—has not equally benefitted certain marginalized groups, despite the new health care law's guarantee of “equality of treatment and opportunities accessing promotion, prevention, diagnosis, treatment, rehabilitation, and palliation for everyone.”¹¹⁴ However, Colombia's story shows that reframing health as a human right can have a transformative and mobilizing effect on society, and potential remains for a rights-based approach to health to further improve the lives of Colombians living with HIV.

Acknowledgments

The authors would like to thank Professor Alicia Ely Yamin for her guidance and support throughout this project; Harvard University's David Rockefeller Center for Latin American Studies and the Harvard T.H. Chan School of Public Health for funding travel expenses; Dr. Hector Castro, Dr. Augustín Conde-Agudelo, and Professor Andrea Parra Fonseca for comprising the community advisory board; and all of the interview participants for their gracious support.

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HIV, Hepatitis C, TB, Harm Reduction, and Persons Deprived of Liberty: What Standards Does International Human Rights Law Establish?

GEN SANDER AND RICK LINES

Abstract

HIV, hepatitis C virus (HCV), and TB in prisons and other places of detention are serious public health concerns, with prevalence and incidence considerably higher than in the general community because of the overrepresentation of risky behavior, substandard conditions, overcrowding, people who inject drugs, and the wholly inadequate prevention, care, and treatment of these conditions, including the denial of harm reduction services. This is not only a severe public health crisis but also a serious human rights concern. This article works to clarify the standards established by human rights law with regards to HIV, HCV, TB, and harm reduction in prisons by examining international and regional case law, minimum standards on the treatment of prisoners and public health, as well as the work of UN treaty bodies, Special Rapporteurs, and prison monitoring bodies. It is imperative that urgent steps are taken to close the gap between human rights and public health standards on the one hand, and effective

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Competing interests: None declared.

This research was co-funded by the European Commission under the Criminal Justice Programme. The contents of this publication are the sole responsibility of the authors and can in no way be taken to reflect the views of the European Commission.

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Background

HIV, hepatitis C virus (HCV), and tuberculosis (TB) epidemics are a major public health concern around the world. Although all affect the population at large, they have emerged as an especially severe problem in prisons and other places of detention worldwide. Prison populations have a significantly higher prevalence, and in some contexts a higher incidence, of these diseases than the general public. A recent review of the global epidemiology of HIV, HCV, and TB in prisoners estimated that, of the roughly 10 million people detained worldwide on any given day, 3.8% are living with HIV, 15.1% with HCV, and 2.8% with active TB.¹ Throughout this article, the terms ‘prison,’ ‘detention’ and ‘closed settings’ are used interchangeably to refer to all places where people are deprived of their liberty. Similarly, the term ‘prisoner,’ ‘detainee’ and ‘people deprived of their liberty’ are used interchangeably to refer to all persons deprived of their liberty.

Prison settings represent high-risk environments for the transmission of these diseases for a number of reasons. For one, poor and marginalized communities are overrepresented in prison populations worldwide.² Many of the factors that contribute to disproportionate levels of incarceration, such as poverty, discrimination, and criminalization of drug use and possession, also put these populations at increased vulnerability to similarly disproportionate rates of HIV, HCV, and TB. For example, people who inject drugs are 24 times more likely to acquire HIV than the rest of the adult population, while HCV and TB prevalence are also much higher among this population.³

Punitive approaches to drug use have resulted in the mass incarceration of people who use drugs. Currently, around one in every five prisoners is serving time for a drug offense, and it has been estimated that 56-90% of people who inject drugs will be incarcerated at some stage of their lives.⁴ Despite the secure and allegedly drug-free nature of closed custody settings, many people continue to use drugs on an occasional or regular basis while in detention. Injecting drug use is common in prisons in every region of the

world, and sharing of injecting equipment—sometimes with 15-20 people—occurs out of necessity.⁵ Intensifying this risk of infection and related ill health are the substandard conditions in which detainees are frequently held. Overcrowding, poor sanitation, inadequate ventilation and means for maintaining personal hygiene, and lack of access to clean drinking water and nutritional food are common in prisons and contribute to high rates of disease and death. These poor conditions invariably exist within a climate of violence, humiliation, and discrimination that creates barriers to accessing health care services, which are often weak or inadequate to begin with.

Despite this reality, the provision of HIV, HCV, and TB treatment and prevention programs, including evidence-based harm reduction services such as needle and syringe programs (NSPs) and opioid substitution therapy (OST), remain extremely limited in prisons in comparison to what is available in the broader community. Currently, while 90 countries implement NSPs in the broader community, only eight make the service available in at least one prison. At the same time, while 80 countries provide OST in the broader community, only 52 provide the service in at least one prison, and only 43 countries provide HIV treatment in prisons.⁶

Ill health and poor conditions in prisons do not only concern prisoners and prison staff; they are issues of much wider public health concern. Around one-third of people incarcerated worldwide return to their communities every year, and because recidivism is common, especially among people who use drugs, there is a high degree of mobility between prison and community.⁷ Prison health, therefore, is intimately connected to public health.⁸ This is not just a public health concern, however, but also a human rights imperative.

Human rights, health, and persons deprived of liberty

Under international human rights law, persons deprived of their liberty retain all fundamental rights and freedoms, apart from those that are unavoidably restricted by the fact of their incarceration.⁹

Like all persons, therefore, detainees have a right to health.

The cornerstone protection of the right to health in international law is found in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), but several provisions found in a range of other widely ratified international and regional human rights treaties also protect prisoners' health rights.¹⁰ Some of these specifically articulate the right to health, while others, such as the prohibition of torture and ill treatment, for example, offer indirect protection. The prohibition of torture and ill treatment imposes positive obligations on states to protect the lives and/or well-being of persons deprived of liberty, which has been interpreted by several human rights mechanisms to require government authorities to safeguard the health of prisoners.¹¹ As will be demonstrated, the right to health and freedom from torture and ill treatment are indivisible and interdependent, particularly in closed settings.¹²

The highly generalized language used to articulate health rights in human rights treaties does not shed much light on the specific entitlements and obligations to which they give rise. UN treaty bodies, however, have provided useful operational guidance in their work to help understand the contours and content of particular rights. According to the UN Committee on Economic, Social and Cultural Rights (CESCR), for example, the right to health is not a right to be healthy; rather, it is an inclusive right that extends not only to timely and appropriate medical care, but also to the underlying determinants of health, such as access to adequate sanitation facilities, healthy environmental conditions, essential drugs, and health-related education and information.¹³ This broad understanding of the right to health is important in the context of places of detention.

Clarifying the normative content of detainees' right to health entitlements, and the obligations that these impose on state authorities, requires an examination of international and regional treaty and case law, minimum standards on the treatment of prisoners and public health more generally, as well as the work of UN treaty bodies, Special

Rapporteurs, and prison monitoring bodies. The following sections rely on these sources to identify some of the most relevant entitlements and obligations that stem from the right to health of prisoners in the context of HIV, HCV, TB, and harm reduction. Before turning to that, however, a brief word on standards will be helpful. Some standards, such as the absolute ban on torture and ill treatment and the obligation to respect the right to health by refraining from denying or limiting equal access for all persons to health services, are protected by international and regional treaties, as well as national constitutions and laws. Other public health and human rights standards, such as those included in the UN Standard Minimum Rules for the Treatment of Prisoners, codify much more specific entitlements and obligations with regards to, for example, adequate medical care for persons in detention. While the latter do not formally enjoy the status of international law, and are technically non-binding "soft law" instruments, a strong argument can be made that they have become accepted minimum legal requirements for governments to meet.¹⁴

A right to non-discrimination and equivalence of care

Like with many other socioeconomic rights, the right to health is subject to both resource availability and progressive realization. Yet regardless of their economic situation, states must fulfill minimum core obligations with respect to health, including to prisoners. One of these core obligations, which is both of immediate effect and non-derogable, is to "ensure the right of access to health facilities, goods and services, on a non-discriminatory basis, especially for vulnerable and marginalised groups."¹⁵ Detained against their will, prisoners are at the mercy of the prison authorities, which puts them in a uniquely vulnerable position. Effectively deprived of the ability to provide for themselves, it has been argued that state actors have heightened obligations vis-à-vis prisoners.¹⁶ This is reflected in the CESCR's General Comment 14.¹⁷

In the context of harm reduction in prisons, the former UN Special Rapporteur on the right to health has stated that "If harm reduction pro-

grammes and evidenced-based treatment are made available to the general public, but not to persons in detention, that contravenes international law.”¹⁸ Indeed, the importance of ensuring non-discriminatory access to health facilities, goods, and services in prisons has been widely endorsed in human rights and public health standards, guidelines, and other documents. Several standards of humane treatment of prisoners make reference to non-discrimination in accessing health care, including the European Prison Rules, the UN Basic Principles for the Treatment of Prisoners, and the revised UN Standard Minimum Rules for the Treatment of Prisoners, which state that “Prisoners should enjoy the same standards of health care that are available in the community, and should have access to necessary health-care services free of charge without discrimination on the grounds of their legal status.”¹⁹ It is also reflected in many international declarations and guidelines, including in the World Health Organization’s (WHO) 1993 Guidelines on HIV infection and AIDS in prisons, and various other UN documents and statements.²⁰

Very closely related to the obligation of non-discrimination is the principle of equivalence: the obligation to provide a standard of care that is at least equivalent to that available in the community. It is worth mentioning that despite the principle of equivalence enjoying broad consensus among international health and human rights authorities, including UN bodies, the European Union and the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or punishment (CPT), it has one notable detractor: the European Court of Human Rights. In *Gladkiy v. Russia*, the Court stated that it “does not always adhere to this standard, at least when it comes to medical assistance to convicted prisoners” and that “[freedom from inhuman or degrading treatment] cannot be interpreted as securing for every detained person medical assistance at the same level as in ‘the best civilian clinics.’”²¹ While this position flies in the face of well-established international consensus, it is not very surprising given the Court’s practice of deferring to the judgment

of national authorities, also known as its “margin of appreciation doctrine.”²² The former Special Rapporteur on the right to health has clearly stated that “in the context of HIV and harm reduction, this demands implementation of harm reduction services in places of detention even where they are not yet available in the community, as the principle of equivalence is insufficient to address the epidemic among prisoners.”²³

A right to essential medicines

Another important core obligation vis-à-vis prisoners’ right to health, which is also non-derogable and of immediate effect, is to provide essential medicines as defined by WHO’s Essential Medicines Programme.²⁴ According to the latest WHO definition, essential medicines are “those that satisfy the priority health-care needs of the population” and are “selected with due regard to disease prevalence, evidence of efficacy and safety and comparative cost-effectiveness.”²⁵ They are meant to be available at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at an affordable price.²⁶

WHO’s Model List of Essential Medicines includes morphine, methadone, and buprenorphine, drugs commonly used to treat opioid dependence.²⁷ Because these are classified as “controlled substances” under the international drug conventions, their availability is often limited. Where these essential medicines are available in the community, they are often of poorer quality, not provided on a continuous basis, or simply unavailable in closed settings.²⁸ For example, while 80 countries and territories implement OST in the broader community, only 52 countries provide the service in at least one prison.²⁹ There are several reasons for this, including the common perception that prisons should be “drug-free zones,” unfounded concerns about the provision of OST leading to diversion of medication, violence, and/or security breaches, as well as a preference for abstinence-based treatment.³⁰ Unfortunately, these misconceptions continue to overshadow unequivocal scientific evidence revealing OST to be the most effective treatment in

managing opioid dependence, preventing HIV and HCV transmission, and in caring for drug users living with HIV or other infections.³¹

Again, the obligation to provide essential medicines should be discharged on a non-discriminatory basis, as the Human Rights Council highlighted when it recognized the “responsibility of States to ensure access to all, without discrimination, of medicines, in particular essential medicines, that are affordable and of good quality.”³² From a public health and human rights perspective, it is imperative that essential medicines be equally accessible in places of detention. The former Special Rapporteur on the right to health has called on states to “ensure that all harm reduction measures and drug dependence treatment services, particularly opioid substitution therapy, are available to people who use drugs, in particular those among incarcerated populations.”³³

The right to essential medicines also engages the right to humane treatment. The UN Special Rapporteur on torture recently explained that when “the failure of States to take positive steps, or to refrain from interfering with health-care services, condemns patients to unnecessary suffering from pain, States not only fall foul of the right to health, but may also violate an affirmative obligation under the prohibition of torture and ill treatment.”³⁴ The UN Human Rights Committee also recently confirmed that “physical and mental pain and suffering associated with withdrawal symptoms may amount to torture or ill treatment,” and that states have an obligation to ensure that drug users deprived of their liberty are effectively protected against this pain and suffering through the provision of timely, adequate and scientifically based medical assistance.³⁵

A right to medical care and treatment

The right to medical care and treatment is a critically important element of the right to health and like all other rights, it belongs to everyone, including prisoners. CESCR has explicitly affirmed that “States are under the obligation to respect the right to health by...refraining from denying of limiting

equal access for all persons, including prisoners or detainees ... [to] curative and palliative health services.”³⁶ On a number of occasions, when reviewing the implementation of state obligations, CESCR has expressed a specific concern about inadequate access to health care in prisons and has explained that medical care and treatment must not only be accessible, but also “timely and appropriate.”³⁷

This obligation is also expressed regularly within civil and political rights mechanisms. The UN Human Rights Committee, for example, has affirmed that the obligation to “provide appropriate medical care to detainees” is engaged under Article 10 (prohibition of inhuman and degrading treatment) of the International Covenant on Civil and Political Rights.³⁸ The former Special Rapporteur on torture has also stated that “denial of medical treatment and/or absence of access to medical care in custodial situations may constitute cruel, inhuman or degrading treatment or punishment and is therefore prohibited under international human rights law.”³⁹

The European Court of Human Rights has also recognized the obligation to provide care and treatment specifically for communicable diseases in prisons. In *Gladkiy v. Russia*, the Court held that “the State does have a responsibility to ensure treatment for prisoners in its charge” and that “[a]bsent or inadequate treatment for tuberculosis, particularly when the disease has been contracted in detention, is most certainly subject of the Court’s concern.”⁴⁰ Providing guidance on what “adequate” means, the Court has stated that “The mere fact that a detainee was seen by a doctor and prescribed a certain form of treatment cannot automatically lead to the conclusion that the medical assistance was adequate.”⁴¹

On several occasions, the Court has found that inadequate care and treatment for HIV, HCV, and/or TB has amounted to cruel, inhuman, or degrading treatment.⁴² In *Khudobin v. Russia*, the Court found that in the given context, the absence of medical assistance for a prisoner living with HIV amounted to degrading treatment.⁴³ In *Koryak v. Russia* and *A.B. v. Russia*, the fact that detainees did not receive comprehensive, effective, transparent,

or timely medical assistance for HIV and TB was sufficient for the Court to find that the authorities had failed to comply with their responsibility to ensure the provision of adequate medical treatment, which amounted to inhuman and degrading treatment.⁴⁴ In *Kozhokar v. Russia*, the Court found that the applicant did not receive comprehensive, effective, and regular medical assistance for HIV or HCV during detention, which amounted to degrading treatment.⁴⁵

The Court has also found that inadequate treatment of drug dependence violates the prohibition of cruel, inhuman, or degrading treatment. In a very recent case, *Wenner v. Germany*, the Court established that “the refusal to provide the applicant with drug substitution treatment despite his manifest opioid addiction caused him considerable and continuous mental suffering for a long time.”⁴⁶ The Court concluded that Germany’s failure to provide “comprehensive and adequate medical care in detention, at a level comparable to that which the State authorities have committed themselves to provide to persons in freedom, where drug substitution was available,” amounted to cruel, inhuman, and degrading treatment.⁴⁷ In another especially notable case, *McGlinchey and Others v. UK*, the Court held that the failure of prison health facilities to provide adequate medical care to a prisoner undergoing heroin withdrawal, who subsequently died, constituted ill treatment.⁴⁸ Specifically, the Court found that the prisoner’s suffering derived not from heroin withdrawal but “the failure of prison authorities to take more effective steps to combat her withdrawal symptoms and [that her] deteriorating condition must have contributed to her pain and distress.”⁴⁹ International and regional standards relating to the treatment of prisoners reflect this obligation to provide adequate health care and treatment. The Standard Minimum Rules for the Treatment of Prisoners, for example, explicitly state that “the provision of health care for prisoners is a State responsibility,” which is reiterated in the European Prison Rules.⁵⁰

An important element of the right to health care and treatment in the context of places of de-

tention is that of continuity of care and treatment. People with health issues who move between detention and the community can find short periods in prison very disruptive to their community-based care and treatment programs. Others who start a particular treatment in prison often do not get connected with appropriate aftercare following release, a concern highlighted by WHO, the UN Office on Drugs and Crime (UNODC), and the Joint United Nations Programme on HIV/AIDS (UNAIDS).⁵¹ This important obligation is also explicitly articulated in the revised Standard Minimum Rules for the Treatment of Prisoners. Rule 24(2) states: “Health-care services should be organised in close relationship to the general public health administration and in a way that ensures continuity of treatment and care, including for HIV, tuberculosis and other infectious diseases, as well as for drug dependence.”⁵² Several public health standards also reiterate this important principle.⁵³

A right to preventive health services, including harm reduction

Particularly relevant to the context of HIV, HCV, and TB in prisons is the right to preventive health services. In recognition of this, CESCR has identified the obligation to take measures to prevent, treat, and control diseases as being of comparable priority to the core obligations under the right to health.⁵⁴ It specifically identifies prisoners and detainees as being entitled to this fundamental right, confirming: “States are under the obligation to respect the right to health by...refraining from denying or limiting equal access for all persons, including prisoners or detainees...to preventive... health services.”⁵⁵ More specifically, CESCR has on more than one occasion recommended that states take steps to combat infections within prisons, particularly the most severe, such as TB and HIV.⁵⁶ The Special Rapporteur on torture has also explicitly stated that “states have an obligation to ensure that drug dependence treatment as well as HIV/hepatitis C prevention and treatment are accessible in all places of detention,” and that “needle and syringe programmes should be used to reduce the risk of

infection with HIV/AIDS.⁵⁷

The obligation is also confirmed in international and regional jurisprudence. For example, the UN Human Rights Committee, in its Concluding Observations on Moldova, noted that “Danger to the health and life of detainees as a result of the spread of contagious diseases and inadequate care amounts to a violation of article 10 [prohibition of torture and ill treatment]...and may also include a violation of articles 9 [right to liberty and security of the person] and 6 [right to life].”⁵⁸ The European Court of Human Rights has sustained this view in a number of its judgments. In *Melnik v. Ukraine*, the Court found a violation of the prohibition of ill treatment, in part, for the failure to prevent the applicant’s tuberculosis while he was in prison.⁵⁹ In *Staykov v. Bulgaria*, the Court found the fact that “the applicant fell ill with tuberculosis” while in prison, along with a finding that “the prison authorities’ prevention efforts were inadequate” among the factors contributing to a violation of the prohibition of ill treatment.⁶⁰

This legally binding obligation is also reflected in several prison health standards, WHO and World Medical Association declarations, as well as non-binding resolutions of the Council of Europe and Parliamentary Assembly.⁶¹ The CPT has also confirmed that “the act of depriving a person of his liberty always entails a duty of care which calls for effective methods of prevention, screening, and treatment.”⁶²

There is unequivocal evidence that the most effective way to prevent HIV and HCV infection within prisons is through the provision of harm reduction services.⁶³ This has been endorsed by a number of human rights and public health authorities. CESCR, for example, expressed concern at the rapid transmission of HIV in Tajikistan and Mauritius, in particular among prisoners, sex workers, and people who use drugs.⁶⁴ The Committee specifically called upon the government of Tajikistan to “establish time-bound targets for extending the provision of free...harm reduction services to all parts of the country” and to implement needle and syringe programs and OST based on international best practice standards in prisons.⁶⁵ In a

2009 statement, the UN High Commissioner for Human Rights recognized “the longstanding evidence that a harm reduction approach is the most effective way of protecting rights, limiting personal suffering, and reducing the incidence of HIV,” and stressed that “this is particularly the case for those in detention, who are already vulnerable to many forms of human rights violations.”⁶⁶ Furthermore, the *Madrid recommendation: Health protection in prisons as an essential part of public health*, which was endorsed by representatives from 65 countries as well as the WHO, UNODC, and the Council of Europe, among many others, recognizes “the urgent need in all prison systems for measures, programmes and guidelines which are aimed at preventing and controlling major communicable diseases in prisons,” including “harm reduction measures, including opioid substitution therapy, needle and syringe exchange...and condom distribution.”⁶⁷

It is important to briefly mention that human rights and public health standards, as well as minimum standards on the treatment of prisoners, require that testing and treatment, particularly for HIV and drug dependence, be voluntary and carried out only with the free and informed consent of the prisoner.⁶⁸ As the Special Rapporteurs on the right to health and torture have both affirmed, “Guaranteeing informed consent is a fundamental feature of respecting an individual’s autonomy, self-determination and human dignity.”⁶⁹ In the same breath, confidentiality must be protected, particularly in prison settings where the risk of reprisal is high, and information on health status must not be disclosed to third parties without the consent of the prisoner.⁷⁰

A right to the underlying determinants of health

As already mentioned, the right to health extends not only to health care but also to the underlying determinants of health, which have a considerable impact on whether people are healthy or not. This is particularly relevant in the context of prisons and other places of detention, where overcrowding, inadequate sanitary facilities, poor hygiene, poor nutrition, and inadequate access to drinking water

are often the rule rather than the exception. As conditions of detention are integrally linked to the health status of those held within them, it is no wonder that conditions under which detainees are held have been found to favor the spread of diseases.⁷¹

CESCR has identified housing as “the environmental factor most frequently associated with conditions for disease” and notes that “inadequate and deficient housing and living conditions are invariably associated with higher mortality and morbidity rates.”⁷² The Standard Minimum Rules for the Treatment of Prisoners also recognize that the failure to provide, among other things, adequate space, lighting, ventilation, nutritious food, drinking water, and appropriate hygiene and sanitary installations can be detrimental to the health of persons in detention.⁷³

The Committee Against Torture and the Special Rapporteur on torture have also found that inadequate conditions of detention could amount to ill treatment.⁷⁴ Similarly, the European Court of Human Rights has found that health decline, or the contracting of disease, while in detention may also be judged as evidence that the overall prison conditions are inhuman or degrading.⁷⁵

A right to participation

The right to participation, the basic right of people to have a say in matters that affect their lives, has been described as the right of all rights.⁷⁶ While the essential role of participation in realizing fundamental human rights has been explicitly recognized in all legally binding human rights treaties, it is particularly important in realizing the right to health. CESCR and the former Special Rapporteur on the right to health have identified participation in all health-related decision-making as an important component of the right to health, as well as one of the underlying determinants of health.⁷⁷ One of the core obligations of the right to health is the provision for participation in the development, implementation, and review of the national health plan that focuses on issues affecting the most vulnerable and marginalized, as well as in the health policies and interventions flowing from that plan.⁷⁸ In reality, it may not be possible to ensure every-

one’s participation, but the government has an immediate obligation to obtain a representation of views, particularly of those most vulnerable and marginalized.

Importantly, individuals have a right to “active and informed” participation, which relies on institutional arrangements and specific mechanisms to ensure participation at different stages, as well as capacity-building activities to ensure that people have the ability to participate meaningfully and effectively.⁷⁹ In this context, it is important to note that informed participation relies on the right to health-related education and information.

A human rights-based approach to health (HRBA) requires that prisoners participate in the entire process of prison-based HIV, HCV, TB, and harm reduction programming, from identifying priorities, to designing and implementing programmes, to monitoring and evaluating their impact and effectiveness. Considerable benefits to people’s participation in health decisions have been identified, including increased sustainability and effectiveness of interventions, improvements in the quality of health care and services, empowerment of individuals, enhanced accountability, and positive health and health-related outcomes.⁸⁰

WHO, UNODC, and UNAIDS have recognized the importance of prisoner participation in the context of the development and implementation of policies and initiatives to address HIV in prisons.⁸¹ There is also recognition of the value of the participation of detainees at the European level. In January 2006, the Committee of Ministers of the Council of Europe adopted Recommendation (2006) 2, which contains the revised European Prison Rules. A new Rule 50 requires that prisoners be allowed and encouraged to discuss matters relating to the general conditions of imprisonment with prison administrations. The commentary to the recommendation states that “it is in the interests of prisoners as a whole that prisons should run smoothly and they may well have suggestions to make.”⁸² The CPT has also suggested that prisoners’ own evaluations of existing health care services might represent one element in determining necessary changes to health care systems for the prison population.⁸³

Conclusion

The right to health and the right to be free from ill treatment are increasingly recognized as being interrelated and indivisible, especially in prison contexts, by UN bodies and mechanisms, courts, and prison monitoring bodies. Indeed, as the former Special Rapporteur on the right to health has noted, “The promotion and protection of the right to health...strengthens the prevention of torture and ill-treatment, while the prohibition of torture... reinforces the realisation of the right to health.”⁸⁴

People retain their human rights during incarceration, including their right to the highest attainable standard of health. There is an enormous gap, however, between public health and human rights standards on the one hand, and effective implementation in custody settings on the other. Data revealing the high prevalence rates inside places of detention compared to those in the broader community, for example, demonstrate that this is particularly the case with regards to HIV, HCV, and TB. Despite their vulnerability to ill health, persons deprived of liberty are much less likely to have access to adequate prevention, care, and treatment of these diseases, including harm reduction services. Additionally, they are often held in substandard conditions that favor the transmission of diseases. This clearly creates an imperative for increased and ongoing attention to HIV, HCV, and TB in places of detention, including a focus on the urgent need to scale up harm reduction in these settings.

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Reproductive Health Policy in Tunisia: Women's Right to Reproductive Health and Gender Empowerment

NADA AMROUSSIA, ISABEL GOICOLEA, AND ALISON HERNANDEZ

Abstract

Although Tunisia is regarded as a pioneer in the Middle East and North Africa in terms of women's status and rights, including sexual and reproductive health and rights, evidence points to a number of persisting challenges. This article uses the Health Rights of Women Assessment Instrument (HeRWAI) to analyze Tunisia's reproductive health policy between 1994 and 2014. It explores the extent to which reproductive rights have been incorporated into the country's reproductive health policy, the gaps in the implementation of this policy, and the influence of this policy on gender empowerment. Our results reveal that progress has been slow in terms of incorporating reproductive rights into the national reproductive health policy. Furthermore, the implementation of this policy has fallen short, as demonstrated by regional inequities in the accessibility and availability of reproductive health services, the low quality of maternal health care services, and discriminatory practices. Finally, the government's lack of meaningful engagement in advancing gender empowerment stands in the way as the main challenge to gender equality in Tunisia.

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Competing interests: None declared.

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Introduction

Tunisia is regarded as a pioneer in the Middle East and North Africa in terms of women's status and rights.¹ In 1956, it was the first country in the region to abolish polygamy and, in 1973, was the first to legalize abortion. Moreover, it is the only country in the region that has withdrawn all its reservations to the Convention of Elimination of All Forms of Discriminations against Women (CEDAW). Since 1966, Tunisia has also run a successful family planning program. As part of this program, the National Board for Family and Population was created in 1973. In 1994, the United Nations Population Fund (UNFPA) designated Tunisia as a Centre for Excellence in terms of its population activities.²

The 1994 International Conference on Population and Development (ICPD) marked an important transition in Tunisia's population policy, as it led the country to abandon its focus on purely demographic concerns and instead embrace reproductive health as a priority per se in national health programs.³ In fact, despite the importance of the Millennium Development Goals and the Sustainable Development Goals in putting issues such as maternal health, gender equality, and women's empowerment on the international agenda, the ICPD Programme of Action is still regarded as the most comprehensive international document on sexual and reproductive rights.⁴

Since 1994, women's reproductive health indicators in Tunisia have shown improvements. By 2012, the unmet need for contraception was just 7%.⁵ Skilled attendance at delivery increased from 76.3% in 1990 to 97.6% in 2013, and the maternal mortality ratio declined from 91 per 100,000 live births in 1990 to 46 per 100,000 in 2013.⁶ However, it has not all been progress. According to a 2010 shadow report submitted to the CEDAW Committee by Tunisia's Democratic Women's Association, women in Tunisia are subjected to numerous violations of their sexual and reproductive rights, including discrimination against unmarried women, virginity testing, and the criminalization of homosexuality.⁷

Over the last five years, Tunisia has undergone a political transition characterized by new aspira-

tions for democracy and respect for human rights. Throughout this period, women's rights, including their sexual and reproductive rights, have been one of the most debated topics in the new republic. As a contribution to the post-democratic transition debates concerning women's rights, this article presents a gender-sensitive human rights-based analysis of Tunisia's reproductive health policy between 1994 and 2014.

Theoretical framework

After a long history of marginalization, reproductive rights were globally recognized in the ICPD. Although these rights are still controversial and contested in many settings, they do not represent a new set of rights. Indeed, they reflect the very rights that have been long established in human rights treaties—for example, the right to life, the right to physical integrity and the right to health. As fundamental human rights, reproductive rights are universal, inalienable, indivisible, and interrelated; they apply to all human beings equally without discrimination, and they require application of the principles of participation, inclusion, accountability, and the rule of law. Hence, states are obligated to respect, protect, and fulfill these rights, and citizens can hold the state accountable for this obligation.⁸ This constitutes the basis for a human rights-based approach.

Women's right to reproductive health entails the government's responsibility in providing available, accessible, acceptable, and high-quality reproductive health care services, as well as ensuring that women can make free decisions regarding their sexuality and reproduction.⁹ According to General Comment No. 12 of the United Nations Committee on Economic, Social and Cultural Rights, availability refers to the adequate supply of reproductive health facilities, goods, and services. Accessibility requires that these services be non-discriminatory, physically accessible, affordable, and accessible in terms of their information. Acceptability means that these services and goods must be culturally and ethically acceptable, while quality means that they must be medically and sci-

entifically appropriate.¹⁰

Women's reproductive health and rights are affected by the social organization of gender relations. Gender inequality is responsible for women's vulnerable status and limits their abilities to make free decisions about their bodies and their lives.¹¹ It also leads to harmful practices, such as gender-based violence, which can affect women's health.

Gender empowerment and women's rights, including reproductive rights, are inextricably linked.¹² For example, the right to have control over and to make free decisions about reproduction and reproductive health requires empowerment; women cannot enjoy this right if they are economically dependent or politically excluded.¹³ Education is also crucial for improving women's knowledge about the availability of reproductive health services and for ensuring their access to these services.¹⁴ Moreover, gender empowerment improves women's economic and social status, thus creating a positive environment in which they can claim their rights.¹⁵ Examining the state of gender equality is therefore critical to understanding the environment that shapes women's capacity to exercise their rights.

In this light, we used the Health Rights of Women Assessment Instrument (HeRWAI) to analyze Tunisia's reproductive health policy. Our aim was threefold: (1) to explore the extent to which reproductive rights have been incorporated into the country's reproductive health policy; (2) to determine gaps in the implementation of this policy; and (3) to examine how the gender empowerment process has been influenced by this policy.

Methodology

Study setting

Located in North Africa, Tunisia is a middle-income country with a population of 11 million.¹⁶ According to the 2014 Constitution, Tunisia has been a republic since 1956. However, it was not until 2011 that the country held its first democratic elections. Regional inequities are considered the main barrier to socioeconomic development. Poverty and unemployment are concentrated in the predomi-

nately rural Central West and North West regions, where 26%–32% of the population lives in poverty and 20%–22% are unemployed.¹⁷ Furthermore, Tunisia's cultural context is highly influenced by religion. Under article 1 of the Constitution, Islam is considered the official religion of the country, and the majority of Tunisians are Muslims. Nevertheless, since gaining independence, Tunisia has tried to adopt "secular policies" aimed at the country's modernization.¹⁸

Methods

HeRWAI tool

We applied HeRWAI, an analytical tool developed by Aim for Human Rights, to perform an analysis of Tunisia's reproductive health policy. Built on the human rights framework, this tool assesses the impact of policies on women's health and rights by comparing what is actually happening to what should happen according to the government's human rights commitments.¹⁹

The HeRWAI analysis is performed in six steps:

1. Identify the policy that affects women's health and rights.
2. Explore the government's human rights commitments.
3. Explore the government's capacity to implement the selected policy.
4. Assess the impact of the policy on women's health rights.
5. Hold the government accountable for its obligations to respect, protect, and fulfill human rights.
6. Formulate recommendations and an action plan based on the findings of the analysis in order to enforce the realization of women's rights.²⁰

HeRWAI is one of the most frequently used impact assessment tools for health and human rights. Focusing on women's right to health, it is designed primarily to generate evidence for use in advocacy and lobbying. The tool's flexibility facilitates its adaptation to different types of studies.

Adaptation of HeRWAI in this study

We adapted HeRWAI to a three-stage process based on our three research aims:

- Stage 1: Incorporation of reproductive rights into national policy

First, we collected official data related to reproductive health policy in Tunisia (laws, national programs, and strategies) through an online review of government websites. Included in this data were collaborative strategies between Tunisia and the World Health Organization (WHO) and UNFPA. We considered three international human rights commitments for our analysis: the ICPD Programme of Action, the Beijing Declaration and Platform for Action, and CEDAW. Our assessment of the incorporation of reproductive rights was guided by four indicators proposed by Guang-zhen Wang and Vijayan Pillai: the right to legal abortion; the right to use contraceptive methods; the right to interracial, interreligious, and civil marriage; and the equality of men and women during marriage and divorce proceedings.²³ Additionally, based on the definition of reproductive rights adopted in the ICPD Programme of Action, we added a fifth indicator: the right to reproductive health.²⁴

- Stage 2: Gaps in the implementation of the reproductive health policy

To assess the impact of the reproductive health policy on women’s right to reproductive health, we conducted a literature review using the search terms “reproductive health,” “reproductive rights,” “maternal health,” and “sexual rights,” with the setting “Tunisia.” The literature review included quantitative and qualitative studies, as well as reports published by international organizations. Due to the limited availability of data, we included all identified sources that focused on reproductive health in Tunisia and were published between 1994 and 2014. Data related to the government’s implementation capacity was collected through an online review of government websites.

To determine the gaps in implementation regarding women’s right to reproductive health, we used the four criteria outlined in General Comment No. 14: availability, accessibility, acceptability, and quality of reproductive health services.²⁵

- Stage 3: Status of gender equality and the realization of women’s rights

This stage addressed the influence of the reproductive health policy on gender empowerment in Tunisia. Our analysis was based on a literature review covering the period 1994–2014. We used the search terms “gender empowerment,” “gender equality,” “women’s rights,” and “gender equity,” along with the setting “Tunisia.”

TABLE 1. Summary of the data resources used

Stage of the analysis	Data resources	Literature used
Stage 1: Incorporation of reproductive rights into national policy	National Health Portal in Tunisia National Board for Family and Population Portal Official Printing Office of the Republic of Tunisia website UNFPA Tunisia Office of the United Nations High Commissioner for Human Rights UN Women WHO Tunisia	9 reports 1 conference paper 2 legal texts
Stage 2: Gaps in the implementation of the reproductive health policy	National Board for Family and Population Portal National Health Portal in Tunisia Ministry of Finance Portal UNFPA Tunisia Databases: Web of Science, EBSCO, Pubmed, Scopus	8 reports 3 conference papers 5 studies
Stage 3: Status of gender equality and the realization of women’s rights	National Board for Family and Population Portal National Institute of Statistics UN Statistics Division Databases: Web of Science, EBSCO, Pubmed, Scopus	5 reports 5 studies 1 conference paper

During the three stages of analysis, we considered data available in English, French, and Arabic. Table 1 summarizes the main data resources used.

Findings and discussion

Incorporation of reproductive rights into national policy

Promulgating laws that protect reproductive rights constitutes the first step toward the integration of these rights into reproductive health policies, as these laws represent the legal framework for the formulation of strategies and programs related to reproductive health. In Tunisia, the right to use contraceptives and the right to abortion have been protected under law since 1961 and 1973, respectively.²⁶ The right to reproductive health has been incorporated through the guarantee of service provision in various national health programs. Free access to contraception, abortion, and counseling for all women is ensured through the country's family planning program.²⁷ Moreover, as part of Tunisia's antenatal program, initiated in 1990, and its National Strategy to Reduce Maternal and Neonatal Mortality, initiated in 1998, pregnant women are ensured the right to five prenatal consultations and two postnatal consultations free of charge.²⁸ Breast cancer screening and cervical cancer screening have also been introduced into basic health care services as part of the country's National Cancer Control Plans.²⁹

Since 2001, as part of the National Program to Combat Sexually Transmitted Diseases (STDs) and HIV/AIDS, free access to antiretroviral drugs has been guaranteed, along with free, voluntary, and confidential HIV tests. The prevention and treatment of sexually transmitted infections has also been included in primary health care services.³⁰ However, access to HIV treatment for vulnerable populations (intravenous drug users, homosexuals, and sex workers who are not authorized by the Ministry of Internal Affairs) is hindered by Law 92-52, which severely penalizes drug use, and by articles 230 and 231 of the Penal Code, which impose jail sentences in cases of sodomy and illegal prostitution.³¹

Despite this increased availability of health services, however, the attainment of reproductive health is limited by laws that perpetuate gender inequality. Women's right to civil marriage is violated by an administrative regulation that prohibits Tunisian women from marrying non-Muslim men.³² Moreover, gender inequality during marriage is maintained by article 23 of the country's Personal Status Code, which names the husband as the head of the family. Finally, inequality in legal rights can be observed in the case of divorce, where women are at risk of losing their right to custody of their children if they remarry, while men are not.³³

Our analysis of national legislation and health strategies demonstrates that although Tunisia started adopting laws promoting reproductive rights (mainly the right to contraception and the right to abortion) in the 1960s, its progress since ICPD has been slow. This calls into question the government's commitment to place reproductive rights at the core of its reproductive health policy, as it agreed to do when it signed the ICPD Programme of Action and the Beijing Declaration and Platform for Action.³⁴ As Adrienne Germain et al. have asserted, advancing reproductive rights requires that the government implement accountability mechanisms to monitor progress and redress shortcomings. While Tunisia submits periodic reports to United Nations treaty bodies, it has not developed national accountability mechanisms to monitor the realization of reproductive rights.³⁵ Developing standards and benchmarks to guide such monitoring is critical for allowing a more comprehensive assessment of the realization of reproductive rights in Tunisia.³⁶

Gaps in the implementation of the reproductive health policy

In Tunisia, women's right to reproductive health has been incorporated into various plans and programs. Nevertheless, there is no comprehensive strategy to include the package of essential reproductive services within the country's primary health care system, as recommended in the ICPD Programme of Action. UNFPA has stated that the absence of consensus on an affordable basic pri-

mary health care package in Tunisia represents a barrier to universal access to reproductive health care.³⁷ Moreover, despite the private sector's growing role in the provision of reproductive health services, there are no coordination plans with the government to ensure the affordability of essential reproductive health care services.

In 2012, the total government expenditure in health was estimated to be 7% of the national budget.³⁸ In the last two years, 15% of the Ministry of Health's budget was allocated to the implementation of basic health care programs, including reproductive health programs, yet only 13.8% of this portion was allocated to the National Board for Family and Population. Additionally, our exploration revealed that in 2014, only 10% of all human resources were allocated to the implementation of basic health programs.

Regional inequities in the accessibility and availability of reproductive health services

Reproductive health services are provided mainly by a network of 2,091 primary health care centers, 36 reproductive health centers, and 20 youth centers.³⁹ According to WHO, 95% of Tunisia's primary health care centers are geographically accessible to the population.⁴⁰ However, as noted by UNFPA, only 10% of the primary health care centers situated in the North West, Central West, and South East provide a basic package of reproductive health services, compared to the good availability of these services in the North and Central East regions.⁴¹ In addition, in rural areas, family planning services are provided via mobile clinics.⁴² Despite

the efficiency of mobile units in overcoming the poor health care infrastructure in many areas, the number and coverage of these units have decreased significantly in recent years; indeed, in 2013, only one mobile clinic was available.⁴³

Regional inequities in women's access to reproductive health care are further reflected in women's reproductive health indicators, such as maternal mortality ratios (see Table 2). In 1994 and 2008, the maternal mortality ratios in the North West, Central West, and South East were remarkably higher than the nationwide ratios.⁴⁴ Tunisia's national committee on maternal mortality found that the high ratios in the North West and Central West were due to a lack of blood supply, equipment, and medicines, as well as insufficient human resources.⁴⁵

Low quality of maternal health

As Table 2 shows, maternal mortality ratios between 1994 and 2008 also increased in urban Tunis, which reflects the low quality of the city's maternal health services. In fact, a study conducted in 2010 demonstrated that the low quality of maternal care services, including delays in diagnoses and inadequate treatment, explained the capital's increased maternal mortality during this period.⁴⁷ Moreover, another study estimated that 75.3% of maternal deaths in public hospitals between 1999 and 2004 were avoidable. These deaths were due mainly to underestimation of the woman's risk, inadequate follow-up during the postpartum phase, and delays in care.⁴⁸

The persistence of regional inequities in

Table 2. Evolution of Tunisia's maternal mortality ratio (per 100,000 live births)⁴⁶

Region	1994	2008
Tunis District	40.0	50.8
North East	50.4	27.9
North West	94.0	67.0
Central East	57.4	30.5
Central West	105	55.9
South East	62.7	56.8
South West	92.8	36.7
Total	68.9	44.8

women's access to reproductive health care and the low quality of maternal care point to the government's failure to mobilize sufficient human and financial resources to implement national reproductive health programs. One of the main barriers to improved health service delivery in Tunisia is the excessive centralization of decision making.⁴⁹ As explained by Tim Ensor and Jeptepkeny Ronoh, the government must decentralize this process if it hopes to implement reproductive health policies tailored to local populations' needs and to improve the efficiency of health system delivery. Health system decentralization can also empower local communities when it involves participatory approaches in program planning and implementation.⁵⁰

The capacity to implement reproductive health programs also depends on the macroeconomic context. Sumati Neir, Sarah Sexton, and Preeti Kirbat have pointed out that structural adjustment programs and the lack of international funding for reproductive health programs have contributed significantly to many countries' failure to implement the ICPD Programme of Action.⁵¹ According to the authors, structural adjustment programs have led to a decline in public health expenditures in low- and middle-income countries, thus reducing their capacity to provide adequate reproductive health services.⁵² Tunisia's structural adjustment program, which has been in place since 1986, led public spending on health to decline from 10% during the 1970s and 1980s to 5.7% in 2008.⁵³ However, there are no published studies that explore the impact of this program on the country's public health system.

A study conducted in 2004 to assess the realization of economic, social, and cultural rights in Tunisia found that regional inequities negatively affected not only the right to health but also the rights to education, to work, to housing and access to drinkable water, and to a decent standard of living.⁵⁴ The North West and Central West were considered the most deprived regions. The findings of these two studies confirm the interdependency among fundamental human rights, demonstrating that women's reproductive rights cannot be fully realized without addressing the underlying determinants of health.

Discriminatory practices

Discriminatory practices represent one of the main barriers to women's access to adequate reproductive health services. In Tunisia, such practices affect primarily unmarried women and people living with HIV. According to the family health survey conducted by the National Board for Family and Population in 2002, health workers considered spousal consent a normal precondition for providing contraceptives to women, despite the fact that no official instructions justifying this practice exist.⁵⁵ This precondition not only excludes single women from accessing contraceptives but also interferes with women's right to make free choices about contraception. Another study, conducted in 2012 in four countries where abortion is legal, found that 26% of Tunisian women in the study had been denied abortion: 7% because of the gestational period and 15% because of nonmedical reasons, including being single, the absence of spousal consent, and non-indicated medical tests.⁵⁶

Furthermore, according to WHO, single women are excluded from the primary health care system's treatment and care for sexually transmitted infections, as these services are geared mainly toward married women.⁵⁷ Discriminatory attitudes against single women have also been found in the private health sector. A study conducted in 2011 to assess the availability and accessibility of emergency contraception in Tunisia revealed that some pharmacies had adopted a policy of not providing contraceptives to single women.⁵⁸

Discrimination against single women seeking contraception and abortion is due largely to societal taboos around extramarital and premarital sexual relations.⁵⁹ Indeed, the only culturally accepted "framework" for sexual relations in Tunisia is marriage.⁶⁰

Status of gender equality and the realization of women's rights

Reproductive health policy has played an important role in women's empowerment in Tunisia. The promulgation of the Personal Status Code in 1956 marked a shift in women's emancipation, as it improved their legal and social status in the family

by abolishing polygamy and unilateral repudiation and by setting the legal age of marriage for women at seventeen.⁶¹ More recent changes in the code have further supported gender equality within marriage through the abolition of the wife's duty to obey to her husband (1993) and the establishment of the system of conjugal partnership of gains (1998).⁶² These achievements have been strengthened by the guarantee of free access to education, which has been in place since 1958, and mandatory access to education, which has been in effect since 1991.⁶³ As a result, Tunisia has increased gender parity in secondary and tertiary education since 2000.⁶⁴ Recently, between 2006 and 2013, the number of female students graduating from college was almost twice that of male students.⁶⁵

Despite these signs of progress, however, Tunisia is far from achieving gender equality. Women's unequal status in marital relationships continues to operate through non-egalitarian legislation and deeply embedded patriarchal attitudes and social norms. Legislation that upholds dowry payments, inequality in inheritance, and men's leadership in households represents barriers to women's equality. Furthermore, there is a decoupling between the legal rights of women in Tunisia and their "real" status in society and the family. Patriarchal stereotypes propagate women's subordination and deprive them from enjoying the rights enshrined in the Personal Status Code.⁶⁶ Gender inequality in its most severe form is reflected by the findings of the 2010 National Survey on Violence against Women, which revealed that 47.6% of women between the ages of 18 and 64 have experienced at least one form of gender-based violence during their lives. The survey also revealed that the violence occurs first in the intimate sphere (e.g., at the hands of a husband or partner) and then in the family sphere (e.g., by a father or brother).⁶⁷

Moreover, despite achievements in education, women have higher rates of illiteracy and lower rates of employment than men. Tunisia's last census, conducted in 2014, revealed a 25% illiteracy rate among women, compared to a rate of 12.5% among men.⁶⁸ In the North West and Central West, the illiteracy rate among women reached 40%. Furthermore,

women's workforce participation rate remained unchanged—at 26%—between 2006 and 2014. Finally, in 2014, the unemployment rate among college-educated women was 40.8%, compared to just 20.2% among their male counterparts.⁶⁹

Despite the adoption of laws that ensure gender equality in employment, many factors contribute to women's low economic participation in Tunisia. Discriminatory practices in the private sector lead to unequal opportunities for women when they enter the labor market, restricting their chances of being hired, earning an equal wage, and accessing leadership positions.⁷⁰ Moreover, conservative traditions dictating that women's main role be that of mother or wife challenge their efforts to achieve economic autonomy.⁷¹

Another aspect of gender inequality can be seen in women's participation in decision making and political life. In 2009, women accounted for 26.17% of all parliamentarians, with this number rising to 29% in 2011 and 33.18% in 2014.⁷² Nonetheless, a study examining their role in Parliament suggested that their participation in decision making was limited.⁷³ In 2011, the government adopted a gender parity law requiring the alternation of male and female candidates in each electoral list; however, women represented only 7% of the heads of these lists in the 2011 legislative elections, reflecting their restricted role.⁷⁴ Additionally, women occupied only 7.3% of decision-making posts within national-level public agencies.⁷⁵

Barriers to the realization of gender equality and reproductive rights

The liberalization of abortion, greater rights to contraception, and the promotion of women's status within the family represent important steps in women's empowerment. However, stagnation in the advancement of reproductive rights in the last 20 years has constrained progress toward real gender equality.

This slow progress can be attributed in part to women's limited participation in economic and political life, which has restricted their ability to advocate for their rights, as well as their opportunities to effect change in national laws and

policies. Women's limited participation in political decision-making was exacerbated by the country's general climate of repression prior to 2011, in which human rights, including women's rights, were systematically violated.⁷⁶ As argued by Vijayan K. Pillai and Rashmi Gupta, democracy is a prerequisite to true gender equality, for women's empowerment starts with a recognition of their rights as citizens.⁷⁷ Democratic transitions in Latin America and Africa indicate that women's equality is strengthened as democracy enables them to claim their rights, including their reproductive rights.

Social development is also important for promoting gender equality and reproductive rights, as policies targeting social inequalities increase women's access to education, jobs, and better health.⁷⁸ The high rates of illiteracy among women in the North West and Central West demonstrate that women's empowerment in Tunisia is greatly affected by regional socioeconomic inequities. Rural women have not benefitted as much from the social and legal progress made in women's status at the national level, as the marginalization of rural areas excludes them from participating in political and socioeconomic life.⁷⁹

Moreover, gender empowerment is a complex process affected not only by the socioeconomic and political context but also by cultural norms and religion. In recent years, women's empowerment in Tunisia has faced a backlash from a conservative wave of Islam that interprets the religion as confining women to a subordinate role in society.⁸⁰ In fact, the emergence of conservative Islamic ideology in Tunisia has been accompanied by a resurgence of traditional patriarchal norms in society that threaten women's rights. Since patriarchal norms in Tunisia usually use religion as a moral justification, real gender equality cannot be achieved without a separation between religion and politics.⁸¹

Finally, gender empowerment requires that the government adopt effective interventions around gender equality. Tunisia's commitment to the Beijing Declaration and Platform for Action means that it must mainstream gender in all policies and programs as part of a strategic approach to achieve gender equality. Although Tunisia has begun to do

this in recent years through the creation of gender focal points in ministries, the missions of these focal points have yet to be defined.⁸²

Methodological considerations

This study applied a human rights assessment tool to systematically examine the reproductive health policy of a country considered to be a pioneer in the region. Our findings reveal critical limitations in the incorporation of reproductive rights and in the implementation of Tunisia's reproductive health policy. Nevertheless, our study drew from secondary data only, and the data available was limited. Further research is needed to explore women's access to reproductive health services, particularly in underprivileged areas; the acceptability and quality of these services; and health providers' interpretation of reproductive rights. This will enable a fuller assessment of the implementation of Tunisia's reproductive health policy. Further research is also needed to explain the gaps in the policy's implementation and to indicate pathways for enhancing the realization of reproductive rights in Tunisia.

Since 2011, Tunisia has undergone an important political transition, which may be having an impact on the reproductive health policy. However, due to a lack of data, our analysis did not explore the impact of this transition on the formulation and implementation of the country's reproductive health policy. A recent article by Pinar Ilkcaracan looks at this transition's impact on reproductive rights, indicating that women's access to safe abortion has been further restricted in the wake of Islamists' political ascendance in 2011.⁸³ Nonetheless, further research is needed to capture the impact of this political transition on the interpretation and implementation of reproductive rights.

Conclusion

Although Tunisia has made important steps toward incorporating reproductive rights into its reproductive health policy, there are significant shortcomings in the implementation of this policy, in addition to a lack of meaningful adoption of ac-

tions to achieve gender equality.

Analyzing policy through a human rights lens is crucial for improving women's access to reproductive health care. Issues such as the denial of legal abortion and discriminatory attitudes can be considered human rights abuses, which the government has the responsibility to prevent. In this sense, it is necessary to reform health professionals' training to improve their capacity to deliver reproductive health services that meet human rights standards. As our study reveals, one of the main gaps in the implementation of Tunisia's reproductive health policy is the imbalance across regions in terms of the accessibility and availability of reproductive health services. Reducing regional inequities in women's access to reproductive health care requires tackling their root causes: poor infrastructure, poverty, and political marginalization.

Advancing reproductive rights and achieving gender equality are primarily the government's responsibility; however, these aims also depend on the advocacy efforts of women, youth, and civil society. The process of advancing reproductive rights should be conceptualized within a broader framework that links human rights to social justice. This is particularly relevant in Tunisia's current political context, as the new Constitution explicitly protects the right to health and outlines the state's obligation to enforce women's rights and to protect women from violence. New, constitutional spaces for holding the state accountable to its commitments have thus been opened. Our study provides evidence that regional inequities in women's access to reproductive health services, the low quality of maternal health services, and discriminatory practices affecting single women are critical points for demanding accountability.

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Health for All? Sexual Orientation, Gender Identity, and the Implementation of the Right to Access to Health Care in South Africa

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Abstract

The framework of health and human rights provides for a comprehensive theoretical and practical application of general human rights principles in health care contexts that include the well-being of patients, providers, and other individuals within health care. This is particularly important for sexual and gender minority individuals, who experience historical and contemporary systematic marginalization, exclusion, and discrimination in health care contexts. In this paper, I present two case studies from South Africa to (1) highlight the conflicts that arise when sexual and gender minority individuals seek access to a heteronormative health system; (2) discuss the international, regional, and national human rights legal framework as it pertains to sexual orientation, gender identity, and health; and (3) analyze the gap between legislative frameworks that offer protection from discrimination based on sexual orientation and gender identity and their actual implementation in health service provision. These case studies highlight the complex and intersecting discrimination and marginalization that sexual and gender minority individuals face in health care in this particular context. The issues raised in the case studies are not unique to South Africa, however; and the human rights concerns illustrated therein, particularly around the right to health, have wide resonance in other geographical and social contexts.

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Competing interests: None declared.

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Introduction

In all regions, people experience violence and discrimination because of their sexual orientation or gender identity. In many cases, even the perception of homosexuality or transgender identity puts people at risk. Violations include—but are not limited to—killings, rape and physical attacks, torture, arbitrary detention, the denial of rights to assembly, expression and information, and discrimination in employment, health and education.¹

Sexual and gender minority individuals in health care

Evidence from around the world highlights that sexual and gender minority patients experience discrimination, stigmatization, and even denial of care in the health system due to their sexual orientation and gender identity. Those grouped as “sexual and gender minorities,” however, do not constitute a homogenous group, and social exclusion, marginalization, and experiences of discrimination, as well as specific health needs, vary considerably. Differences between lesbian, gay, and bisexual (LGB) individuals (sexual minorities), and transgender, gender non-conforming, and gender-diverse individuals (gender minorities) are significant. However, the minority status of all individuals within this broad group, as well as social exclusion, discrimination, marginalization, and violence, is, for each of them, rooted in societal heteronormativity: society’s pervasive bias toward the gender binary and opposite-gender relationships, which marginalizes and excludes all non-heteronormative sexual (LGB) and gender (T) identities. For this reason, I purposefully employ the term “sexual and gender minorities,” instead of LGBT, to emphasize their minority status and the common source of oppression, while acknowledging that this oppression acts on different identities (sexual orientation or gender) in different ways. These are even more heterogeneous when taking other forms of oppression, such as race, ethnicity, gender, (dis)ability, and nationality into account.

There is great potential in applying health and human rights frameworks to analyzing the

instances of discrimination, marginalization, and exclusion faced by sexual and gender minority individuals in health care contexts. Analyses of sexuality, including sexual orientation, in health and human rights, however, are relatively novel: before the 1993 World Conference on Human Rights in Vienna, and the subsequent 1994 International Conference on Population and Development in Cairo, sexuality, sexual rights, and sexual diversity had not formed part of the international health and human rights discourse.² These newly emerged “sexual rights” were founded on the principles of bodily integrity, personhood, equality, and diversity.³ In the past two decades, emergent scholarship has tackled the complex issues of sexuality, sexual agency, sexual diversity, and sexual violence within a health and human rights framework, which includes a focus on sexual orientation and gender identity, and, thus, on sexual and gender minority individuals.⁴ Analyses that employ a health and human rights framework to analyze specific experiences of sexual and gender minority individuals in health care, however, remain rare—even more so in contexts outside of Europe and North America, even though the exclusion, marginalization, and discrimination of sexual and gender minority individuals in health care is increasingly well documented. For example, in a Canadian study, Brotman and colleagues found that being open about their sexual orientation in health care settings contributed to experiences of discrimination for lesbian, gay, and bisexual people.⁵ In South Africa, an emerging body of literature documents health system bias against sexual and gender minorities: for example, Lane and colleagues interviewed men who have sex with men in Soweto, and revealed that all men who disclosed their sexual orientation at public health facilities had experienced some form of discrimination.⁶ Such discrimination, and also the anticipation thereof, leads to delays when seeking sexual health services such as HIV counseling and testing.⁷ Gender minority individuals, who are recognized as a key “at risk” group due to socio-economic marginalization and exclusion, and who experience high levels of violence because of such marginalization and gender non-conformi-

ty, encounter multiple layers of discrimination in South African health care facilities, ranging from verbal abuse to denial of care.⁸

It is crucial to note that such discrimination is not only perpetrated by individual health care providers, but is deeply rooted in the health system itself. Historically, medical research produced the “scientific” evidence to support powerful normative, discriminatory beliefs pertaining to gender, sex, sexuality, and identity, and was thus deeply prohibitive of non-conforming sexualities and gender identities.⁹ Until 1973, homosexuality was considered a mental illness and listed as such in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM), indicating the consensus of psychiatry at the time that sexual and romantic attraction to somebody of the same sex was unnatural, pathological, and could be cured through psychotherapy or electro-shock aversion therapy.¹⁰ Until 1992, it was listed as a diagnosis in WHO’s International Classification of Disease.¹¹ Gender identity disorder, the diagnosis for feeling that one’s assigned sex at birth does not match one’s felt gender identity, remains a classification both in the DSM as well as in the current ICD-10, and is pervasively used in relation to transgender people.¹² While such a diagnostic classification might be needed to facilitate access to gender-affirming treatment, many transgender interest groups have pointed out that it also further pathologizes and stigmatizes gender non-conforming identities.¹³ In a recent report, the UN Special Rapporteur on torture recognized the particular vulnerability of marginalized groups to torture and ill-treatment in health settings, citing “[s]tructural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination.”¹⁴

The impact of social exclusion, discrimination, and stigmatization on the health of sexual and gender minority people has been increasingly well documented over the past decade.¹⁵ Sexual and gender minority populations have a higher prevalence of mental health concerns, including suicide ideation and attempts, depression, and anxiety disorders.¹⁶ Lesbian women and transgender people,

especially those living in poor socioeconomic circumstances, are more vulnerable to HIV infection than socio-economically matched heterosexual and cisgender peers. A recent study from southern Africa showed that one-third of 591 participating women who had sex with women had experienced sexual violence, demonstrating HIV risk for a population previously considered exempt; moreover, there was a 10% self-reported rate of living with HIV.¹⁷ In light of the impact that social and economic exclusion, violence, and minority stress due to discrimination and stigmatization have on the health of sexual and gender minorities, it has been suggested that sexual orientation and gender identity should be recognized as a social determinant of health, much like gender, socio-economic status, and others.¹⁸ Similarly, the UN High Commissioner for Human Rights has emphasized that homophobia (the irrational fear of and hatred of lesbian, gay, and bisexual people) should be considered as significant and comparable to sexism, racism, or xenophobia.¹⁹

Not only sexual and gender minority patients are impacted by heteronormativity and homophobia in the health systems. Accounts of health care providers who openly identify as lesbian, gay, bisexual, or transgender point to ongoing stigma and discrimination within the health care profession and health professions education.²⁰ For example, 62% of medical students across 92 US medical institutions reported exposure to anti-gay comments.²¹ In a survey of sexual and gender minority physicians, 22% reported that they had been socially ostracized, 65% had heard derogatory comments about sexual and gender minority individuals, and 34% had witnessed discriminatory care of a sexual or gender minority patient.²²

Provisions of civil, social, economic, and political rights for sexual and gender minorities in the context of health care

More recent international provisions for the right to the highest attainable standard of health acknowledge the impact that social and economic discrimination based on sexual orientation and gender identity have on access to and quality of

health care. The International Covenant on Economic, Social and Cultural Rights (ICESCR) makes no mention of these two markers, likely due to the time of its drafting and adoption in 1954 and 1966, respectively, but lists a number of “other statuses” that can lead to discrimination.²³ Paragraph 32 of General Comment 20 on non-discrimination in economic, social, and cultural rights (2009), specifies that “other status” includes sexual orientation and “states parties should ensure that a person’s sexual orientation is not a barrier to realising Covenant rights.”²⁴ Paragraph 12.b of General Comment 14 (2000), which operationalizes the right to health, states that non-discrimination is a key dimension of accessibility to health care; and paragraph 18 of General Comment 14 elaborates that Article 2.2 and Article 3 of the Covenant proscribe “any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of [...] *sexual orientation* [...] which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health” (italics added for emphasis).²⁵

The health and human rights framework for sexual and gender minority individuals in South Africa

The South African Constitution (1996) has one of the strongest provisions on the right to health worldwide. The right to health is covered under Article 27, together with rights to food, water, and social security.²⁶ Article 27(a) provides that everyone has the “right to access health care, including sexual and reproductive health care.” Further sections provide for the right to sufficient food and water and social security, including appropriate social assistance if people are unable to support themselves and their dependents. Article 27 requires the state to take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights. These constitutional provisions have been employed previously to force the state to provide antiretroviral treatment for the prevention of mother-to-child transmission

of HIV.²⁷ After a 20-year campaign, South Africa finally ratified the ICESCR in early 2015.

Two additional documents specifically outline patients’ rights. The South African Patients’ Rights Charter, specific to health care contexts, and the Batho Pele Principles (meaning “People First”) that are applicable for all public services provided by the South African government.²⁸

South Africa’s constitutional and legislative framework for sexual and gender minorities is among the most progressive globally. The constitution provides that the state is obliged to “respect, protect, promote and fulfill” the rights enshrined in the Bill of Rights.²⁹ Central to the Bill of Rights is the Equality Clause in Section 9, which mandates that nobody may be discriminated against based on, among other grounds, their sex, gender, or sexual orientation. Section 10 guarantees that everyone has inherent dignity and the right to have their dignity respected and protected.

Further rights enumerated in the Bill of Rights include the right to life (Section 11), as well as the right to security of the person, including the right “to be free from all forms of violence from either public or private sources,” the right “to security in and control over their body,” and the right “not to be treated or punished in a cruel, inhuman or degrading way” (Section 12).

Emanating from this constitutional mandate, sexual and gender minority individuals enjoy a range of civil rights in the country. A range of legislative and policy reforms after 1996 have sought to remove laws drafted under apartheid that criminalized or discriminated against sexual and gender minorities, of which I will only list those pertaining to health and access to health care. The Medical Schemes Act of 1998 defines “dependent” to include same-sex partners and therefore extends medical insurance benefits to same-sex partners; the Domestic Violence Act of 1998 expands the definition of domestic relationships to recognize cohabitation by unmarried people including same-sex couples; and the Refugees Act of 1998 recognizes gender and sexual orientation as grounds for persecution and, thus, for seeking asylum in South Africa.³⁰ In 2006, the president of South Africa signed into law the

Civil Union Act, which recognizes “the voluntary union of two persons [...] registered by way of either a marriage or a civil partnership,” and therefore guarantees marriage equality to same-sex couples.³¹

The progressive and protective South African legal framework is unique on the African continent. While two other countries in the southern African region (Lesotho, and, in 2015, Mozambique) have decriminalized same-sex activity, the laws of most African countries hold provisions that outlaw same-sex activity, which are usually remnants of British colonial law.³² There are vast differences in the enforcement and consequences of these laws across African countries, ranging from the death penalty to what Epprecht calls a “*de facto* culture of tolerance [...], notwithstanding sometimes harsh laws and elite homophobic rhetoric” (emphasis in original).³³ In recent years, public health arguments that seek to reduce the impact of HIV on criminalized populations, such as men who have sex with men, have resulted in slow and careful shifts in attitude and approach.³⁴ For example, in 2014, the African Commission on Human and People’s Rights passed Resolution 275, which strongly urges States to end all acts of violence and abuse, whether committed by State or non-state actors, including by enacting and effectively applying appropriate laws prohibiting and punishing all forms of violence including those targeting persons on the basis of their imputed or real sexual orientation or gender identities, ensuring proper investigation and diligent prosecution of perpetrators, and establishing judicial procedures responsive to the needs of victims.³⁵

Despite these high-level shifts, homophobic and transphobic violence, persecution, and state repression remain a threat to the health and safety of sexual and gender minority individuals in many African countries.³⁶ It is noteworthy that even in South Africa, the progressive and affirming stance of the constitution towards sexual and gender minority people is not reflected in the dominant attitudes in South African society; statements by public figures indicate that deeply conservative views about gender and sexuality prevail.³⁷ For example, in 2010 Jerry Matjila, South Africa’s

then-representative at the United Nations, objected to the inclusion of sexual orientation in a report on racism at the UN Human Rights Council in Geneva. He argued that to include sexual orientation would be to “demean the legitimate plight of the victims of racism.”³⁸

In the following two case studies, I explore the experiences of Thabo (a pseudonym), a young gay man, and Palesa (also a pseudonym), a young lesbian woman, in two different health facilities in South Africa. In doing so, I (1) highlight the conflicts that arise when sexual and gender minority individuals seek access to a heteronormative health system; (2) discuss the international, regional, and national human rights legal framework as it pertains to sexual orientation, gender identity, and health; and (3) analyze the gap between legislative frameworks that offer protection from discrimination based on sexual orientation and gender identity and their actual implementation in health service provision. The narratives from these case studies are taken from a larger, cross-sectional, qualitative study on sexual and gender minority peoples’ experiences in public health care, of which I was the principal investigator.³⁹ Both case studies use pseudonyms to preserve the participants’ anonymity. The study was approved by the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (HREC: 033/2013), and individual research participants gave their permission for their anonymized data to be published in academic literature.

Case study one: Thabo

Thabo’s story

Thabo is a young black gay man living in a peri-urban township near Pretoria, which is one of the three capital cities of South Africa. He attends the local technical university that provides students with an applied education to enter into specialized positions in the labor market. Thabo is out to the majority of people in his life, including his mother, with whom he still lives; and he regularly attends events of the LGBTI student group on his campus. He describes himself as “a flamboyant queen,”

and expresses his gender identity in a feminine, non-conforming way. When I interviewed him in April 2013 about his experiences using public health facilities, he told me about an admission to the nearest district hospital after being pursued by a group of men in a homophobic attack, during the course of which he broke both his arms when trying to escape by jumping from a second-floor balcony. He was taken to the emergency room by a friend (ambulances often take a long time to reach patients living in townships), where he eventually recounted the story after being asked numerous times by the nurse on duty. He included the homophobic motivation of his attackers, and thereby effectively disclosed his sexual orientation. The nurse told him that he “got what he deserved,” and when he was transferred to the ward to await further surgical treatment, he discovered that she had told the ward nurses on duty about his sexual orientation. This information was passed on to nurses on later shifts, such that throughout his three-day stay he felt singled out, could discern the nurses’ disparaging attitudes towards him, and was frequently the source of hospital gossip, including when he was present. A local prayer group that visited the ward daily to provide spiritual support to patients prayed at his bedside to rectify his “devious” sexuality. When he requested that they leave, or that he be transferred to another ward to be out of their reach, the nurses did not intervene, and the prayer group visited regularly to continue the homophobic prayers. He did not appear to know about the Batho Pele principles, and did not lodge a complaint about the discriminatory treatment he received because he was scared of the negative ramifications this might have on his ability to access treatment at the facility in future. After he had had surgery for both his arms, he was discharged. He did not return for any follow-up appointments, and chose to have his casts removed at a different primary care facility where nobody knew him.

Analysis

Using a right to health framework to analyze Thabo’s story, the right to non-discrimination in access

to health care (paragraph 12.b and paragraph 18 of General Comment 14) seems immediately relevant, as well as the provisions of the South African Patients’ Rights Charter and the Batho Pele Principles for all public services in South Africa.⁴⁰ However, this framework does not suffice to thoroughly analyze the homophobic discrimination and judgment that Thabo experienced, as well as the failure to recognize his attack as a homophobic hate crime. Cohen and Ezer write that “Even the basic right of access [...] benefits from the lens of human rights and its focus on non-discrimination and equality.”⁴¹ Drawing on such a comprehensive human rights framework allows the recognition of a number of Thabo’s rights that were violated during his stay at the health facility. These are outlined in Table 1.

It is important to analyze Thabo’s experience through an intersectional framework. Intersectionality (the ways in which different social identities are enmeshed) aims to understand the “simultaneity of interlocking systems of oppression”, by, for example, race, class, gender, sexual orientation and ability, in the experience of individuals.⁴² In Thabo’s case, it provides an important context for understanding factors of vulnerability to violence and discrimination. The South African health care system is highly unequal, with an under-resourced public health system that caters for up to 80% of the population at a cost relative to patients’ income, and a well-resourced private health system whose cost prohibits all but about 16% of the population from using it.⁴³ Access to health care is therefore highly dependent on class, race, and geographical location, given the unequal distribution of wealth and income in the country due to centuries of colonialism and the apartheid system.⁴⁴

In Thabo’s case, accessing the private health system was not an option given his limited financial capacity. Thabo’s race also significantly influenced his experience of homophobia, both as the reason for seeking health care, and within the health system. In South Africa, there exists considerably more violence against sexual and gender minority persons of color, in particular against visibly gender non-conforming people.⁴⁵ Homophobic

sexual violence against black lesbian women (often problematically termed “corrective rape”) has been documented increasingly since the early 2000s, and there are significantly more cases of hate crimes against gay men of color than white gay men.⁴⁶ This points to complex vulnerabilities shaped by race, gender, and class, and highlights the fact that gender non-conforming people of color are at significantly higher risk of experiencing homophobic violence.

Thabo’s experience of the health facility as an unsafe and discriminatory space is not unusual. As mentioned above, an emerging body of literature

confirms that sexual and gender minority patients are routinely discriminated against, ridiculed, or even denied services by health care providers, in disregard of the protective legislative provisions in the South African constitution and their related policies.⁴⁷ This is not unique to sexual and gender minority patients. Evidence on nurses’ decision-making can help to illuminate some of the reasons behind the discriminatory behavior exhibited by health care providers in Thabo’s case. First, studies with South African nurses providing sexual and reproductive health services to adolescents

TABLE 1. International health and human rights framework for case studies

Human right	Instrument	Case studies
The right to non-discrimination and equality	International Universal Declaration of Human Rights (UDHR) (Art. 2) International Covenant on Economic, Social and Cultural Rights (ICESCR) (Art. 2) International Covenant on Civil and Political Rights (ICCPR) (Art. 26) The African Charter on Human and Peoples’ Rights (Arts. 2 and 3) National South African Constitution (Section 9) South African Patients’ Rights Charter (Section 2.3(f)) Batho Pele Principles (Section 4)	Due to his sexual orientation, Thabo was treated with disdain by the nurses and was subjected against his will to religious practices aimed at changing his sexual orientation. Palesa was denied access to HIV counseling and testing based on her sexual orientation and the nurses’ erroneous assumptions.
The right to privacy and confidentiality	International UDHR (Art. 12) ICCPR (Art. 17) National Batho Pele Principles (Section 2.7)	Information about Thabo’s sexual orientation—irrelevant to his medical treatment—was passed on not only to the entire nursing staff of his ward, but also to the members of the prayer group.
The right to access to health care	International ICESCR (Art. 12), read with General Comment 14 National South African Constitution (Section 27)	Dimensions of General Comment 14 on access to health care can be considered with respect to discrimination and non-availability in access.
The right to a remedy	International ICCPR (Art. 2.3) International Convention on the Elimination of all Forms of Racism (Art. 6) National South African Patients’ Rights Charter (Section 2.12) Batho Pele Principles (Section 7)	Health care staff did not record the homophobic motivation of this assault, making any potential investigation or prosecution difficult. Difficult for Thabo to complain about the discriminatory treatment he received at the health facility.

show that health care providers base their service delivery on their own values and their perceived 'moral worth' of a patient.⁴⁸ By using their discretion, they effectively re-interpret—and sometimes ignore—law and policy, and trade it for their own moral judgment, which is more likely to be the case if the patient, or the health issue at hand, is perceived as controversial or morally 'charged.'

Given that the majority of South Africans (61%) consider homosexuality to be 'not acceptable,' it is more than likely that many health care providers also share discriminatory views of sexual and gender minority patients.⁴⁹ Second, bias against sexual and gender minority individuals remains high within the health system. Fallin-Bennett recently commented on how the widespread 'implicit bias' that physicians teaching in medical education hold against sexual and gender minority individuals can 'create a cycle that perpetuates a professional climate reinforcing the bias.'⁵⁰ Role modeling is an important way through which attitudes and behaviors are fostered in health service delivery.⁵¹ This can not only provide a climate of acceptance for sexual and gender minority discriminatory behavior, but also create pressure for health care providers who are sympathetic to conform to conservative and discriminatory norms.

A more structural analysis of Thabo's experience underscores that while health rights violations are usually perpetrated by individual health care providers, they are also steeped in a system that tacitly tolerates such discriminatory behavior. For example, there are no policies either at health facility level or within institutions of health professions education that recognize sexual orientation or gender identity as grounds for discrimination and offer protection thereof, leaving little or no possibility for recourse for sexual and gender minority patients and health care providers who experience such discrimination. Existing general complaint policies require patients to complain within the same facility that discrimination occurred. As Thabo's case shows, patients are often reluctant to follow this policy and previous research from South Africa confirms that only between 6% and

29% of health service users would actually make a complaint.⁵² While newer complaints mechanisms have been set up in recent years, including a toll-free hotline by the Department of Health, such options are likely to not seem like viable options to sexual and gender minority individuals who have come to expect homophobic discrimination at all levels of the health system.⁵³ Often, the perception of further victimization, or of future negative consequences at facility level, acts as a deterrent to lodging a complaint.

A potential solution could be to take such cases to one of the high-level oversight bodies established to monitor professional conduct, for example, the Health Professions Council of South Africa (which registers all medical practitioners), the Nursing Council of South Africa, or the Human Rights Commission. Such a decision, however, requires not only a thorough knowledge of the existence, mandate, and working of these bodies, but also financial resources and networks that most South Africans who use public health care do not possess. While media exposure of malpractice and poor health service delivery has increased the attention on the quality of services provided, none of the profiled instances has focused on sexual orientation or gender identity-related discrimination yet. Further, no case of health care discrimination on the grounds of sexual orientation or gender identity in health care has been brought to any of the professional oversight bodies, or to any level of the judiciary.

An intersectional analysis allows us to tease out the complex dynamics that play out in the implementation of the right to access to health care, that result not only in easily measurable indicators such as access, but also in the interpersonal relations between sexual and gender minority patients and health care providers. In such complex 'messy' situations, the framework of human rights in patient care seems to be more adept at capturing the complexity of these encounters, and to analyze the more subtle experiences of marginalization and exclusion that patients like Thabo encounter.

Case study two: Palesa

Palesa's story

Palesa is a young black lesbian woman who I interviewed in May 2013. She had recently finished her undergraduate university degree, and at the time of our interview, lived in a student area in Cape Town and worked as a waitress in a restaurant. Palesa exclusively has sexual and romantic relationships with women, but she does not conform to a 'typical lesbian' image, and, as she told me, often passes as heterosexual with people who do not know her well. Palesa wanted to go for an HIV test after she had met her current partner of three years, in order for her and her then-new partner to make informed decisions about their sexual health behavior. She decided to go to the local public primary health facility, which she had visited previously for various health concerns. During these visits, her sexual orientation had never come up, and she did not see the need to disclose it to the health care providers. When she went for her session of voluntary HIV counseling and testing, the nurse began by going through the pre-test questionnaire, aimed at identifying HIV risk behaviors that could be addressed in the post-test counseling session. When Palesa—prompted by the questionnaire—said that she was sexually active but was not using condoms or contraception, the nurse checked a number of boxes on her questionnaire in quick succession. When the nurse asked her why she was not using condoms, Palesa hesitated briefly, realizing that in answering this question she either needed to disclose her sexual orientation or lie, and then told the nurse that she only had sex with women. Without asking any further questions, the nurse exclaimed that Palesa was not at risk for HIV, and that she should go home and not waste her time any longer. Palesa was taken aback, and left the clinic quickly. She has not attempted to have another HIV test since.

Analysis

As with Thabo's case study, Palesa's narrative can be analyzed by focusing on the right to accessing health care. The nurse's refusal to offer her an HIV

test is a clear violation of the right to access health care (Art. 27(a) of the South African Constitution), as well as discrimination in health care accessibility (Section 12.b of General Comment 14). As with Thabo's case, however, a more thorough analysis of the human rights in this patient care situation is useful to tease out the nuanced rights violations, taking into account the health and human rights framework in Table 1.

Unlike Thabo, the violations of Palesa's rights were not caused by her visible non-conformity to heteronormativity. Rather, the nurse's denial of an HIV test for Palesa was borne out of her erroneous assumption that women who have sex with women are not at risk for HIV, coupled with her inability to adequately inquire about sexual health behavior and risk behavior in Palesa's case. Emerging research points out that one-third of women who have sex with women in Southern Africa have experienced sexual violence, and that this is a significant risk factor for HIV.⁵⁴ These findings clearly contradict the nurse's erroneous perception of Palesa not being at risk for HIV, and also underline that there are crucial follow-up questions to be asked when a patient discloses same-sex activity (for example, inquiring about sexual relationships with people of the opposite sex and experiences of sexual violence). This lack of competency is due to the invisibility of non-conforming sexual orientations and gender identities in health system policies, planning, and services, as well as in health professions education. Unlike Thabo, therefore, Palesa's discrimination was not rooted in negative and discriminatory attitudes, but rather in ignorance about the specific health concerns of lesbian women.

In South Africa, health professions education does not address routinely the social determinants of health, contextual vulnerabilities, and specific health needs of sexual and gender minorities.⁵⁵ As a result, health care providers are often ill-equipped to provide quality care to sexual and gender minority patients. While studies from other contexts have shown that health care students who received training on sexual and gender minority health-related topics had better knowledge

and were more confident with sexual and gender minority patients, student nurses and doctors in South Africa are currently not provided with these competencies.⁵⁶ Further, it has been shown that while the formal curriculum is important, it is not the only influence that determines health profession students' competence for providing care to sexual and gender minority patients. The hidden curriculum—a term used to describe the implicit, often highly gendered, and discriminatory values that are taught to students in institutionalized education settings—plays a crucial role in teaching students about institutional values, institutional climate, and implicit assumptions about worth within the health care and medical education system.⁵⁷ Studies on the experiences of sexual and gender minority students in South African health sciences faculties suggest that the influence of the hidden curriculum is as strong in this context as elsewhere, and contributes to the marginalization of sexual and gender minority individuals and their health concerns.⁵⁸

Using a human rights-based framework can help to identify the consequences of the invisibility of such topics in health professions education. This, in turn, can support efforts to name and address this invisibility, and advocate for an understanding of sexual orientation and gender identity as social determinants of health, and the inclusion of sexual and gender minority health in health professions education and continuous professional development courses⁵⁹

Discussion and conclusion

The framework of human rights in health care provides a useful lens for analyzing rights abuses in health settings, in that it places patients at the center, focuses attention on discrimination and social exclusion, and zooms out from the individual patient-provider relationship to examine systemic issues and state responsibility.⁶⁰ In this article, I have demonstrated the application of this framework to analyze discrimination due to sexual orientation and gender identity in the South African public health system. As the case studies il-

lustrate, the progressive equality legislation around sexual orientation and gender identity in South Africa is not necessarily a predictor for the successful implementation of the right to access to health care for sexual and gender minority patients. The case studies therefore highlight two important issues:

1. The need to recognize sexual orientation and gender identity as causes for human rights violations in health care; and
2. The need to analyze such rights violations through a comprehensive human rights framework that takes into account the various intersecting marginalizations that people experience.

As the case studies demonstrate, the human rights violations that both Thabo and Palesa experienced were perpetrated by individuals, but were indicative of larger systemic issues of homophobia and invisibility. The lack of responsive complaint mechanisms, combined with the lack of training and knowledge about sexual and gender minority health, missed opportunities for values clarification training, and the complexities of health care providers' decision-making perpetuates the marginalization and invisibility of sexual and gender minority patients in the health system. As a result, even when protective policies do exist, they are not implemented adequately.

While the South African Constitution offers some of the best protection to sexual and gender minority individuals, there is a gap between constitutional protection and the reality of health care provision. In other countries, homosexuality, transgender identities, and/ or same-sex practices are criminalized.⁶¹ The UN High Commissioner on Human Rights highlights that “the criminalization of homosexuality may deter individuals from seeking health services for fear of revealing criminal conduct, and results in services, national health plans and policies not reflecting the specific needs of LGBT persons.”⁶² The Special Rapporteur on Health echoes these observations and notes that, “Criminal laws concerning consensual same-sex conduct, sexual orientation and gender identity

often infringe on various human rights, including the right to health.⁶³

Considering the impact of such criminalizing legislation on health care access underlines the need for taking sexual orientation and gender identity into account when analyzing human rights in health and patient care. The Yogyakarta Principles on the Application of International Human Rights Law in relation to Sexual Orientation and Gender Identity, which illustrate the application of human rights law to issues of sexual orientation and gender identity, can provide a useful tool for including sexual orientation and gender identity in such analyses of health and human rights.⁶⁴ There is, however, considerable debate for and against such a compartmentalization of sexual and gender minority rights.⁶⁵ Further there is a vast difference in the understanding of the term ‘sexual rights,’ which supposedly encapsulates these rights.⁶⁶

While a detailed discussion of the implications of these tensions is beyond the scope of this article, the geographical, historical, social, and political specificity of sexual and gender minority rights claims needs to be acknowledged and considered. South Africa’s unique progressive position with regards to sexual and gender minority rights places the country in a unique position to negotiate the necessity of such rights without defaulting to the claim of universality, which is often the political reason for other African countries to reject sexual and gender minority rights.⁶⁷ The carefully articulated public health-motivated arguments for sexual and gender minority rights currently emerging across many African countries are an important example of context-specific, health-based rights claims for sexual and gender minority individuals.

In summary, in this article I have reviewed the international provisions around health and human rights for sexual and gender minority patients. I have presented two case studies from South Africa, which examine the divergence between the law and policy framework and its implementation, and stress the necessity for including a focus on sexual orientation and gender identity in analyzing human rights in health and patient care. These case studies highlight the complex and intersecting dis-

crimination and marginalization that sexual and gender minority individuals face when accessing care in a historically and epistemologically deeply heteronormative health system. In my conclusion, I point to the importance of challenging state-sponsored and -enacted homophobia in order to realize the right to health for sexual and gender minorities, and stress the importance of using a comprehensive, yet carefully context-specific, human rights analysis.

Acknowledgments

I would like to thank Thabo and Palesa, who shared their stories with me; the anonymous reviewers for their constructive feedback on the first version of the manuscript; Talia Meer and Sarah Spencer for their feedback on various versions of this article; and the South African Social Science and HIV Programme (SASH), a joint program of the University of Cape Town with Brown University, for the fellowship that supported me during the writing of the manuscript.

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Australia's Efforts to Improve Food Security for Aboriginal and Torres Strait Islander Peoples

DEANNA DAVY

Abstract

Australia is a wealthy country; however, available evidence suggests that food security among Aboriginal and Torres Strait Islander peoples has not yet been achieved. Aboriginal and Torres Strait Islander peoples living in remote, regional, and urban parts of Australia experience food insecurity for a number of reasons that usually include low income and a lack of access to affordable and healthy food. The much higher rate of illness and disease that this population experiences compared to non-indigenous Australians is directly related to food insecurity. This paper examines the food insecurity among Aboriginal and Torres Strait Islander peoples and recent Australian government efforts to combat this problem. The paper first considers what constitutes a human rights-based approach to achieving food security. Second, it describes the food insecurity that currently exists among Aboriginal and Torres Strait Islander peoples across the three pillars of food access, food availability, and food use. Third, the paper critically examines recent and current Australian government policy aimed at improving food security. The paper concludes with some reflections regarding how the Australian government can improve its

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Competing interests: None declared.

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Introduction

Available evidence suggests that food security for Aboriginal and Torres Strait Islander (ATSI) peoples in Australia has not yet been achieved. ATSI peoples living in remote, regional, and urban parts of Australia are vulnerable to food insecurity for a range of reasons that tend to include poverty, low income or welfare dependence, and a lack of access to affordable and healthy food. Food insecurity among ATSI peoples has a long history that began with the colonization of Australia and today is exacerbated by government policy interventions and economic influences.¹ The much higher rate of illness and disease that ATSI peoples experience compared to non-indigenous Australians is directly related to food insecurity and is a clear consequence of the barriers related to food availability, access, and use faced by ATSI peoples. There is an unacceptable food-related health gap between ATSI peoples and non-indigenous Australians, revealing an urgent need to improve food security for ATSI peoples throughout the country.

This paper examines food insecurity among ATSI peoples, as well as Australian government efforts, particularly since the early 2000s, to improve their situation. The paper first considers what constitutes a human rights-based approach to achieving food security. Second, it describes the current food insecurity among ATSI peoples in Australia. Third, the paper critically examines recent and current Australian government policy in the area of food security for ATSI peoples. The paper concludes with a discussion of key points and reflects on the way forward for improving food security among ATSI peoples in Australia.

A human rights-based approach to food security

Undertaken under the auspices of the United Nations (UN) Food and Agriculture Organization (FAO) is the recent elaboration of a set of voluntary guidelines outlining key elements of an “enabling environment” for food security.² The guidelines seek to promote a rights-based approach to food security at the national level that emphasizes “hu-

man rights, the obligations of States and the role of relevant stakeholders.”³

As the guidelines point out, a human rights-based approach to food security underscores “universal, interdependent, indivisible and interrelated human rights.”⁴ Such an approach emphasizes the achievement of food security as an outcome of the realization of existing rights. It includes the principles of individual agency, public participation in decision making and public affairs, the right to freedom of expression, and the right to seek and receive information, including in relation to decision making about policies on realizing the right to adequate food. The guidelines also point out that a human rights-based approach to achieving food security “should take into account the need for emphasis on poor and vulnerable people who are often excluded from the processes that determine policies to promote food security and the need for inclusive societies free from discrimination by the State in meeting their obligations to promote and respect human rights.”⁵ Under a human rights-based approach to food security,

*[p]eople hold their governments accountable and are participants in the process of human development, rather than being passive recipients. A human rights-based approach requires not only addressing the final outcome of abolishing hunger, but also proposing ways and tools by which that goal is achieved. Application of human rights principles is integral to the process.*⁶

Thus, a human rights-based approach to food security involves the active participation of people in determining the best approaches for ensuring equitable food security. It is an approach that highlights individual agency in decision making and the involvement of people in their government’s affairs. When applied to the Australian context of achieving food security for ATSI peoples, a human rights-based approach emphasizes the importance of acknowledging the interrelatedness of key rights, of recognizing the agency of ATSI peoples, and of engaging these peoples, who are often excluded from government decision-making processes, in determining policies and approaches to improve food security.

Food insecurity among ATSI peoples in Australia

According to the Australian Bureau of Statistics, 713,600 of Australia's 23 million people are indigenous.⁷ Thus, indigenous Australians represent approximately 3% of the country's population. Of the indigenous population, approximately 90% self-identify as Aboriginal, 6% as Torres Strait Islander, and 4% as both Aboriginal and Torres Strait Islander.⁸ The Northern Territory, a vast state covering 1.3 million square kilometers in the north of the country, has the highest percentage of indigenous people, with 29.7% of the territory's residents self-identifying as indigenous.⁹

There are no reliable figures on the number of indigenous persons living on the continent prior to European arrival in 1788, but scholars estimate the number to lie somewhere between 315,000 and 750,000.¹⁰ During this time, indigenous peoples lived in all parts of the country as nomadic hunter-gatherers.¹¹ Their survival depended on a comprehensive knowledge of local flora and fauna.¹² It is believed that indigenous people consumed a varied diet with high nutrient density, in which animal foods were a major component, as well as uncultivated plant foods such as roots, starchy tubers, seeds, fruits, and nuts.¹³

The arrival of European settlers led to a vast number of land development initiatives, which meant that much of the land that Aboriginal people used to hunt and gather was destroyed.¹⁴ Trees and plants were removed, animals were killed or moved elsewhere as their habitat was destroyed, and waterways were polluted.¹⁵ Furthermore, with the deaths of Aboriginal people at the hands of settlers, and the forced separation of families, Aboriginal kinship systems suffered, and knowledge of the preparation of traditional foods was lost.¹⁶ Thus, European arrival in Australia adversely affected indigenous peoples' access to and use of traditional foods, as well as the retention of indigenous knowledge of traditional foods—a phenomenon that has contributed, to some extent, to the current food insecurity situation among ATSI peoples.¹⁷

Today, food insecurity contributes to inequities in health and life expectancy between

indigenous and non-indigenous people in Australia. The Australian Bureau of Statistics estimates that ATSI males born in 2005–2007 could expect to live to 67.2 years, which is 11.5 years less than the expected 78.7 years for non-indigenous males.¹⁸ Similarly, the life expectancy for ATSI women born in 2005–2007 is 72.9 years, which is 10 years less than the expected 82.6 years for non-indigenous women.¹⁹ Poor nutrition among ATSI peoples has been linked to poor individual and community health outcomes and is recognized as a significant contributing factor to the total burden of disease for indigenous Australians.²⁰ Chronic diseases are estimated to account for 80% of the mortality gap between ATSI and non-indigenous Australians aged 35–74.²¹

Food insecurity among ATSI peoples varies in severity across the country. Today, there are an estimated 80,000 indigenous Australians living in remote communities, and many have poor access to fresh and nutritious food, largely due to their distance from cities.²² The National Aboriginal and Torres Strait Islander Health Survey has found that nearly 30% of Aboriginal adults worry at least occasionally about going without food; this figure is even higher among people living in remote areas.²³ Of ATSI peoples living in remote areas, 36% are likely to run out of food, compared to 20% of indigenous people living in non-remote areas.²⁴ ATSI peoples over 55 years of age are more likely than non-indigenous Australians to go without food, due to a lack of money (17% compared to 2%).²⁵

The World Health Organization's declaration on food security highlights the three pillars that food security is built on: food access, meaning sufficient financial and other resources for people to obtain appropriate food for a nutritious diet; food availability, meaning sufficient quantities of nutritious food available on a consistent basis; and food use, meaning the appropriate use of food, based on knowledge of basic nutrition and care.²⁶ In this light, ATSI peoples' capacity for food security is undermined by poor food access (due to, for example, low income) and poor connectivity between communities and food stores; poor food availability (for example, high costs of food and limited availability

of nutritious foods); and poor food use (for example, inadequate household infrastructure, including food storage and food cooking facilities).²⁷

Food access

Sue Booth and Alison Smith suggest that ATSI peoples are particularly vulnerable to food insecurity due to welfare dependency, low incomes, and poverty.²⁸ ATSI households are 2.5 times more likely to be in the lowest-income-bracket households than are non-indigenous households.²⁹ The unemployment rate among ATSI peoples is three times higher than it is for non-indigenous Australians.³⁰ The median weekly individual income in 2006 for an ATSI person was AUD278, which was slightly more than half of the median income for a non-indigenous Australian (AUD473).³¹ Finally, welfare-dependent families in urban areas of Australia are thought to spend up to 40% of their income on food in order to achieve adequate nutrition.³²

International evidence suggests that income is not the only factor that determines food security. Employment status, level of educational attainment, house ownership, and housing costs are also relevant factors in determining a person's degree of food security.³³ In Australia, ATSI peoples are disadvantaged across all socio-economic measures.³⁴

A lack of connectivity to food stores also poses significant challenges for people living in remote areas.³⁵ Furthermore, communities living in remote areas may be forced to go without food for extended periods of time due to adverse weather or poor road conditions.

One survey found that in the Northern Territory, 55% of communities lacked access to fresh food for extended periods of time.³⁶ Residents of this vast territory may have to travel up to several hours by vehicle to reach the closest regional center (such cities generally have a medium-sized grocery store) to purchase fresh food, such as fruits and vegetables, when nutritious food is unavailable in local shops due to bad weather or other reasons. Alternatively, they must rely on frozen or prepackaged food, such as instant noodles and chips, which generally lack adequate nutritional value.

Food availability

In certain parts of Australia (with the exception of, for example, remote mining regions), income levels have been found to decrease with geographic remoteness; at the same time, the cost of food, particularly healthy food, rises significantly in remote areas compared to urban centers.³⁷ Statistics from 2011 show that the labor-force participation rate among ATSI peoples was lowest in remote areas, at just 50%.³⁸ Overall, labor-force participation among ATSI peoples of working age declined as geographic remoteness increased.³⁹ Moreover, while approximately 50% of ATSI men aged 15–64 were employed in 2011, only 43% of women were employed.⁴⁰

Factors that can contribute to higher food prices, particularly in remote areas, include freight charges, store management practices, and reduced retail competition in remote communities with small populations.⁴¹ The combination of higher levels of unemployment, lower levels of income, and higher food prices means that the percentage of income spent on food increases, thus making a healthy diet even more difficult to achieve for ATSI peoples living in remote areas of Australia.⁴²

The variety and quality of nutritious food are also much worse in remote community stores compared to stores in major cities.⁴³ Convenience foods, which are energy dense and lacking in nutrition, are often the most readily available source of food for many people in remote communities.⁴⁴ It thus follows that while awareness-raising campaigns on choosing healthy foods to eat, food preparation and cooking, and budgeting for food purchase play an important role in improving food security among ATSI peoples, the effectiveness of such initiatives is dependent on healthy food actually being available and accessible in the first place.⁴⁵

Food use

Finally, with regard to the World Health Organization's pillar of food use, poor environmental health infrastructure is a major impediment to food security. In ATSI communities, only 6% of houses have functioning nutritional hardware, such as a storage space for food, adequate bench space for preparing food, refrigeration, and a functioning stove and sink.⁴⁶

Australia's efforts to improve food security among ATSI peoples

There are three tiers of government in Australia: federal, state and territory, and local. In recent decades, interventions to improve food security among ATSI peoples have come from all three levels of government.⁴⁷ Programs have been implemented to improve food access, food availability, and nutrition status among ATSI peoples, with some positive results and valuable lessons learned for future programs and interventions. However, food insecurity persists for many ATSI peoples, particularly those living in remote parts of Australia.

Close the Gap campaign

In his 2008 apology to the Stolen Generation, former prime minister Kevin Rudd established a series of targets to reduce the economic and social gaps between indigenous and non-indigenous Australians, especially the gap in infant and child mortality rates.⁴⁸ This commitment is now widely referred to as “Close the Gap” and forms the federal government’s approach to ATSI issues. The Close the Gap campaign for health equity aims to eliminate ATSI health inequalities within a generation. The campaign has introduced a number of initiatives to promote good nutrition and healthy-eating practices, with a focus on the most remote communities. Despite its positive intentions, the campaign has attracted its fair share of criticism. For example, as Sara Hudson has commented, Close the Gap is about reducing inequities and inequalities between indigenous Australians and non-indigenous Australians; however, the government has not introduced policies or programs that reflect an understanding that achieving this goal will require providing indigenous communities with access to the same level of services and facilities that non-indigenous Australians have.⁴⁹ Indeed, government efforts to close the gap will have to extend beyond the goal of providing the same level of services and facilities between indigenous and non-indigenous Australians to address the many inequities described in this paper, including a lack of access to nutritious and affordable food, poor health indicators, and a lack of employment opportunities.

National Aboriginal and Torres Strait Islander Peoples in Australia Nutrition Strategy and Action Plan

Between 2000 and 2010, the government’s National Aboriginal and Torres Strait Islander Peoples in Australia Nutrition Strategy and Action Plan (NATSINSAP) outlined a framework for improving ATSI peoples’ nutrition through concerted action across all levels of government and in collaboration with the food industry, nongovernmental organizations, and indigenous peoples. Building on existing efforts to improve access to nutritious and affordable food in urban, rural, and remote communities, the strategy focused on seven key areas: food supply in remote and rural communities; food security and socio-economic status; family-focused nutrition promotion; nutrition issues in urban areas; the environment and household infrastructure; training and employment of an indigenous workforce to promote nutrition; and national food and nutrition information systems. The NATSINSAP recognized that poor nutrition plays a key role in the poor health of ATSI peoples and the disproportionate burden of chronic disease that they experience.

Jennifer Browne, Sharon Laurence, and Sharon Thorpe suggest that despite limited funding, there was significant progress in some of the priority areas of the NATSINSAP, such as training of a nutrition promotion workforce, and improved food supply in remote communities.⁵⁰ Other scholars, however, have pointed to the limitations of the NATSINSAP; for example, the strategy lacks an ongoing source of funds, and there has been no formal review of the strategy to evaluate its effectiveness.⁵¹ Furthermore, for the strategy’s priority areas of improving food security, nutrition issues in urban areas, and environment and household infrastructure, both government funding and policy action have been limited.⁵²

Hudson posits that the key “achievement” of NATSINSAP was the collaboration between five state and territorial jurisdictions of the Remote Indigenous Stores and Takeaways Project, which consists of guidelines for stocking healthy food and marketing strategies to promote the use of healthy food.⁵³ However, Hudson points out that

this project showed only limited evidence of increased sales of fruits and vegetables.⁵⁴ She argues that healthy-eating programs appear to make a positive change in communities that are already motivated to eat better but are of “limited value in areas where store committees and managers are not motivated to change their food stocking practices.”⁵⁵

Despite marketing campaigns’ limited ability to change people’s food choices, the federal government continues to commit large amounts of Commonwealth funding to them. In November 2008, the Council of Australian Governments announced an additional AUD40.95 million (in addition to the AUD29.7 million already provided) to extend the Measure Up healthy-eating social marketing campaign by an additional three years.⁵⁶ Hudson argues that the problem with initiatives such as Measure Up is that they imply that low-income people make poor food choices because they lack the education to know any better.⁵⁷ Some members of ATSI communities resent the government for assuming that they need to be taught which foods are nutritious and which are not.⁵⁸ By continually directing Commonwealth money to healthy-eating social marketing campaigns, the federal government fails to address the underlying reasons for ATSI peoples’ unhealthy diets. For example, most healthy-eating campaigns have not considered the lack of sufficient health “hardware,” such as functioning kitchens, refrigerators, and stoves in ATSI communities.⁵⁹ Many ATSI families purchase takeaway food because they do not have the facilities to store or cook food at home.

Outback Stores

Another government strategy to improve ATSI food security is Outback Stores, a company established by the government in 2006 to manage remote stores in indigenous communities. The company seeks to overcome the factors that inhibit the provision of fresh and competitively priced produce in remote stores, such as financial mismanagement, food stocking policies, and poor infrastructure.⁶⁰ Indigenous Business Australia, a statutory authority of the federal government, manages the scheme.

Since 2006, the federal government has provided AUD8.1 million to implement computerized point-of-sale systems in the Outback Stores, as well as an additional AUD40 million in loans to develop store infrastructure.⁶¹

There are currently 27 Outback Stores in the states and territories of Queensland, Western Australia, and the Northern Territory. Under the scheme, stores continue to be owned by the community but community members must sign, on a fee-per-service basis, a long-term agreement with the company. Community members are entitled to receive reports providing information about their store’s financial and social performance, and to submit questions regarding any of the scheme’s decisions that are made on behalf of the community.

In 2008, former prime minister Rudd asked the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs to conduct an inquiry to examine the effectiveness of Outback Stores in improving the management of stores in remote areas of Australia. In 2009, the committee released its report, *Everybody’s Business: Remote Aboriginal and Torres Strait Community Stores*, which was based on 112 submissions and evidence heard at hearings. The report offered 33 recommendations for improving the role and management of remote stores, as well as strategies for improving food supply and affordability, transport, and sector regulation. Unfortunately, as Hudson has pointed out, the government has largely ignored the report’s recommendations.⁶²

Amanda Lee et al. highlight the positive elements of Outback Stores, such as the fact that one of the scheme’s key goals is to improve the provision of nutritious food, as well as the fact that the scheme may serve as a potential model to support sustainable employment and economic development in remote communities.⁶³ Other commentators are far less admiring. For example, Hudson argues that despite the company’s assurances that it works with communities to meet their differentiated needs, it also insists that store committees sign over control of the stores’ operations, which leads to these committees being stripped of their decision-making power.⁶⁴ Without the appropriate application of the

human rights principle of community participation, the Outback Stores scheme may be yet another example of the federal government doing something *for* ATSI communities, instead of *with* them, leading to the entire scheme ultimately failing.

Hudson suggests that the Outback Stores scheme has also resulted in some unfortunate consequences. For example, the AUD77 million of government funding that has been spent on these stores has made it more challenging for independent community stores to continue operating.⁶⁵ Government subsidies for Outback Stores have made it less economically attractive for remote communities to start their own stores and for ATSI peoples to pursue other methods of obtaining and selling nutritious food, such as growing fruits and vegetables in gardens.⁶⁶

National Strategy for Food Security in Remote Indigenous Communities

The Council of Australian Governments' 2009 National Strategy for Food Security in Remote Indigenous Communities aimed to improve food security among ATSI peoples living in remote communities through sustained, coordinated action around food supply and nutritious food consumption. The strategy's five key actions consisted of (1) national standards for stores and takeaway shops; (2) a national quality improvement scheme to implement these standards; (3) stores' incorporation under the Corporations (Aboriginal and Torres Strait Islander) Act; (4) a national healthy-eating action plan; and (5) a national workforce action plan.

The Australian National Audit Office's 2014 assessment of this strategy found that of the five desired actions, only the national healthy-eating action plan for remote indigenous communities was completed, despite a mid-2010 time frame for the completion of all actions.⁶⁷ According to the assessment report, the strategy did not establish a framework to coordinate food security initiatives, and, as a result, the Australian government's food security initiatives continue to operate in isolation from one another; furthermore, they are focused mostly on the Northern Territory, leading other states and territories to receive insufficient attention.⁶⁸

Welfare quarantining

Under welfare "quarantining," the federal government segregates welfare payments so that a particular portion may be used *only* for food purchases. As argued in a submission by several nongovernmental organizations to the UN Committee on Economic, Social and Cultural Rights, while the aim of this policy is to increase access to food among ATSI peoples, its implementation has in some cases actually hindered this access.⁶⁹ The report explains that under the welfare quarantining system, the purchase of food can be made only from government-approved stores, which means that ATSI peoples may have to travel longer distances to purchase food.⁷⁰ The policy has also forced many small community stores to shut down due to insufficient revenue, as their customers have redirected to the government-approved stores.⁷¹ Furthermore, the high amount of administration required to implement the scheme has led to errors, such as insufficient store vouchers being available at Centrelink offices (the federal government agency responsible for providing services and unemployment benefits to low-income Australians). This has meant that some people have not had vouchers to buy food and others have received vouchers valued at a lower amount than they are actually entitled to.

Also significant is the fact that welfare quarantining greatly reduces ATSI peoples' ability to determine their own sustenance. Under this policy, ATSI peoples experience great difficulties in accessing government money to pay, for example, for repairs to vehicles that are required for hunting, or for hunting supplies.⁷² This hinders their ability to use the land for food and to access traditional foods.

Discussion and conclusion

Access to, the availability of, and the quality of food are key concerns for vulnerable groups in Australia. Indigenous Australians enjoy less access to nutritious foods than does the wider population. Remoteness and poverty are more common among indigenous Australians than among their non-indigenous counterparts and are key factors that limit ATSI peoples' access to nutritious food. The

much higher rate of illness and disease related to poor nutrition in ATSI communities is a clear consequence of the barriers related to food availability, access, and use faced by ATSI peoples.

The food security challenges faced by ATSI communities highlight the interconnectedness of human rights. For example, the rights to adequate food and good health are intricately linked to the right to adequate housing. Without adequate housing infrastructure—such as food storage space, refrigerators, and functioning stoves—the rights to adequate food and good health are greatly compromised, as ATSI households cannot cook or store fresh, nutritious foods and are thus forced to rely on takeaway food. Government policies and campaigns to address food insecurity can work, but when governments fail to consider the interdependency of key human rights, the effectiveness of such interventions is reduced. While the Australian government's interventions to improve food security among ATSI peoples recognize the importance of access to fresh food and nutrition education, these campaigns do not always address the important relationships among key rights. Social marketing nutrition campaigns have been negatively received in ATSI communities because they have been based on the assumptions that these communities do not know how to recognize healthy food and that telling ATSI peoples what food is healthy will solve the current health inequities between indigenous and non-indigenous Australians. The same campaigns have neglected to consider that they will inevitably fail as long as there is a lack of adequate public transportation to reach stores that sell fresh produce, sufficient income to purchase fresh food, or, indeed, good-quality fresh produce to purchase in the first place.

Past and current Australian government policies that have disregarded a human rights-based approach to achieving food security have limited ATSI peoples' participation in relevant decision-making processes. Food security policies, absent a human rights-based approach, fail to acknowledge ATSI peoples' agency and perspectives; as a result, decisions are made for ATSI peoples

rather than with them. This inevitably limits ATSI peoples' ability to make decisions about the sources of their food and to make economic decisions about where to spend their money on food. These are rights that are particularly important for indigenous people, who often live on their traditional lands and value the right to hunt and consume traditional foods.

It may be concluded that successive Australian governments' food security policies for ATSI peoples have had limited success because they have not considered the interrelatedness of key rights and have not adopted a human rights-based approach to achieving food security. Despite some moderate success in specific policy areas, overall, the Australian government's campaigns have not managed to significantly improve food security among ATSI peoples. Evidence of this can be found in Australia's five-year reports to the UN Committee on Economic, Social and Cultural Rights describing the country's progress toward food security. The committee's review of Australia's fourth report on the implementation of the International Covenant on Economic, Social and Cultural Rights noted an incomplete and unaddressed assessment of the right to food, suggesting an absence of effective policies in the area of food security.

Improving food security among ATSI peoples in Australia also requires addressing inequities in social status; focusing on issues related to employment, income, welfare, and education; improving access to adequate housing; and improving public transportation in remote communities. The Australian government needs to consider the interrelatedness of key human rights in its attempts to develop policy and build cross-sector collaborations to address food security for ATSI peoples. Coordination across multiple sectors—including health, housing, transportation, education, human services, employment and training, social services, child protection, and food—as well as across all levels of government is necessary to address food insecurity among ATSI peoples in urban, rural, and remote areas of Australia. Success in improving food security requires a closer adherence to a

human rights-based approach that invites the active participation of ATSI peoples in determining solutions to food insecurity and health-related inequities.

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The Mental Health of Children and Parents Detained on Christmas Island: Secondary Analysis of an Australian Human Rights Commission Data Set

SARAH MARES

Abstract

This paper describes secondary analysis of previously unreported data collected during the 2014 Australian Human Rights Commission Inquiry into Children in Immigration Detention. The aim was to examine the mental health of asylum-seeking parents and children during prolonged immigration detention and to consider the human rights implications of the findings. The average period of detention was seven months. Data includes 166 Kessler 10 Scales (K10) and 70 Strengths and Difficulties Questionnaires (SDQ) for children aged 3-17 and parental concerns about 48 infants. Extremely high rates of mental disorder in adults and children resemble clinical populations. The K10 indicated severe co-morbid depression and anxiety in 83% of adults and 85.7% of teenagers. On the SDQ, 75.7% of children had a high probability of psychiatric disorder, with lower conduct and hyperactivity scores than clinic populations. Sixty-seven percent of parents had concerns about their infant's development. Correlations were not found between time detained or parent/child distress. Multiple human rights breaches are identified, including the right to health. This is further evidence of the profound negative consequences for adults and children of prolonged immigration detention. Methodological limitations demonstrate the practical and ethical obstacles to research with this population and the politicized implications of the findings.

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Disclosure: The author received a fee for her role as Royal Australian and New Zealand College of Psychiatrists (RANZCP) Consultant to the 2014 AHRC Inquiry into Children in Immigration Detention (February-April 2014).

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Introduction

In 2014, the Australian Human Rights Commission (AHRC) conducted an inquiry into immigration detention of children. This paper reports secondary analysis of data not analyzed or included in the inquiry report that was collected by the AHRC in March 2014 from children and families detained on Christmas Island (CI). Data included 166 Kessler 10 Scales (K10) for adults and adolescents, and 70 Strengths and Difficulties Questionnaires (SDQ) for children aged 3-17, plus responses from parents of 48 infants to questions about their wellbeing. The human rights implications are discussed.

Background

The UNHCR reports that 65.3 million people around the world are currently displaced, including 20 million already identified as refugees. More than half are children.¹ Australia is a signatory to the UN Refugee Convention (1951), and in December 1990 ratified the Convention on the Rights of the Child (CRC).² The CRC rights are largely enacted in policies for Australian children but not incorporated in law. Australia maintains a generous offshore refugee resettlement program, in stark contrast to the reception given to asylum seekers arriving by boat without documentation. Numbers are small in international terms: In 2013 and 2014, Australia granted positive refugee determinations for 4,949 people, which was 88% of those who had arrived by boat.³

Since 1992, Australia has had a policy of mandatory indefinite detention of all children and adults arriving by boat without valid documentation. This has been extended to include offshore processing and changes to the migration zone. In September 2012, the government reinstated third country processing and announced a regional settlement arrangement (RSA) under which people arriving by boat after July 19, 2013 would be transferred to Nauru or Manus Island in Papua New Guinea for processing, precluding resettlement in Australia. Between July 2013 and December 2014, while the RSA was negotiated, adults and children

remained detained in Australian mainland centers and on CI, a remote island in the Indian Ocean, northwest of Australia.

Australia's policies and practices have been the subject of sustained criticism from local and international human rights and medical organizations, including the UNHCR.⁴ For detained asylum seekers, the rights to work, education, human dignity, non-discrimination, equality, the prohibition against torture, privacy, and access to information, as well as the freedoms of association, assembly, and movement are all demonstrably compromised, with consequent impact on the right to health. There are identified breaches to the International Bill of Rights, the International Covenant on Civil and Political Rights (ICCPR), and the CRC, and evidence of demonstrable harm caused by indefinite detention and its consequences.⁵ Recent concern has particularly focused on conditions for those held indefinitely under the RSA on Nauru and Manus Island.⁶ In 2015, the UN Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment concluded in relation to the regional processing centers that "the Government of Australia...has violated the right of the asylum seekers, including children, to be free from torture or cruel, inhuman or degrading treatment, as provided by articles 1 and 16 of the CAT."⁷ The AHRC has conducted two inquiries into immigration detention of children, the first in 2002 (reported in 2004), and the second in 2014. The 2004 report states that the failure "to protect and promote the mental health and development of children ... not only constitutes a breach of a child's right to mental health, development and recovery, it also amounts to cruel, inhuman and degrading treatment."⁸ The AHRC found Australia in breach of multiple articles of the CRC, in particular Article 3(1), which states, "the best interests of the child must be a primary consideration in all actions concerning children."⁹ The 2014 report identified that "the laws, policies and practices of Labor and Coalition Governments are in serious breach of the rights guaranteed by the Convention on the Rights of the Child and the International Covenant on

Civil and Political Rights.” The conclusion of this inquiry aligns with scientific studies: “Prolonged, mandatory detention of asylum seeker children causes them significant mental and physical illness and developmental delays, in breach of Australia’s international obligations.”¹⁰

The Australian government’s responses to the two inquiries differed.¹¹ In 2004, evidence of the harms caused by immigration detention was considered new, and while the immigration minister disputed the findings, there was no sustained attack on the AHRC. Protective amendments to the Migration Act followed a change of government in 2007. The 2014 report was received with great hostility, including claims that the AHRC president had lost the government’s confidence and should step aside.¹² There was a sustained political attack on the AHRC with little attempt to deny the evidence that Australia’s policies cause significant harm. The Australian Border Force Act, enacted in 2015, potentially criminalized medical witnesses who spoke out about their experiences within immigration detention.¹³

Detained families and children receive health care through a government contractor, currently International Health and Medical Services (IHMS). Decisions about health needs and care provision are not transparent and there is no independent oversight or review body. Staff at IHMS and the Immigration and Border Protection system are subject to employment contracts and laws that prohibit disclosure of details surrounding detention conditions, which potentially puts them in conflict with professional standards and obligations.¹⁴ Some doctors previously employed by IHMS have argued that health workers in immigration detention may be condoning torture.¹⁵ In addition, given that detention itself is pathogenic, access to health care—no matter how adequate or independent—cannot sufficiently protect or treat detainees.

In mid-2014, IHMS began reporting Kessler Psychological Distress Scale (K10) mental health data from detained adults to the Australian government, and starting in mid-2015, they included Strengths and Difficulties Questionnaire

(SDQ) data from children. This data was released under the Freedom of Information Act (FOI), and while it was not subject to scientific scrutiny, it clearly demonstrates clinical levels of mental health problems in detained adults and children, and shows deterioration over the period of detention. SDQ screening from 45 children shows that 82% were significantly symptomatic, scoring in the abnormal or borderline range.¹⁶

Scientific literature

Displaced adults and children face multiple, cumulative risks, including conflict-related exposure, trauma, and losses pre-migration, in transit, and post-arrival. Host countries support or undermine their wellbeing, with post-migration detention and insecure asylum status being particularly detrimental.¹⁷ In 2002, this author, with other colleagues, first published descriptions of the impact of the harsh physical and psychological environment within Australian immigration detention on children and families.¹⁸ Researchers subsequently carried out small quantitative studies demonstrating that the system was causing harm to children.¹⁹ This added to existing research about detained adults.²⁰ Despite their methodological variety and limitations, international studies and review papers consistently show poor mental health among asylum seekers who have been detained, and there is evidence that even brief periods of detention—including in open centers—can impact children’s functioning.²¹ Rates of mental disorder are higher than in non-detained refugees with similar pre-migration risks, and length of detention is directly related to severity of symptoms.²² Unaccompanied children, predominantly adolescents, have particular vulnerabilities due to their separation from family.²³ There is a small qualitative literature on the wellbeing of pregnant and postpartum asylum seekers, but barely any reports regarding detained infants and young children.²⁴ Infancy and early childhood is a period of profound dependency and rapid development, when cumulative adversity—including neglect, violence, and parental mental illness can have

long-term impacts across multiple developmental domains. Infants are over-represented in displaced populations, but a review by Fazel and colleagues identifies only 5 of 44 studies that include children under five.²⁵

The study

Methods

The primary data was collected in March 2014 during the AHRC National Inquiry into Children in Immigration Detention. The author was Royal Australian and New Zealand College of Psychiatrists (RANZCP) consultant to the Inquiry and was involved in developing the methodology and collecting the data. Detailed observations made during AHRC visits to CI are reported elsewhere.²⁶ This study undertakes secondary analysis of data that was collected but not analyzed as part of the inquiry and was obtained under FOI in July 2015. It is therefore secondary and in the public domain. Redaction of gender and country of origin occurred before release under FOI. The project was submitted to the South Western Sydney Local Health District Human Research Ethics Committee (HREC/15/LPOOL/556), which was satisfied that the rights of participants had been protected.

Context

Christmas Island (CI) is a tiny island in the Indian Ocean covered in dense tropical forest. Small areas are cleared for phosphate mining, and there is a coastal settlement and diverse local population of about 2,000. Island life is dominated by the influx of staff and facilities associated with Australia's immigration and border protection services.

Families were held in indefinite detention on CI with the threat of transfer to Manus or Nauru or resettlement in third countries. Despite their designation as Alternative Places of Detention (APOD), the camps that housed families and unaccompanied minors resembled prisons. They were harsh and cramped, surrounded by high double fences—some of which were electrified—and guards were stationed at security gates. The

ground was hard and stony, there was no grass, limited shade, and white phosphate dust covered everything. Families slept in small cabins with limited privacy, some shared bathrooms. There was little for anyone to do.

In this institutionalized setting, protective experiences for children were largely absent. Risks included exposure to parental mental illness, adult violence, and self-harm; family separations; and a developmentally impoverished environment. All adults and children were woken for head counts at 11 pm and 5 am, when they had to state their ID numbers. ID cards were required when lining up for meals or medical care. Children had few places to play safely and had received only a few weeks of schooling in the previous year.

The 2014 AHRC report identifies multiple breaches of the CRC in relation to the rights to development, health, education, and treatment with humanity and dignity.²⁷

Ethical considerations

Research with detained populations is difficult and contentious, as it intersects medicine, politics, human rights, ethics, and law. In Australia, there are additional practical and political barriers.²⁸ These include extreme access limitations associated with the often very remote and penal nature of detention centers. Restrictions are justified on the basis of security, and prevent independent scrutiny and research on the impact of Australia's policies. If access was possible, obtaining informed consent is problematic, particularly with children, and given the extreme cultural and linguistic complexity of the population. Recent legislative changes, including the Australian Border Force Act (ABF) potentially criminalize individuals, including the author, who speak or write about the detention environment or contact with detained asylum seekers.²⁹

Secondary analysis of an existing data set involves further consideration of existing data in order to answer the original research question using a different technique, or to present differing or additional interpretations. The approach has been used more with quantitative than qualitative data.³⁰ It raises ethical questions about consent

and protection of original participants.³¹ Multiple steps were taken to protect participants during primary data collection and release under FOI. It was impracticable to obtain explicit consent for this study, which was not anticipated when the data was collected. It is also impossible to identify, locate, or recontact participants. Detention of children and families on CI ceased in December 2014, and all detainees have been transferred to Nauru or Manus, returned to their country of origin, or held temporarily in Australian centers or the community. This project is consistent with the aims of the primary data collection and adequately protects participants.

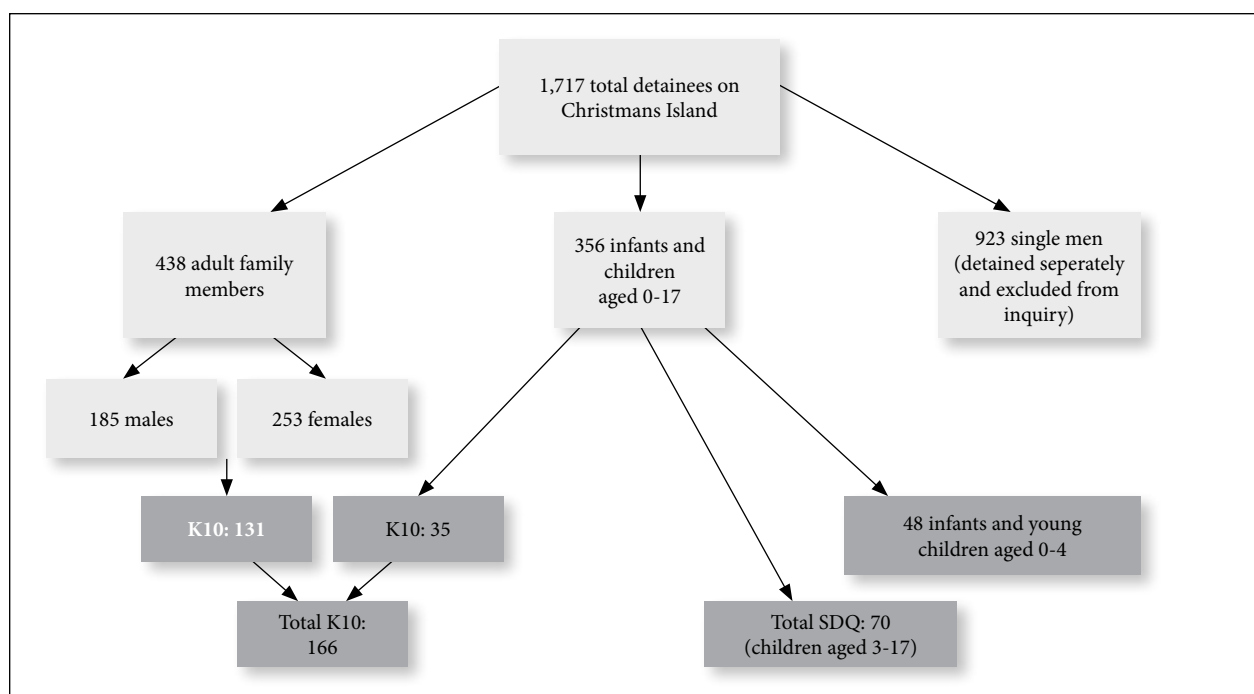
Primary data collection

In March 2014, children across Australia's immigration detention network had been detained for an average of eight months and were from 16 language groups, predominantly from Iran, Sri Lanka, Iraq, Afghanistan, Vietnam, Somalia, and a small number from Syria. The second largest group was Rohingya children, identified as stateless.³² The AHRC inquiry obtained approval from the Department of Immigration and Border Protection

(DIBP) to access detention centers in Australia, including CI. DIBP data shows that 1,717 detainees were held there before the AHRC visit in March 2014.³³ This included 923 single men separately detained and excluded from the inquiry. All family members and 41 unaccompanied minors (UAM, children under 18 years old without family) were invited to participate. There were 356 children aged 0-17 years held with 438 adults (185 men and 253 women). Twenty-five infants had been born into detention and 20 women were pregnant. No processing of asylum claims had occurred since July 2013.

Interviews were conducted in language groups using interpreters. The purpose of the AHRC inquiry was explained. Informal and semi-structured interviews and brief self-report questionnaires were completed. The inquiry methodology is outlined elsewhere.³⁴ Self-report measures included the K10 and SDQ. Only selected questions from these measures were included during visits to other detention centers and all data was collated for the report. Therefore, K10 and SDQ data from asylum seekers on CI has not been analyzed previously.

FIGURE 1: Population sample



Measures

The K10 is a self-report scale of psychological distress.³⁵ High distress scores indicate likelihood of a mental disorder. It has been validated in population-based and clinical populations and with a wide range of language and cultural groups, including refugee populations.³⁶ The SDQ is a brief behavioral screening questionnaire completed by the parent or carer, or self-reported for children aged 12-17. It is used in population and clinical studies to identify those at risk of mental illness. The 20 items are summed to create a “total difficulty” score ranging from 0-40 and 5-factor subscales (hyperactivity-inattention, emotional symptoms, peer problems, conduct problems, and prosocial behavior).³⁷ It has been used with migrant and refugee children, making it an appropriate measure in this population.³⁸

Secondary analysis

The AHRC provided data from 365 people under FOI. This included 174 adults, 77 without children, and 97 adults in 69 family groups. The 191 children represent 48% of the 356 children then detained on CI. Time in detention, ages of children, exposure to violence, and parental concerns was provided. Gender, individual country of origin, and language

group was redacted. Complete K10s were available and analyzed for 131 adults and 35 adolescents aged 12-17, 166 in total, and 70 SDQ for children aged 3-17. Parental concerns about 48 infants were collated.

Limitations

The data available for analysis has many limitations. It is not possible to determine whether this is a representative sample of the population detained on CI in March 2014; however, age and language group distribution of all children then detained in Australia was similar.³⁹ AHRC inquiry team members collected primary data in extremely noisy and distressing circumstances. Redaction of gender and country of origin information limits the richness of possible analysis. Levels of distress may have influenced participation. The data is incomplete in that there is only data (time in detention, SDQ and/or K10 data) for 131 adults and 105 children aged 3-17, and qualitative data on parental concerns about 48 infants. Some data was omitted or entered incorrectly during primary collection or FOI release. Five children had no age recorded, 15 are identified as UAM, yet 58 are not recorded as being part of a family and 77 of the 173 adults are not recorded as having children. This is likely to represent single women detained with the families, but may

TABLE 1: Population data

	Age	Number	K10	SDQ (ages 3-17)
Adults	18 and over	173	131	
Children	0-4	48 (25.1%)		
	5-11	104 (54.4%)		
	12-17	39 (20.4%)	35	
With parents	12-17	24/39		
Unaccompanied	12-17	15/39		
			Total K10 = 166	
Total children	Mean 7.64	191		Total SDQ =70
Family groups		69		
Time detained	Mean	Range	SD	
	209.5 days (7 months)	90-390 days	62.36 days	

The 129 children for whom data was available for secondary analysis included 48 infants and young children (37.2 %) aged 0-4, 52 (40.3%) aged 5-11, and 29 (22.5%) aged 12-17. Five children without recorded ages were allocated the mean age of 7.64 years (SD 4.89). There were 69 family groups (at least one adult and one child) with 36.7% of children in single-parent families, and 29.3% with two parents. A further 3.6% are identified with three adult carers, presumably grandparents or aunts. Number of children ranged from one to six per family, with 39.9% of families having one or two children. The mean length of time in detention for all adults and children was 209.5 days (7 months), with a range of 90 to 390 days and SD of 62.36. This includes infants born into detention.

also indicate data entry errors. Oral translation of English language self-report measures by interpreters may have altered reporting. There are also minor age variations in versions of the SDQ, and in the disorderly circumstances, these were used randomly for children aged 3-17.

Statistical analyses

Demographic data was collated. K10 and SDQ data was entered into a database with incomplete data excluded. Total problem and specific symptom scores were analyzed. The SDQ was scored assuming parent report and analyzed using 5-factor analysis. Parent concerns in response to specific questions about infants were collated. Descriptive analysis of socio-demographic characteristics and mental health

outcomes was undertaken to assess bivariate associations between parent and child indices. Multilevel analysis based on Actor-Partner Interdependence Model (APIM) and structural equation modelling was applied to examine for dyadic associations between parent and child outcomes.

Results

Kessler 10

There were 166 complete K10s: 139 for adults and 26 for teenaged children (aged 12-17). The prevalence of mental disorders was determined using the National Survey of Mental Health and Well-Being likelihood bands.⁴⁰ (Table 2). These results indicate very high rates of severe distress, with 83% of adults and 85.7%

TABLE 2: K10 results

	N	Percentage (%)
Parents/Carers	Total = 131	
Likely to be well (score <20)	1	0.7
Likely to have mild mental disorder (20-24)	9	6.9
Likely to have moderate mental disorder (25-29)	12	9.2
Likely to have severe mental disorder (30 or over)	109	83.2
Children (12-17 years)	Total = 35	
Likely to be well (score <20)	1	2.9
Likely to have mild mental disorder (20-24)	3	8.5
Likely to have moderate mental disorder (25-29)	1	2.9
Likely to have severe mental disorder (30 or over)	30	85.7

TABLE 3: K10 Anxiety/Depressive symptoms

Parent/Carer N=131 (P) Children 12-17 years N=35 (C)	P	C	P	C
Anxiety symptoms	None (%)		Most/All (%)	
Feeling nervous	12.2	5.7	87.8	94.3
Feeling so nervous that nothing could calm them down	13	14.3	87	85.7
Feeling restless or fidgety	14.5	8.6	85.5	91.4
Feeling so restless that they couldn't still	17.6	8.6	82.4	91.4
Depressive symptoms				
Feeling depressed	0.8	2.9	99.2	97.1
Feeling so sad nothing could cheer them up	3.1	2.9	96.9	97.1
Feeling that everything was an effort	7.6	5.7	92.4	94.3
Feeling worthless	9.9	8.6	90.1	91.4
Feeling tired out for no good reason	11.5	5.7	88.5	94.3
Feeling hopeless	13	5.7	87	94.3

of teenagers indicating severe disorder. Symptom responses were ranked highest to lowest with adolescents most often reporting *depressed, hopeless, and worthless*, while for adults it was *depressed, worthless, and tired for no good reason*. When K10 items for anxiety (items 2, 3, 5, 6) and depression (1, 4, 7, 8, 9, 10) were scored (Table 3), all participants met criteria for mixed anxiety and depression. The K10 does not enable PTSD to be differentiated.

Strengths and Difficulties Questionnaire (SDQ)

There were 70 complete SDQ for children aged 3-17. The age distribution shows 52 (74%) aged 3-11 and 18 (26%) aged 12-17. Although it is likely some SDQ for adolescents were self-reported, this cannot be distinguished and all were scored as parent-reported. Strong correlations have been found between self- and parent-reported SDQ in one study of refugee

children.⁴¹ Fifty percent of children had abnormal total difficulty scores and another 25.7% had borderline scores; in total, 75.7% of children had a high probability of psychiatric disorder (Table 4) Symptom distribution by five-factor analysis showed high rates of emotional symptoms with 71.5% abnormal and another 7.1% with borderline emotional symptom scores, indicating 78.6% of children had significant emotional symptoms. Conduct scores were lower with 39.85% of children with borderline or high conduct symptoms, 48.6% had borderline or high hyperactivity scores and 55.7% had abnormal peer problem scores. Prosocial behaviors were abnormal in 32.9% of children.

Infants and young children (aged 0-4)

The AHRC questionnaire asked: *Do you think your child's emotional and mental health has been*

TABLE 4: SDQ Scores

SDQ scores	N=70	Percentage (%)
Total difficulties score		
Abnormal (>17 total score)	35	50
Borderline (14-16 total score)	18	25.7
Normal (0-13 total score)	17	24.3
Emotional symptoms score		
Abnormal	50	71.5
Borderline	5	7.1
Normal	15	21.4
Conduct problems score		
Abnormal	25	35.7
Borderline	6	8.6
Normal	39	55.7
Hyperactivity score		
Abnormal	25	35.7
Borderline	9	12.9
Normal	36	51.4
Peer problems score		
Abnormal	12	17.1
Borderline	27	38.6
Normal	31	44.3
Prosocial behavior score		
Abnormal	16	22.9
Borderline	7	10
Normal	47	67.1

affected by being in detention? and *Do you have concerns about your child's development?* Responses and specific concerns were collated for the 48 children under five. (Table 5) Thirty-two (67%) parents identified concerns about the impact of detention on their infant's emotional or mental health and 11 (23%) identified concerns about development. The most frequent were socio-emotional symptoms including *nightmares and sleep problems, always worried, upset or sad, fighting with others, restless, agitated*. The most frequent developmental concern was *poor eating/low weight gain*.

Correlations

This study did not find correlations between length of detention and severity of psychological distress for adults or children. (Table 6) Nor were there significant associations within families between parent K10 and paired children's SDQ scores.

Discussion

Despite many limitations, this sample is arguably worth analysis and reporting because of the extremely limited health data about detained children and parents, the human rights implications of

TABLE 5: Concerns about infants and young children (aged 0-4)

Has your child's emotional and mental health been affected by detention?	
Yes	32 (67%)
No	2
No answer/not sure	14
Do you have concerns about your child's development?	
Yes	11 (23%)
No	4
No answer/not sure	33
Total	48
Specific concerns (ranked)	
Nightmares, sleep problems	18
Always worried/upset/sad	15
Fighting with others	10
Restless, agitated	8
Anxious, clingy, won't leave room	7
Poor eating/low weight gain	6
Not socializing	5
Not able to play or learn	4
Nail-biting/headaches/other	4
Toileting/constipated	3
Bedwetting/incontinent	3
Always shouting/ screaming	2
Self-harming/head banging	2
Not talking	2
Not crawling/walking	1

TABLE 6: Correlations

Correlations		Sig Value
*LOD = Length of detention		
Between child K10 and LOD*	Non-sig >.05	0.881
Between adult K-10 and LOD	Non-sig >.05	0.549
Between child SDQ and LOD	Non-sig >.05	0.223

the findings, and the impossibility of undertaking this research in conventional ways. It provides data on rates of probable mental illness, allows some description of symptom profiles, and attempts examination of data within families. Bias in the data is potentially in either direction, with under- or over-reporting of distress. It is of significant public interest that the mental health and human rights consequences of this aspect of Australian government policy are analyzed and reported in standardized, measurable ways.

As this study and the government's own data show, immigration detention has severe health and mental health consequences for the majority of detained adults and children. Rates of psychiatric disorder in the CI sample on the K10 dramatically exceed the 12-month prevalence in the general Australian population where affective disorders have a prevalence of 6.2% with 4.1% for depressive disorder, and anxiety disorder prevalence is 14.4% with PTSD at 6.4%.⁴² Rates greatly exceed those reported in a large international meta-analysis of mental health of refugees and conflict-affected people, which found a prevalence of 30.8 % for depression and 30.6% for PTSD.⁴³ There is evidence of the adverse effects of detention on mental health post-release, but very little data on the mental health of currently detained asylum seekers. A small Australian study of detainees from one ethnic group using other standardized self-report measures found very high rates similar to this study, with 100% of detained adults meeting criteria for major depression and 86% diagnosed with PTSD.⁴⁴

The high SDQ total problem scores for children in this sample more closely resemble Australian clinical than community populations. Rates of mental disorder in community samples are between 9% and 14%, while a study of 130 children referred to a mental health service (CAMHS) identified 85% of children with borderline or abnormal behavioral/emotional symptoms on SDQ.⁴⁵ High symptom scores in the CAMHS group showed 72% emotional, 78% conduct, 60% hyperactivity/inattention, 64% peer relationship problems with low prosocial scores in 38%.⁴⁶ Overall problem scores are similar (75.7% of the CI sample and 85% of the clinical group) with

notably lower rates of conduct (38.9% compared with 78%) and hyperactivity/inattention (46% versus 60%) symptoms than the clinic population.⁴⁷

Distress in the CI sample was higher than in children held in open European asylum centers or in the UK community. A study of 267 asylum seekers' children in open centers in the Netherlands found 50% of children aged 4-11 with significant symptoms, 38% in the abnormal range and 12% at borderline levels. Factors such as maternal mental health, parental loss, and family size were more important than length of detention.⁴⁸ A Danish study found that 26% of 246 children living with their families in open centers scored above caseness on total scores; 50% had significant emotional problems, 18% raised hyperactivity scores, 11% conduct problems, and 19% peer problems. Only 3% had abnormal pro-social scores.⁴⁹ A UK study of community-based migrant and refugee children using the SDQ found that 27% of refugee children, 9% of ethnic minority children and 15% of white children met case criteria.⁵⁰ Refugee children showed particular difficulties in emotional symptoms, consistent with the current study. Parents reported significant concern about their infants, and this vulnerable group deserves more attention in studies of displaced populations.

The lack of correlation between distress and time detained may represent a ceiling effect given the significant period detained and the pervasively high distress levels. The lack of correlation between parent and child distress may be explained by the statistical method (pairing one child with one parent). This is an inadequate measure of children's exposure to adult mental illness or disturbed family relationships. In closed detention, many interacting factors in the institutionalized environment alter family functioning and therefore the quality of parent-child interactions. In addition, children were in constant proximity to many adults, 83% of whom were likely to have a severe mental disorder. Potential protective factors outside the family, such as schooling, were largely absent. The available data does not enable analysis of children's exposure to specific or cumulative risks, including factors prior to their detention by Australia.

It is important to acknowledge that K10 scores indicate 14.3% of teenaged children and 17% of adults without significant symptoms. On SDQ, almost a quarter of children were not rated as of concern. There is no information, including about family factors, which might account for apparent resilience or under-reporting in adverse circumstances. Studies of refugees in the community identify belief systems, social support, and a range of psychological strategies as important, but literature on resilience and coping in detained child and adult asylum seekers is limited.⁵¹ The UN General Assembly Human Rights Council recently re-affirmed “The right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and emphasizing that mental health is an integral part of that right.”⁵² The harms caused to child and adult asylum seekers are no longer denied by the Australian government, and instead repeatedly justified on the grounds of deterrence.⁵³ The use of mistreatment as deterrent contravenes the 1985 United Nations High Commission for Refugees (UNHCR) Guidelines on the Detention of Asylum Seekers, which explicitly state that this is contrary to the principles of international protection.

Conclusion

This study adds to the scientific literature, witness reports, and the Australian government’s own evidence of the profound negative consequences of detaining asylum-seeking children and families. There are few studies of families during prolonged immigration detention and fewer that include children under 5 years. A majority of parents had concerns about their infant’s health and /or development. K10 and SDQ scores indicate extreme rates of psychological distress and probable disorder in children and adults and teens with co-morbid anxiety and depression at clinical levels. Detention may have specific psychological impacts on children, resulting in higher rates of emotional symptoms but lower hyperactivity and conduct scores than in clinical groups. The profound access limitations and lack of independent health care provision and monitoring make detailed analysis of potential

contributing and cumulative risk factors impossible.

Australia’s current immigration policies violate detainees’ human rights in multiple ways, including their right to health, by causing severe psychiatric distress and disorder in adults and children. Untreated or inadequately treated mental illness has ongoing consequences and increases the risk of self-harm and suicide. This has implications for the immediate and longer-term care of asylum seekers and further highlights the harm caused. The acknowledged methodological limitations of the study are a consequence of the practical, political and ethical obstacles to undertaking research in conventional ways with this extremely vulnerable population. Australia’s harsh immigration and border protection regime is maintained and defended in callous disregard for the people who are harmed. Justification on the basis of deterrence represents a further breach of our humanitarian obligations, raising concern that these practices amount to torture of those detained indefinitely. The findings of this study have scientific, human rights, and undeniable political implications.

Acknowledgments

This work is possible because the Australian Human Rights Commission (AHRC) collected the primary data, which was subsequently released under Freedom of Information legislation (FOI). Australian Government data about the mental health of detained asylum seekers was obtained under FOI by the Guardian newspaper. Any errors or omissions are the sole responsibility of the author.

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Transforming Policy into Justice: The Role of Health Advocates in Mozambique

ELLIE FEINGLASS, NADJA GOMES, AND VIVEK MARU

Abstract

Despite expanding policy commitments in many poor countries, health care is often a failure at the point of delivery. Lack of information, poor enforcement, and power dynamics prevent those whose rights have been violated from pursuing redress. In Mozambique, grassroots health advocates work to address this gap between policy and reality by blending approaches known as legal empowerment and social accountability. They raise awareness of health policy, support clients to seek redress for grievances, and facilitate problem-solving dialogues between communities and health facility staff. In three years we have seen communities begin to overcome a culture of silence. Twenty-one advocates and their clients have achieved redress to over a thousand grievances across 27 health facilities. These cases have resulted in improvements to access, infrastructure, and provider performance. Advocates have supported village health committees to transform themselves from collections of names on a list into active agents for change. Advocates should not be trained and left alone—they are most effective when integrated into a vertical team that provides continuous support and supervision, and that can engage higher levels of authority to solve tough cases. Aggregate data from cases handled by health advocates provides unique insight into how health policy is working in practice. We draw on that information to advocate for systemic changes that affect the entire country, like better policies for combatting bribery and stronger procedures for responding to grievances. We have found that legal empowerment and social accountability practices interact synergistically. Our preliminary experience suggests that when people are equipped to exercise their rights to health, even a poorly resourced system can improve.

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Competing interests: None declared.

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How health systems fail

Alcina

Alcina has lived her entire life in an isolated coastal village in Mozambique's southern region, without access to electricity, running water, or transport. She gave birth to her three children at the local health center—a 17km trek from her home—in 2008, 2012, and 2014. Within moments of each delivery, she was forced to get out of bed and fetch water from the borehole to wash the soiled sheets. “When my daughter was born last year, the nurse and the cleaner didn't treat me with courtesy. I was treated very badly. I was insulted, and when I complained that I was in pain, the cleaner told me to lie back down, and then she slapped me on the face.” Alcina continues, “Many women didn't want to go to the health center. They preferred to give birth at home.”

Jorge

At a bustling health center on the outskirts of Maputo, nearly 8,000 patients living with HIV receive care and treatment. The health facility did not have a CD4 machine on-site (essential for measuring the level of immunosuppression in HIV patients), so blood samples were being transported to a nearby hospital for analysis. Patients' test results were frequently misplaced and delayed, sometimes for months. In October 2015, one of these patients—Jorge—had to return to the health center three times to repeat his blood draw. Each time, he arrived by 6:30 am and waited in line for more than four hours. A medical technician at the health center recalls: “I felt as though I was doing a real disservice to my patients—that I was unable to provide quality care in the absence of a CD4 history. It was impossible to get results back, even for those who were gravely ill.”

Introduction

Despite expanding policy commitments in many poor countries, health care is often a failure at the point of delivery.¹ Practice does not match policy, in part because health facilities are hard to reach and severely understaffed. In addition, stigma,

discrimination, fear, and a pervasive lack of information keep people from seeking and receiving care.² This is particularly true for vulnerable groups such as people living with HIV, women, adolescent girls, orphans and child heads of household, the elderly, and the disabled. Efforts to improve health outcomes around the world primarily focus on the mechanics of delivering care, including clinical training, drugs, and infrastructure. But it is increasingly clear that strengthening the accountability of services to patients is essential if those investments are to succeed.³

In this journal in 2010, one of us (Maru) proposed strengthening the accountability of services to people through a synthesis of two approaches: legal empowerment and social accountability.⁴ Legal empowerment efforts help people to understand, use, and ultimately shape laws and policies. Legal empowerment organizations often deploy grassroots legal advocates—sometimes known as barefoot lawyers, or community paralegals—who form a creative, problem-solving frontline that can bring law closer to people.⁵ The term “social accountability” refers to efforts that “inform citizens about their rights and status of service delivery and encourage participation” in pursuit of fairer, better services.⁶ Despite substantial overlap in mission, these communities of practice have tended not to interact.

In the earlier *Health and Human Rights* article, Maru observed that some social accountability interventions focus exclusively on pressuring local service providers, without engaging the wider network of state authority. Legal empowerment efforts, meanwhile, specialize in pursuing remedies from a range of institutions. On the other hand, legal empowerment organizations have not typically gathered data to proactively identify systemic failures. This is something social accountability groups are known for. For these reasons, Maru argued that the two approaches could work well in tandem.

Drawing on similar observations, Jonathan Fox and others have recently highlighted integrated approaches to accountability, which span vertical levels of authority (local, provincial, and national) and engage horizontally across public institutions, including not just the executive, but also, for

example, the courts, parliaments, human rights commissions, and ombuds offices.⁷

We reflect here on our experience attempting an integrated approach to the accountability of health services in Mozambique. We work with a group, Namati, that is dedicated to legal empowerment. Namati and its partners deploy grassroots legal advocates who help clients protect community lands, enforce environmental law, and secure basic rights to health care and citizenship. Namati also convenes the Global Legal Empowerment Network, which is made up of more than 700 groups from 150 countries. Namati aims to foster learning and collaboration across that wider community. In Mozambique, Namati is registered as a national NGO recognized by the Ministry of Justice. All but one of its 38 staff members are Mozambican.

The grassroots advocates at the center of the effort in Mozambique are called *defensores de saúde*, or health advocates. They engage in three kinds of work. First, they raise awareness of health policy—something common to social accountability and legal empowerment. Second, they engage in case work—supporting clients to resolve specific grievances with respect to health services. This approach comes explicitly from the legal empowerment tradition. Third, drawing from the social accountability experience, *defensores* support dialogue between communities and health facility staff to proactively identify and address system failures.

This essay draws on our own reflections as practitioners and on internal program data. We are currently working with independent researchers to undertake an external evaluation—the researchers will publish those results in a future paper.

We begin with a snapshot of both the reality and the policy of health care in Mozambique. We then describe the three key elements of our approach before returning to the stories of Alcina and Jorge and reflecting on our experience to date. We discuss 1) how we have attempted to overcome a culture of silence about breaches of health rights, 2) the kinds of improvements to health services we have achieved, 3) our experience mobilizing village health committees, 4) the importance of providing adequate supervision and support to frontline advocates, and

5) our effort to translate grassroots experience into system-wide change.

Mozambique context

Health and development

Despite having endured a brutal civil war from 1977 until 1992—a devastation compounded by recurrent droughts and flooding—Mozambique has made considerable strides in reconstruction and public health. In the two decades since the conflict ended, under-five mortality has declined by more than 50%. In 2003, the government established a free national HIV care and treatment program. The number of people receiving lifesaving antiretroviral therapy (ART) quadrupled from 200,000 in 2010 to 800,000 in 2016.⁸ But Mozambique is still at the bottom of the Human Development Index, ranking 180 out of 188 countries in 2015.⁹ More than 40% of children are stunted as a result of chronic illness and malnutrition, and the maternal mortality rate remains among the highest in the world.¹⁰ Even with the recent expansion of HIV services, ART retention rates are low.¹¹ The challenges include extreme poverty and inequality, vast distances to health facilities, and a profound shortage of health care providers. Mozambique has 0.4 physicians and 4.1 nurses and midwives per 10,000 inhabitants—one of the lowest health worker densities in sub-Saharan Africa.¹²

Law, policy, and the right to health

Articles 89 and 116 of the Mozambican Constitution recognize the right to health, guaranteeing that “the State shall promote the extension of medical and health care and equal access of all citizens to the enjoyment of this right.”¹³ The Constitution also provides for the right to ‘popular action,’ under which individuals or groups can bring a case to court in relation to issues such as public health, consumer rights, and environmental conservation, though no such case has ever been raised in relation to public health.¹⁴

The Charter on Patients’ Rights and Obligations (*Carta dos Direitos e Deveres dos Utentes*),

adopted by the Ministry of Health in 2006, elaborates on the centrality of human rights in health services, highlighting human dignity, equality, and ethics as fundamental values. The charter prohibits discrimination on the basis of health status and guarantees the confidentiality of patient information. It gives all patients the right to voice suggestions and grievances, and the right to a timely response.

The Law on Protection of the Individual, the Worker, and the Candidate for Employment Living with HIV and AIDS (*Lei da Protecção da Pessoa, do Trabalhador e do Candidato a Emprego Vivendo com HIV e SIDA; Lei nº 19/2014*) specifies the rights of people living with HIV, including information, free treatment, and protection from discrimination.¹⁵

Mozambique has ratified a number of global treaties, including the Convention on the Rights of the Child, the Convention for the Elimination of all Forms of Discrimination against Women, and the International Convention on the Rights of Persons with Disabilities.

In addition to these national and international legal instruments, the Ministry of Health has developed a range of powerful policies and clinical protocols. The impact of these laws and policies, however, is undermined by insufficient dissemination, poor enforcement, low literacy rates, and power dynamics that prevent those whose rights have been violated from pursuing redress.¹⁶

Namati's approach

Defensores de saúde work to address this gap between policy and reality by supporting communities in exercising their basic rights to health. They present themselves not as watchdogs who would police health care providers but rather as supporters of the system and its staff, many of whom themselves do not have access to the resources or essential information they need to work effectively. We share the same fundamental goal as the government: to improve health outcomes in Mozambique. This framing has been critical in building constructive relationships with both health care providers and Ministry of Health leadership.

We have four criteria when recruiting health advocates: problem-solving ability, a secondary school education, proficiency in reading and writing, and a proven commitment to the common good. As of this writing, Namati employs 21 full-time health advocates: 12 women and 9 men. Each advocate is responsible for between one and three health facilities, depending on patient volume and geographic coverage. Health advocate catchment areas range from 23,000 to 115,000 people (with larger catchment populations in urban and peri-urban facilities). Three program officers and a small technical team provide the advocates with ongoing support.

Namati began working in primarily rural areas of two districts in southern Mozambique in March 2013. One year later we launched a partnership with MSF in several sites in Maputo city. In May 2015, we expanded further to two high-volume government health centers in Matola, and we are now establishing operations in five districts of Inhambane province.

Selection of districts for the initial phase was based on our commitment to conducting regular and intensive supervision, and at the same time containing travel-related costs given our limited budget at the outset. We have viewed this as Phase I of our work, during which we have focused on implementation research to identify a socially grounded model through a process of trial and error. We adapted the program based on regular input from communities and providers and evidence about what was working and what was not.¹⁷

We have conceived of the learning and tweaking as valuable experimentation, along the lines of what Lant Pritchett and colleagues call “structured experiential learning.”¹⁸ We are guided as well by Mansuri and Rao’s findings about participatory approaches to development—that “context, both local and national, is extremely important” and that “strong built-in systems of learning and monitoring, sensitivity to context, and the willingness and ability to adapt are therefore critical in implementing projects.”¹⁹

Our model has evolved to involve three core elements: increasing awareness of health policy,

pursuing solutions to specific breakdowns in health care delivery, and facilitating dialogue between communities and clinics. We have found that when integrated, these approaches offer powerful synergies.

*Providing essential information and education:
The foundation for action*

Health advocates strive to make health-related laws, policies, and protocols accessible to everyone. They address large groups of patients in health center waiting areas. They visit schools, farmers' associations, women's cooperatives, and HIV support groups. They go door to door, speaking with people in their homes. Increasingly, they also engage the public through newspapers, television, and radio.

We take inspiration from South Africa's Treatment Action Campaign (TAC). Forbath describes TAC as "a model for methods of education, outreach and institutional reform that help equip and enable the 'clients' of social programs to participate in reforming and reshaping local state institutions and wider systems of social provision."²⁰ TAC co-founder Mark Heywood writes:

*The right to health...may be recognized in international covenants, national constitutions, and jurisprudence. But it cannot be effectively utilized by community activists unless health itself is better understood; nor can the right to health be pursued without connecting it to issues of law, politics, or governance.*²¹

In Mozambique, as in many countries, most health information that reaches grassroots level is about science or behavior rather than policy. People are taught how malaria is transmitted, for example, and why birth spacing is important, but not which medicines or family planning services they're entitled to.²² Our education efforts intertwine scientific information with specific health protocols so that patients can more effectively advocate for themselves.

Supporting individuals and communities to seek redress for grievances

Many public health facilities in Mozambique have suggestion boxes or registers in place, but they are seldom used. The existing system requires patients,

many of whom are illiterate, to submit feedback in writing. Moreover, fear of retribution and imbalances of power tend to silence the most vulnerable citizens when their rights are violated.²³ Namati's health advocates help clients pursue remedies to grievances. They document the problem clearly, analyze it in relation to health policy, and formulate a potential solution. Whenever possible, advocates and clients aim for amicable resolution with local facility staff. When necessary, they seek redress from higher levels of authority in the ministry. Health advocates collect data on every case they handle: client demographics, the specific nature of the grievance, actions taken towards resolution, and outcomes.

Facilitation of community-facility dialogue regarding health system performance

In addition to seeking redress for specific grievances when they arise, health advocates work with communities to take a more proactive role in the governance of their health services. To do so, we engage an existing structure: the village health committee. According to national guidelines, the role of these village health committees is to "mobilize members of the community to identify health problems in general, with a particular focus on those that affect women and children, as well as to identify respective solutions both within and beyond the community."²⁴

We aim to transform what are often inactive groups into effective institutions for governance. We provide training and ongoing technical support to village health committee members regarding, for example, the patient bill of rights, key health protocols and policies, conflict resolution, and advocacy strategy. Health advocates work with committees to conduct systematic assessments of health services on a biannual basis. The assessment instrument, which incorporates detailed feedback from community members and health workers, assists committees in identifying and prioritizing problems related to provider performance, infrastructure, equipment, and medicines.

Committee members and *defensores* then analyze the root cause of each problem, agree

on strategy, and commit to specific actions and timelines. This process will allow Namati staff, communities, and government to track progress on barriers to the right to health over time.

What happens when people stand up for the right to health

Alcina

When Alcina gave birth to her first two children amidst verbal and physical abuse, she recalls having had nowhere to turn. “We felt helpless. We didn’t know what we were supposed to do when things went wrong.” By the time her daughter arrived in early 2014, however, Namati’s health advocate, Hortência, had been working to support communities in the health center catchment area for nearly a year. The village health committee, which had previously existed only on paper, was now an active group of five women and four men who, with guidance from Hortência, had begun conducting advocacy at local and district level and had gained the trust of both community members and health providers.

After Alcina approached several committee members, they went to speak with Leonor, the cleaner, who denied having slapped and mistreated her patient. Several weeks later, they invited Leonor, the head nurse, and a community leader to a meeting, during which they discussed the incident and the potential impact of such behavior on maternal and newborn health. Leonor finally acknowledged her wrongdoing. Over the next few months, Hortência and the health committee members monitored Leonor’s behavior. An elder woman from the community noted:

Leonor has really changed. The way in which she talks to patients is different. She used to berate everyone, but now she treats people well. Since Hortência’s arrival, we have become capable of applying pressure, and things are improving. In the past, the maternity waiting house was always empty, but now there are pregnant women who come.

According to the head nurse, births at the facility have risen from an average of two births per month

to as many as 12 to 15, which is slightly higher than the national average for a rural catchment area of its size.

Jorge

One morning in October 2015, a group of six patients living with HIV came to speak with Namati’s health advocate, Abudo, in the waiting area outside the HIV clinic to ask if she could help them track down their CD4 test results. The following week, Abudo, together with two of the patients, met with the head of the health center, who shared their concern that the transport of blood samples and results was increasingly disorganized. She showed them a copy of a request she had submitted to district health management nearly two months earlier, asking for a CD4 machine to be installed permanently at the facility. She had not received a response.

Abudo discussed the case with the program officer, Ofélia, and they then requested a meeting with the district director of health. They spoke about the impact the delayed test results were having on patients’ lives, including money spent, time wasted, and increased illness. The district director agreed that given the high patient volume at the facility, a CD4 machine was justified, but in light of many competing priorities, she could not say when it would be procured. As an interim solution, Abudo collaborated with the head of the health center to improve management of blood samples and results by introducing a logbook and limiting responsibility for transport and documentation to one driver who was trained and supported to take on this task. Patients and providers at the health center soon noticed marked improvements. Ofélia continued to advocate at the district level for allocation of a CD4 machine, and in March 2016 a machine was delivered to the health center. Jorge recalls:

In the past, it was very difficult for me. I live more than 20 kilometers from here. I was very weak, and it was not easy for me to get here every day to check on my results. I wanted to abandon treatment. Today, things are different. The care I get is much better. I know that when I come here I will have my results immediately.

Learning and results

Breaking the silence

A series of focus groups conducted in February 2013 as part of a baseline assessment in our original catchment areas suggested that there was virtually no community engagement in governance of the health sector. People are now beginning to come forward; day-to-day violations that affect many people are being noticed and reported. We are slowly chipping away at the culture of silence.

As of August 2016, 21 *defensores* and their clients have taken on a total of 1,307 grievances across

27 health facilities, of which 83% have been resolved (see Table 1). Seventy-four percent of these cases were collective, directly affecting anywhere from 10 to 10,000 people (for example, lack of privacy at the pharmacy window or inadequate number of beds and/or sheets in the maternity ward). Sixty-seven percent of the clients were women.

Rights awareness is low, and there is a widespread belief that any provision of care, even if delivered with apathy or ineptitude, is a gift bestowed upon the patient. In this context, we view an initial rise in complaints not as a sign that health care is worsening, but as an indication that people

TABLE 1. Grievances presented to Namati, March 2013-August 2016

Cumulative grievances, by case status				
	Resolved ¹	In process ²		Total
Number	1,083	224		1,307
Percentage	83%	17%		
Cumulative grievances, by nature of case				
	Infrastructure and equipment ³	Provider performance ⁴	Medicines ⁵	Total
Number	407	844	116	1,367
Percentage	30%	62%	8%	
Cumulative grievances, by type of case				
	Individual	Collective		Total
Number	338	968		1,307
Percentage	26%	74%		
Cumulative grievances, by nature and type of case				
	Infrastructure and equipment	Provider performance	Medicines	
Individual	6%	41%	11%	
Collective	94%	59%	89%	
Cumulative grievances, by gender of client registering case				
	Female	Male		
	67%	33%		

¹ *Resolved* cases have been closed because they have been solved. Health advocates monitor cases for 30 days prior to closing to ensure that there has been no recurrence.

² *In process* cases are those for which we are still actively pursuing a solution.

³ *Infrastructure/equipment* includes lack of medical material such as gloves/bandages, poor hygiene in the facility, lack of equipment such as beds/sheets/x-ray machines, lack of private space for exam, distance between community and health service, lack of ambulance/fuel for ambulance, lack of sufficient providers, other.

⁴ *Provider performance* includes provider absence or tardiness, mistreatment/disrespect/abuse, clinical negligence, discrimination, violation of confidentiality, violation of privacy, lack of sufficient information about prevention/treatment/diagnosis/risks, bribe, lack of rapid response to urgent case, lack of informed consent, other.

⁵ *Medicines* includes lack of medicines and insufficient allocation of medicines.

More than one nature may be attributed to a single case or grievance. For example, a case might be classified both as “provider performance” and as “infrastructure/equipment.”

are beginning to stand up for themselves.²⁵

One challenge we have encountered is relatively lower demand for the help of health advocates in some rural settings. In remote areas with limited geographic access to services, rights violations are more often acts of omission than acts of commission; the vast majority of people living in isolated rural areas simply do not interact with the health system. The act of *not* receiving something is less often recognized and reported as a violation, which means that demand for health advocate services can be slow at the outset even while the need is great. We have learned that sharing examples of successful cases can be helpful in mobilizing others to come forward. These success stories have the power to change expectations and to catalyze a ripple effect in the community.

Identifying trends across individual grievances can also lead to proactive collective action. For example, over the course of one year, several individuals brought complaints against the same provider for refusing to attend to patients in labor or those who were gravely ill. Suspecting other unreported incidents, the health advocate and village health committee called a meeting with the broader community, during which six additional grievances were raised against the nurse. Namati then supported the committee in documenting and presenting the series of testimonies to ministry officials. As a result, the provider was relocated from a remote area to a district hospital, and placed under close supervision.

At some of our sites, *defensores* have helped health providers break their own silence. Many providers struggle to deliver quality services in a system sorely lacking financial and human resources. Some say *são as condições que nos temos*—this is the reality in which we must operate-- and they regard health advocates with indifference or even resistance. But many other providers, like the health center director in Jorge's story above, have come to view us as allies and have sought the assistance of health advocates in addressing problems that keep them from doing their jobs well.

Improvements in health services

We have seen promising results in our first three years, including improvements in quality of care, access to services, infrastructure, and essential medicines. At one facility, Namati registered a collective grievance regarding the chronic tardiness of the nurse responsible for prenatal consults. The health advocate, Leopoldina, first approached the nurse directly but was rebuffed. She then worked with the health center director to call a meeting of maternal and child health providers, during which the group discussed patient rights and the importance of respecting working hours. In collaboration with several members of the health committee, Leopoldina monitored the situation over the next two months and reported improvements in terms of tardiness and a 50% increase in the number of prenatal exams conducted per day.

We have observed numerous examples of increasing adherence to Ministry of Health protocol. At one site, for example, a patient living with HIV and TB raised a complaint regarding the delay in initiating antiretroviral therapy. According to national policy, patients with HIV and TB co-infection qualify to begin ART immediately. With our health advocate's intervention, the patient initiated ART and began receiving nutritional support. The nurse then went through the HIV register and identified 15 additional patients in the same situation, and started all of them on treatment.

We have also seen tangible improvements in the geographic reach of services. Health advocates have worked alongside communities and health committees to advocate for bringing community health workers to isolated rural areas that previously had no access to health services; for increasing frequency of existing mobile clinics; and for improving the number and type of services offered at peripheral sites. Whereas in the past, mobile clinics only offered vaccinations and weighing, for example, several now offer malaria testing, TB and HIV care, family planning, and management of chronic diseases such as hypertension and diabetes.

We have managed to resolve more than 70 cases involving access to medicines, but many of

these resolutions have been ephemeral. Recently, we worked with an epileptic patient who dropped out of school because her seizures had become too frequent and severe. The local health center and district hospital both told her that medicines for her condition were not available. A health advocate ultimately discovered that the medicine was indeed available in the district government pharmacy stores and helped the patient begin treatment. But solutions like these are limited in that they are often short-term, and do not adequately address the systemic causes of the stock-out, including challenges related to logistics and supply chain management.

More promisingly, *defensores de saúde* and community members have identified and pushed for a number of low-cost improvements to infrastructure. At one site, we worked with health center leadership to secure modest funding from the district government to construct a wall separating the pharmacy from the consult room, resulting in an increase in patient privacy and confidentiality.

At multiple sites, health advocates received complaints that outpatient bathrooms were inoperative for extended periods—often months at a time. Patients were urinating and defecating in the grass surrounding the health facilities. We were able to resolve these collective grievances through district-level advocacy, which resulted in the application of flexible funds to restore broken toilets. More recently, in a crowded district hospital, we advocated for renovation of an unused structure to be used for TB care, as infectious TB patients were previously congregating in a hallway with little ventilation just outside the prenatal and under-five consult area.

Many of our cases represent egregious violations of the right to health and of human dignity, and yet a substantial proportion of them are relatively easy to resolve if a vocal advocate is committed to pursuing a solution.

The potential power of village health committees

Although the government assigns significant responsibility to village health committees, it has done little to support them. Where they do exist,

these committees tend to focus almost exclusively on promoting individual behavior change, tracking down patients who have dropped out of treatment, providing home-based care, and ensuring that the grounds of the health facility are well-maintained.

When Namati began implementation in early 2013, there was not a single functioning health committee in our program catchment areas. In several instances, the names of the committee members were on file at the district level, but on arrival we discovered that a number of these individuals were not aware that they were on the committee. In other cases, committees had dissolved or become inactive.²⁶

Health advocates, together with government partners, have focused on vitalizing these committees, ensuring that empty seats are filled with committed individuals and educating committee members about the full scope of their role and about the details of health policy. These committee members become our “super-clients,” identifying many cases and taking part in regular dialogue and advocacy with the health ministry at local and district levels.

At our strongest sites, these committees embody Namati’s vision of public spiritedness and citizen empowerment. As these committees assume a more active role, health advocates have been able to reduce the intensity of their engagement, increasing their coverage area to include another health facility. If we can reproduce this dynamic, it will make scale-up more plausible and less costly.

Where we have had less success working with village health committees, common factors include members who were selected based purely on political affiliation, lack of motivation to engage in unpaid work, and limited capacity of the health advocate supporting the committee.

The vital role of supervision, support, and a vertical network for the pursuit of justice

Health advocates cannot fulfill their potential if left on their own. The advocates need to be connected to a larger team—including each other, lead advocates, program officers, and senior experts in public health and law—for two reasons.²⁷ First,

continuous supervision and support is necessary to ensure that advocates are consistently serving with excellence. We bring the entire team together every two months to provide updates on policy and science and to share emerging challenges and good practices. Our program officers and lead advocate also conduct regular visits to each advocate. The visits are an opportunity to review case files, watch the advocate in action, and discuss strategy on difficult cases.

We have developed a method of internal spot-checks, whereby our database randomly selects several recently closed cases every month for review. The monitoring and evaluation officer reviews the files in these cases and conducts separate interviews with the advocates and clients involved.

Client feedback on questions such as “were you satisfied with how the case was handled?” and “how can we do better?” helps us monitor the quality of the advocates’ efforts. We also ask, “can you describe the process of resolving the case?” “did you learn anything and, if so, what?” and “have you helped anyone else since?” The three latter questions give us a sense of whether we are genuinely achieving legal empowerment, whereby the advocates are not solving problems on behalf of clients (“I will solve this for you”), but rather the clients are taking an active role (“we will solve this together”), and in the process, clients are becoming more knowledgeable and capable of advocating for themselves in the future.

Several health advocates have interacted with government health staff in a confrontational manner, which is counterproductive. In these circumstances, we have found it useful to establish informal mentorships through which the health

advocate who is having difficulty spends time shadowing another, more experienced health advocate.

In addition to quality control, the second crucial function for the support network around health advocates is providing help with tough cases. We need our own vertical network in order to effectively pursue solutions from the vertical network of government authority. As the following table illustrates, different types of cases require different levels of intervention.

Grievances related to infrastructure and equipment often require more formal advocacy at higher levels and take longer to resolve. The average time of resolution for these cases is 85 days, as compared to 50 days for cases related to provider performance and 57 days for those related to medicines. Improvements to infrastructure and equipment—for example, a separate room for HIV counseling and testing or a shaded seating area with benches for patients—normally require budgetary support, which involves sometimes lengthy bureaucratic processes.

In some cases, health advocates have collaborated closely with facility leadership, health committees, and community members to draft and submit petitions and written requests to district and provincial government, with varying levels of success. In other cases, the program officer has participated in the annual district budget planning exercise to advocate for inclusion of a particular item.

Fewer cases involving provider behavior have required us to go beyond the level of the facility—just 18 out of 844. Among these 18 exceptions are bribery allegations, which often involve numerous providers working in collusion. In those cases, the health facility director is often aware of the problem

TABLE 2. Resolved cases by case type and engagement of vertical network—grievances presented to Namati, March 2013-August 2016

	Infrastructure/ Equipment	Provider performance	Medicines
Health facility supervisor	218	535	75
District level	43	16	22
Provincial level	4	1	5
National level	1	1	1

but is reluctant or unable to intervene effectively, either because of fear of retaliation, limited management capacity, or both. In addition, health workers are often unwilling to harm a colleague's career by reporting on the colleague's misbehavior. In these cases, when a remedy is unattainable at the facility level, and because of the sensitivity of the allegations, our program officer and legal adviser help the health advocate and clients to approach district level authorities in the ministry.

In one case involving the suspected bribery of maternity patients, discussions with the health advocate led the district health director to call several community meetings in which he heard patient complaints firsthand. After investigating these claims, the director took formal disciplinary action against one medical technician. He followed up over the next few months, meeting regularly with health facility leadership and health committee members. He introduced a new district-wide policy of publicly posting phone numbers of key personnel—including his own—in an effort to curb the practice of bribery and encourage patients to seek redress for grievances when violations do occur.

Other cases have been less successful. In Maputo, where power is highly centralized, health center directors tend to have less autonomy than in the other areas where we work. At one busy urban facility, there were frequent complaints about delayed initiation of consults: patients typically begin queuing at 6:00 am, as the facility is supposed to open at 7:30, yet at this particular site a handful of providers were regularly arriving to work one to two hours late.

After hearing from the health advocate and committee members, the facility director called an all-staff meeting. In the days that followed, she instituted a new policy by which the head nurse was to monitor an attendance log. A number of health workers gamed this system by signing in and then leaving during the day, only to return to sign out at 3:30 pm. Despite clear evidence that this was taking place, the director did not take any disciplinary action. District leadership has been unresponsive, and the problem persists.

It is difficult to say why some attempts at

remedies from ministry authorities succeed while others fail. When presented with specific claims via in-person meetings, formal letters, or petitions, health officials are often prompted to take action. Leadership may be aware of common violations of patients' rights in the broad sense—for example, that a particular facility has a problem with theft of medicines—but the presentation of concrete evidence demonstrating a breach of policy makes it easier to intervene. In other cases, officials refuse to act.

There are multiple variables at play, including the skill of the advocates and the responsiveness of the particular officials involved. The state is, of course, not a monolithic structure.²⁸ We try to identify champions of patients' rights within the government and cultivate relationships with them. These allies vary by location and include health center directors, the chief nursing officer at the district level, influential traditional authorities, and provincial directors.

Translating grassroots experience into systemic change

We track data rigorously on every case the advocates take on, and every community-facility dialogue they facilitate. In the aggregate, this information provides invaluable insight into how health policy is working in practice. We draw on this information to propose systemic changes that can affect the entire population, not just those living in catchments where health advocates are active.

We convey recommendations through quarterly reports to government, issue-specific policy briefs, and in-person meetings. A recent brief based on the bribery cases we have handled, for example, explains how to detect when bribery is taking place (common signs to look for) and proposes reforms for curtailment.²⁹ The health ministry distributed 200 copies to hospital directors and incorporated recommendations into its training materials. We are currently collaborating with the ministry to develop a new national strategy on prevention of bribery in the health sector.

In 2015, the Ministry of Health asked Namati to assist in revising its national policy on the “qual-

ity and humanization” of health services. Based on our experience, we have proposed new guidelines for grievance redress and national implementation of the health facility assessment process we have used to catalyze dialogue between communities and health facility staff.

Going forward, we aim for clients to take part directly in not just resolving their own cases, but in advocating for systemic change. True legal empowerment means that ordinary people can not only understand and use the law, they can shape it too.

Conclusion

Our preliminary experience suggests that when people are equipped to exercise their rights to health, even a poorly resourced system can improve. We have found value in blending legal empowerment and social accountability practices. The health advocates’ three modes of action—popular education about health policy, regular community-facility dialogues, and a rigorous case-based approach to resolving grievances—interact synergistically.

Heightened awareness leads more people to raise grievances and to participate in the community-facility dialogues. The dialogues uncover system failures and provide a forum for resolving as many problems as possible at the facility level. The case-based approach allows advocates to pursue redress systematically for those problems that aren’t resolved through dialogue. With the help of a vertical team, health advocates and their clients can engage every rung of state authority in pursuit of a solution. For people like Alcina and Jorge, health services transform from something for which they should be grateful, even when the services are dysfunctional, into something in which they can take part.

One might worry that deploying advocates in a small proportion of the country could end up redistributing limited resources to communities that happen to have health advocates—grease for squeaky wheels—rather than improving the system as a whole. We have three thoughts in relation to that concern.

First, we do not believe that the health system is zero-sum. Many improvements are possible

within existing resource constraints, and persuading officials to respond in specific instances may increase rather than diminish their responsiveness overall. Second, even at a small scale, this grassroots experience can create a compelling basis for advocating reforms that affect the entire population. For that reason, it’s important to deploy advocates in multiple provinces or regions—even before serving the entirety of any province—so that the data can tell a nationally representative story.

Third, these efforts should not stay small scale. We estimate that advocates could serve the entire country for roughly 1% of the national health budget.³⁰ Even if the money is made available, the prospect of scale poses challenges. Is it possible to maintain dynamism and excellence if the number of *defensores* grows dramatically? Can the vertical network that supports health advocates—which we have found to be crucial for both quality control and for engaging the full network of state authority—be scaled in proportion to the advocates themselves? These are challenges we are eager to take on.

We are keen to collaborate with other groups pursuing the right to health and to see *defensores* across many countries collecting a common core set of data on the grievances they address—information on the nature and prevalence of different types of problems and the ways in which those problems are resolved. That information could be a basis for comparative methodological learning on how health advocates can be effective across different social and legal contexts. We can get better at what we do by learning from one another.

This would also create a multinational portrait of how health systems are working, and how they respond to citizen action. A coalition of groups could harness that information to identify and advocate systemic reforms to the practices of international bodies like UNICEF and the Global Fund on AIDS, TB, and Malaria.

We believe that the right to health will not be realized through top-down reforms alone, or even through democratic elections every few years. We the people need to take part daily in the rules and institutions that shape our lives.

Acknowledgments

We would like to express our deep gratitude to the health advocates, village health committees, health providers, and communities whose story this is, for their perseverance in the face of injustice. Huge thanks also to Eric Friedman, Alice Goldenberg, and Akhila Kolisetty for invaluable research assistance; to Marta Schaff and two anonymous peer reviewers for insightful feedback that significantly improved the essay; and to Open Society Foundations (OSF), the UK Department for International Development (DFID), the Skoll Foundation, Centro de Colaboração em Saúde (CCS), Centers for Disease Control and Prevention (CDC Mozambique), the U.S. President's Emergency Plan for AIDS Relief (through a sub-agreement with CCS), Open Society Initiative for Southern Africa (OSISA), Médicos Sem Fronteiras (MSF) and Oxfam Novib, without whom this work would not be possible.

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Terminal Patients and the Right to Refuse Medical Treatment in Argentina

MARTÍN HEVIA AND DANIELA SCHNIDRIG

Abstract

The right to health has many dimensions. On the one hand, it entails positive duties for states to protect the health of individuals. On the other, it encompasses patient decision making regarding personal health, an idea which is closely linked to the right to autonomy and the right to free development of the individual—that is, to dignity.¹ This is why the informed consent of the patient and her right to make a choice according to her own values should be honored, even when her decision may seem irrational or imprudent. When patients are incapable of providing informed consent—for example, if the patient is unconscious—the law can authorize certain persons to act as a proxy on their behalf. In Argentina, the Patients’ Rights Act (2009) as amended by the Death with Dignity Act (2012) states that if a patient is unable to provide informed consent, consent may be provided on her behalf by her close relatives, affinal kin, or legal guardian, in this order of preference.² The Patients’ Rights Act also permits patients to set up advance directives regarding health decisions to be made if they become terminally ill. In 2015, the Argentine Supreme Court of Justice discussed the scope of patient autonomy in the case *D., M.A. s/ declaración de incapacidad*.³ This case presented a question that had yet to be explored by the court: how can we determine an unconscious patient’s will if she does not have written advance directives concerning whether a life-sustaining medical treatment should be continued? This article examines the grounds of the Argentine Supreme Court’s decision in *D., M.A.* First, we describe the case law that existed prior to *D., M.A.* Then, after explaining the facts of the case, we discuss the ruling and raise doubts about its scope.⁴

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Competing interests: None declared.

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Case law prior to *D., M.A.*

The Argentine Supreme Court had previously ruled on patients' right to autonomy in the cases *Bahamondez* (1993), and *Albarracini Nieves* (2012). Both cases dealt with patients who needed blood transfusions but, as Jehovah's Witnesses, refused treatment.

In *Bahamondez*, the patient was conscious when he refused the transfusion. Justices Fayt and Barra held that human dignity is inviolable and that other values are instrumental compared to respect for persons.⁵ Thus, *Bahamondez* was free to refuse the blood transfusion. This ruling was issued before the constitutional amendment of 1994, which conferred constitutional status on the right to health.⁶

In *Albarracini*, the patient was hospitalized in a critical condition while unconscious. He had previously signed an affidavit before a notary public where he had stated his wish not to receive blood transfusions even under risk of death. With the Patients' Rights Act already in effect, the Supreme Court considered that patients, when accepting or refusing a specific treatment, "have the right to make a choice according to their own values or points of view, even when it may seem irrational or imprudent, and that free choice must be respected."⁷

Facts of the case

Marcelo Diez suffered a traffic accident in the Province of Neuquén in 1994 that left him hospitalized and unconscious. He underwent several surgical procedures and was administered various analgesic drugs. He required permanent care to satisfy his basic needs.

His sisters legally requested an authorization to discontinue artificial hydration and nutrition and all therapeutic treatments used for Diez's artificial life support. The request was denied by the court of first instance and the court of second instance. The Supreme Court of Justice of Neuquén granted their request.

The court framed its ruling around the Patients' Rights Act, despite the fact that the act was passed after the accident. The Office of the Public Prosecutor for Incompetent Persons (Ministerio

Público de Incapaces) and the *ad litem* curator of Diez appealed the judgment, arguing that he was not in the terminal condition required by law. Thus the case was brought to the Argentine Supreme Court of Justice.

The Supreme Court ruling

The Supreme Court explored three questions. The first concerns how to determine the situations in which a patient may refuse treatment. The court based its decision on article 2 of the Patients' Rights Act, which allows patients to refuse treatment and hydration and nutrition procedures when they suffer from an irreversible disease or are terminally ill. Although Diez was not terminally ill, the court considered him to be in an irreversible and incurable condition because of his injuries and the fact that according to medical experts, there was no medical precedent that suggested a prospective recovery.⁸ Under this reasoning, the court subsumed the case under the permission granted by the Death with Dignity Act.⁹ Furthermore, the court considered life support measures to be included in the "medical treatments" mentioned by the law.

The second question lies at the heart of the case: how should cases where patients cannot express their will be decided? The Patients' Rights Act regulates informed consent, which must be personal. Diez did not have formal advance directives, unlike *Albarracini Nieves*. The law also provides for situations where patients, for any reason, are unable to consent, in which case their relatives may consent on their behalf. The court analyzed whether it was possible to determine the will of Diez if he had no formal advance directives, concluding that it was possible to do so. An affidavit signed by Diez's sisters was enough to determine his will.¹⁰

However, the court emphasized that Diez's will had to be represented in the affidavit and that his sisters were not deciding on his behalf but merely voicing the will of their brother.¹¹ As the court stated:

What the [aforementioned] legally designated prescribed individuals must express is the will of the unconscious patient and his personal appreciation regarding his non-transferable idea of human dig-

*nity before becoming permanently and irreversibly unconscious.*¹²

Thus the Supreme Court adopted a more restrictive interpretation of the Patients' Rights Act. If Diez had not expressed to his sisters his wish to be taken off life support in a case like this, the request might have been denied in light of Diez's lack of consent.

The Supreme Court intended to prevent individuals from making this type of decision on behalf of somebody else based on their own understanding of "life with dignity." Diez's sisters may well have thought that, in that condition, their brother's life was not worth living. Therefore, the Supreme Court asserted that its ruling

*in no way entails approval or endorsement of a distinction between lives worth living and lives not worth living and it should not be understood to concede that the right to life may be restricted on account of the severity or seriousness of a physical or mental condition, or consent that the right to medical or social care for supporting a patient's quality of life may be limited.*¹³

That being said, when describing the requirements for determining whether consent exists, the court used a very lax standard. In this case, an affidavit signed by Diez's sisters was enough to determine that Diez had provided advance directives.

Is this a way to provide flexibility to the strict standard set for consent by representation? This may well be the case, as it proves difficult to imagine other ways of determining the will of the patient. This is an imperfect solution but may be the one that closest reflects the will of the patient. Nonetheless, such a solution could be controversial if a third party claimed that the patient's will was different. In that scenario, there is no obvious way to resolve the conflict.

Therefore, on the one hand, the Supreme Court's ruling seems to revoke the authority that the law had granted to family members to decide on behalf of the patient. On the other, it is often hard to find evidence of the patient's will regarding terminal care, as people rarely voice their wishes in that regard.¹⁴

The third question concerns how doctors

should deal with future cases. The Supreme Court stated that there is no legal obligation to require a judicial authorization for these types of cases. In this regard, the court followed its precedent on the decriminalization of abortion.¹⁵ Furthermore, it stated that there is a need to develop protocols to regulate a possible conscientious objection by health care providers. In *F., A. L. s/ medida autosatisfactiva*, the Supreme Court established guidelines for protocols for conscientious objection to abortion, which we think are applicable to these cases as well. The court stated that health institutions should allow their staff to exercise their right to conscientious objection without compromising patients' rights—for example, by requiring that the conscientious objection be expressed at the time that the protocol enters into force to guarantee that every health institution has staff to provide these services.¹⁶

Conclusion

We conclude with a final consideration: what is the scope of the Supreme Court's ruling? On the one hand, the court based its decision on the principle of autonomy and on the idea that each and every individual is solely responsible for making his or her major life decisions (in this line of reasoning, suicide, for instance, is not objectionable). On the other, the court cited the Patients' Rights Act to make the point that euthanasia procedures are not permitted.¹⁷ However, if autonomy is a fundamental value, just as self-induced death should not be objectionable, is outlawing euthanasia consistent with that value? Should patients be required to die a heroic death?¹⁸ In fact, the Supreme Court has previously held that the law cannot expect or require people to act heroically—that is, to "make enormous and immeasurable sacrifices."¹⁹ Following this line of thought, shouldn't Argentina be obligated to decriminalize euthanasia?²⁰ The autonomy-based arguments used by the Supreme Court in *D., M.A.* seemingly lead to that conclusion.²¹ This is a very active discussion in other countries (for example, in Canada) and an important forthcoming debate in Argentina.²²

Acknowledgment

The authors wish to thank Federico Rovillard Simoneschi for translating excerpts from the court rulings and translating a draft in Spanish.

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BOOK REVIEW

Rethinking Health and Human Rights through Emancipatory Frameworks around Dignity and Well-being

BEATRIZ GALLI

Power, Suffering, and the Struggle for Dignity

Alicia Ely Yamin, Foreword by Paul Farmer, published by University of Pennsylvania Press, 2016

Alicia Ely Yamin's book *Power, Suffering, and the Struggle for Dignity* is necessary reading for advocates, practitioners, and students from any discipline interested in understanding the intersection between human rights and health. It underlines the importance of applying a rights-based framework to health systems, policies, and laws that cause suffering, social inequalities and injustices in countries and regions around the world. The author examines the interdependence between social epidemiology, social medicine, public health, law, sexual and reproductive health, and human rights. She explores the interdependence between health and other human rights including the right to sexual autonomy, bodily integrity, and access to education, clean water, transportation, and housing. She highlights the evolving field over time and how the emergence of new identities based on sexual orientation and gender identity demand a holistic approach to traditional human rights, as well as a more emancipatory rights frameworks based on dignity.

In analyzing the human rights-based approach (HRBA) to health, Yamin argues the importance of considering existing patterns of discrimination and inequalities in our societies, and how these patterns are reflected in our health systems. This approach considers health systems as core social institutions, which explains the need to move beyond conventional public health analysis and solutions in order to bring about a social transformation that can impact people's lives, health, and well-being. It aims toward a social transformation for individuals most affected by power dynamics and is key in promoting transformative relationships between duty-bearers and rights-holders. It also incorporates the notion of accountability in relationships of entitlement, and obligations between, for example, providers and patients and policy makers and citizens. In describing how a human rights-based approach operates, Yamin touches on issues largely invisible in traditional public health analysis, which is more focused on individual behavior and biological risk fac-

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Competing interests: None declared.

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tors than the real conditions in which individuals and communities live and experience multiple and intersectional forms of discrimination. Yamin highlights issues relevant to our historical moment in time—a moment when the global movement for sexual and reproductive health and rights calls for the need to place peoples' human rights and dignity at the center of the new sustainable development agenda. This approach is critical when considering public health emergencies such as the Zika epidemic, massive violations of women's and girls' sexual rights, high sexual violence rates, lack of access to safe abortion and contraception, and a host of other issues. It has been more than 20 years since the 1994 International Conference on Population and Development in Cairo, yet women and girls are still experiencing major consequences of states' continued and systematic neglect in protecting sexual and reproductive health rights.

Sexual and reproductive health rights are central to the global health and development agenda, but the implementation of these rights at the national level has been slow, due to states' failure in promoting incremental changes to the policy and legal environment. Yamin uses the debate over abortion laws as an example of how a health service, which is only required by women, can be denied based on moral grounds and religious views that create discriminatory barriers to health care, unnecessary suffering, and human rights violations.

Yamin argues that a woman, depending on her race, ethnicity, or where she was born and lives, may not have access to an enabling environment where she is able to exercise her basic human right to reproductive self-determination, including the right to make informed and voluntary decisions about continuing or ending her pregnancy, the right to personal integrity, the right to enjoy sexual autonomy, and the right to be free from avoidable death due to unsafe abortion. She states, for example, that even in countries where abortion is legal based on the right to privacy and autonomy, its implementation is disconnected from the social and economic conditions in which women can exercise these rights. This reality is reflected in the poor health outcomes of marginalized women and girls.

It highlights the social and gender inequalities, and discrimination in health care access that continue to happen despite legal change or when governments are not held accountable to peoples' human rights.

Despite some important public health advances, such as the worldwide decline in maternal mortality, countries are still facing high rates of preventable deaths due to unsafe abortion—especially in middle- and low-income countries, particularly those located in less-developed regions. Women in these societies lack access to safe and legal abortion and have to confront criminal laws, morbidity, or death when they challenge their fate as mothers and caregivers by choosing to end their unwanted pregnancies. Yamin's focus on social inequalities, cultural practices, and social norms are key aspects throughout the book. She demonstrates how these factors impact people's experience of life choices, health rights, and well-being. According to the book's central argument, enabling women to live with dignity requires "rethinking the nature of the problem as well as the solution." This is particularly true for an issue such as maternal mortality, which should be seen not only as a medical problem and lack of access to good quality of care, but as a social and political issue. The author reflects on how health systems and political leaders have failed to value women's health, and how they could instead prioritize women's health needs through effective policy interventions and resource allocation.

Power, Suffering, and the Struggle for Dignity provides the reader with a strong evidence base demonstrating that suffering is a matter of injustice and not simply the result of fate or divine will. She shows how applying a human rights framework can enable us to shift our thinking and expand our understanding of harmful cultural practices so that we can challenge power relations, especially in such a contested field as sexual and reproductive health and rights. Yamin provides us with examples of successful remedies that have the potential to provide redress and an end to violations of fundamental human rights and dignity caused by extreme poverty and inequality affecting people's health in practice. She describes

how rights-based strategies developed through policy reform programs, law reform, litigation, and social mobilization have the potential to effect social change, while offering alternatives to address pervasive discrimination in health care settings in specific local contexts. Through these concrete examples, she illuminates how human rights are not just abstract principles, but can be materialized through transparent political decision-making processes, judicial decisions, political participation, structural changes, and resource allocations.

Yamin is a global leader in this emerging and evolving field of health rights that challenges conventional public health interventions and proposes new rights-based strategies for social movements as the way to achieve social change. The uniqueness of this book comes from her personal testimonies and reflections as a passionate advocate, which provide a rich narrative of her experiences where she has lived and worked. This close look at the reality in which people live when they are deprived of basic human rights makes us understand why social determinants of health, human rights, non-discrimination, gender equality, social justice, and dignity are inseparable concepts.

BOOK REVIEW

Advancing Global Health and Human Rights in the Neoliberal Era

GILLIAN MACNAUGHTON

Global Health, Human Rights and the Challenge of Neoliberal Policies

Audrey R. Chapman, published by Cambridge University Press, 2016

In her latest book, *Global Health, Human Rights and the Challenge of Neoliberal Policies*, distinguished public health and human rights expert Audrey Chapman presents an in-depth examination of the conflicts between neoliberalism, the dominant economic policy framework in the world today, and the international human right to health, an ethical and legal commitment of all members of the United Nations. The book is remarkable for offering both an accessible account and a deep critical analysis of the impacts of current market-based approaches to health care and the social determinants of health. Reflecting a broad and deep knowledge of public health and human rights law and policy, Chapman carefully builds her argument step-by-step, taking the reader from the evolution of the normative framework for the right to health through a sequence of domestic and international policies that directly challenge the realization of this right. Scholars, policy makers, activists, and anyone concerned with public health, human rights, and the well-being of people in the new millennium should read this book.

In chapter one, Chapman presents the right to health as “an emergent human right.” By this she means that health and health care have been recognized relatively recently as human rights in domestic and international instruments, that the right to health has gradually been accepted over time as a “legitimate” human right, and that interpretation and conceptualization of the content of the right and the related obligations is progressing steadily. Nonetheless, implementation of the right to health has been challenged in the last three decades by the global dominance of the neoliberal paradigm. This theme of the right to health as an emergent human right confronted by a hostile policy framework backed up by powerful players informs the text from cover to cover. In this light, Chapman reveals the myriad ways that neoliberal economic and social policies favor the wealthy and powerful, while disadvantaging—literally leaving to suffer

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Competing interests: None declared.

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and die—those most in need of health care and the social determinants of health.

The emerging normative content of the right to health—the foundation on which Chapman builds her argument—is set forth in chapter two, “Evaluating Interpretations of the Right to Health.” Chapman draws on article 12 of the International Covenant on Economic, Social and Cultural Rights, which recognizes the right of everyone to the enjoyment of the right to health, as well as the state obligations stemming from that right. She then relies on General Comment No. 14 of the Committee on Economic, Social and Cultural Rights, which elaborates on the content of article 12. Chapman was, in fact, one of the experts who took part in the discussions leading up to issuance of the general comment in 2000. Viewing the right to health as an emergent right, she believes, like the committee, that the content of the right evolves with developments in human rights (such as a gender perspective), health challenges (such as HIV/AIDS), advances in epidemiological research (such as the importance of preventative strategies), and even changes in the use of language over the past fifty years (such as the change from “industrial hygiene” to “healthy workplaces”). Thus, while relying on article 12 (adopted in 1966) and General Comment No. 14 (adopted in 2000), Chapman questions some of the key concepts in the general comment, such as the minimum core content of the right to health, more fully develops the notion of a collective right to health, and presents an expanded list of areas in need of further conceptualization. Indeed, throughout the book, Chapman explains the accepted norms, presents the current controversies, and then weighs in on the debates.

Chapter 3, “Health and Human Rights in the Neoliberal Era”, frames the conflict that is the crux of the book. In this chapter, Chapman describes and juxtaposes the post-World War II welfare state, based on ideals of social citizenship, solidarity, and human rights, with the neoliberal state dominant over the last three decades, based on the ideal of the market as the fundamental organizing principle for economic and social life. In light of this compari-

son, Chapman explains the normative dissonance of neoliberal and human rights-based approaches, concluding that the two ideologies are fundamentally incompatible. With respect to health, she maintains:

A human rights approach rests on a conception of health and health care as social or public goods of special importance that are designed to benefit the whole population. In contrast, neoliberalism tends to promote the view of health care as a commodity whose price, availability, and distribution, like other consumer goods, should be left to the marketplace.¹

The commodification of health care, Chapman explains, transforms health care into a consumer good—like a candy bar or a television—and the relationship of health care provider and patient into a mere commercial transaction. The rationale for market-based approaches to health and health care is that competition will make the system more efficient and thus improve well-being. Chapman, however, discusses a wealth of research that demonstrates to the contrary that market-based approaches lead to greater inequality, reduced access, institutional corruption, and a host of other ills that result in weakened health systems and poorer health at an overall greater cost.

In chapter 4, “Private Sector Provision, Health, and Human Rights,” Chapman focuses on privatization, one tenet of neoliberalism. International human rights law is neutral, in principle, with regard to the type of economic system a state pursues, provided that it is consistent with democracy and the realization of human rights.² Nonetheless, several human rights treaty bodies have expressed concern over the privatization of health care and have explicitly put states on notice that they remain accountable for the right to health and health care in the private sector. In this light, Chapman argues that privatization has a detrimental impact on the right to health. As she explains, “Privatized health care affects both the values on which effective realization of health rights depend and the institutional capacity of the government to implement a right to health approach.”³ First, she contends that pri-

vatization challenges the ideals of social solidarity necessary to realizing the right to health and may also result in unequal, tiered health care systems providing different levels of health care based on income. Additionally, ensuring accountability—a core human rights principle—is more complex for private or mixed health care services, as it requires regulation, licensure, and monitoring of a wide range of personnel, facilities, goods, and services. As private health care providers and insurers often have incentives to reduce expenses to increase profits, accessible mechanisms for monitoring and accountability are serious concerns. Privatization also results in fragmented health care systems, which complicate efforts to develop and implement national health plans. “Importantly, data do not support claims often made by private sector advocates that private health sector institutions are more efficient, accountable, or effective than public sector institutions.”⁴ In the end, Chapman calls for the human rights community to pay greater attention to research on the impacts of private provision and financing of health care on the realization of the right to health.

Chapter 5, “Globalization, Health, and Human Rights,” paints a bleak picture in which the global economic system promotes “market fundamentalism and a form of super capitalism” that “reorders social and political priorities away from social welfare.”⁵ As Chapman describes it, the World Bank imposes policy conditions on loans, including reduced public spending and user fees for health care and the underlying determinants of health, which negatively affect economic and social rights, especially for the poor. The World Trade Organization is authorized to impose sanctions for violations of international trade agreements, often preventing governments from protecting their people against transnational corporations. And transnational corporations wield tremendous economic power that often exceeds the influence of states that host them. Even the unprecedented rise in international aid to health has been detrimental in some respects, as it has promoted disease-specific vertical interventions and has fragmented and weakened

health systems in recipient countries. In this global neoliberal environment, it is difficult for states to engage in people-centered, human rights-based policymaking, and human rights mechanisms simply do not have the power and influence of the World Trade Organization to impose trade sanctions and the World Bank to deny loans. Further, the advice offered by international human rights mechanisms to overcome conflicts between trade and human rights has not been widely adopted. Chapman concludes that “the hope for the future is that human rights will inspire more effective civil society efforts to counter the deleterious impacts of globalization on health.”⁶

Next, in chapter 6, “Achieving Improved Access to Medicines,” Chapman provides an in-depth analysis of the impact of neoliberal policies on the right to medicines as a component of the right to health. Here, Chapman details the complexities of the conflict between the right of access to medicines (as defined in international human rights law) and the intellectual property regimes operating in domestic and international spheres. In particular, the chapter focuses on the World Trade Organization’s Agreement on Trade-Related Aspects of Intellectual Property (TRIPS) and TRIPS-Plus agreements, pointing out the detrimental roles played by the pharmaceutical industry and the United States in ensuring that essential medicines remain beyond the reach of two billion people around the globe. The chapter also refutes the argument that intellectual property laws serve an important role in providing incentives for drug research and development, explaining that pharmaceutical companies consequently focus on developing drugs that are the most profitable rather than those that address the greatest health needs of the population. On a more optimistic note, Chapman points to several alternatives that would provide incentives to develop medicines that are needed in low-income countries, as well as examples where the human rights community has been successful in mobilizing people to pressure governments into improving policies on access to medicines. The chapter concludes with an explicit list of recommended policy reforms to

counter the neoliberal approach to development and provision of medicines, beginning with the adoption of an explicit human rights framework for law and policymaking on access to medicines.

Chapter 7, “The Social Determinants of Health, Health Equity, and Human Rights,” argues that the realization of the right to health will require greater attention to, and investment in, the social determinants of health. In this chapter, Chapman compares the work of the Commission on the Social Determinants of Health (CSDH) with that of the human rights community on the right to health, demonstrating numerous ways in which collaboration between the two communities could improve progress toward realizing the right to health. In particular, she notes that the CSDH rejected, against the advice of the CSDH secretariat, the use of the human rights framework in its report, resulting in a substantially less persuasive rationale for the importance of empowerment, participation, and voice, as well as diminishing the potential role of human rights in holding governments accountable for implementing the many recommendations in the report. On the other hand, Chapman also argues that the human rights community has much work to do on the social determinants of health, including engaging more consistently with research from social medicine and social epidemiology, giving greater emphasis to the collective dimensions of the right to health, adopting a more expansive and substantive conception of equality, and challenging the inequitable distribution of power, money, and resources. She concludes that her recommended menu of changes “would require a fundamental reorientation of the health and human rights field.”⁷

The final chapter of the book, “Right to Health Perspectives on Universal Health Coverage,” examines what Chapman calls “[o]ne of the most hopeful global health policy developments in recent years.”⁸ Indeed, from a human rights perspective, the growing interest in and commitment to universal health coverage (UHC) is a welcome development. Most notably, the new health goal in the 2030 Agenda for Sustainable Development includes the target to “achieve universal health

coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines.”⁹ Chapman goes as far as to say that “UHC can be considered to be an expression of the right to health.”¹⁰ Nonetheless, she notes, not all paths to UHC are consistent with human rights. In particular, the expansion of health care through private for-profit providers and insurers, favored in the neoliberal paradigm, is ill-suited to ensuring health care coverage for underserved populations or improving their health outcomes. In view of this conflict, Chapman sets out a framework of right-to-health requirements for UHC. Her detailed comparative analysis of health care systems across countries explains and illustrates a human rights-based approach to UHC, discussing features such as health care financing schemes and benefit packages, as well as implementation of the core human rights principles of participation and accountability. The chapter makes a major contribution to the burgeoning new scholarship on pathways to UHC with its recommendations for embedding these pathways in the ethical and legal obligations of the right to health.

Over the past several years, a small group of human rights scholars has addressed the conflict of neoliberalism with economic and social rights generally and the right to health in particular.¹¹ Yet this is the first monograph to carry out an in-depth analysis of the multiple ways in which neoliberal policies contradict government obligations to respect, protect, and fulfill economic and social rights generally and the right to health specifically. The book draws on examples from around the world to illustrate the adverse impacts of a wide array of neoliberal policies, examining the implications of marketization, commercialization, and privatization in high-, middle-, and low-income contexts. Global in reach, the book also incorporates research from a wide range of academic disciplines, from public health and social policy to domestic and international law. In short, Chapman provides a global, interdisciplinary, and comprehensive examination of the impact of international

and domestic neoliberal policies on health care, the social determinants of health, and, ultimately, the realization of the right to health for all.

The international human right to health is now recognized around the world—except, as Chapman highlights, notably in the United States. However, the legal obligations for the right to health, including health care and the social determinants of health, are compromised by the globally dominant neoliberal policy framework. Chapman details the multiple ways in which governments have implemented neoliberal policies—including privatization, marketization, and commercialization of health care and social determinants of health—consistent with business interests in the global North, at the expense of the enjoyment of the right to health in both developed and developing countries. In light of the conflicts between neoliberal policies and the right to health, Chapman challenges the health and human rights communities to collaborate more fully in efforts to reject market-centered approaches to health policy and engage a people-centered, human rights-based approach, grounded in social epidemiology and social medicine. Her rich exploration of the subject matter reflects her multi-decade scholarship on the right to health and human rights-based approaches to health, and a deep understanding of the challenges that neoliberal policies pose for the realization of this emergent right. Specialists and non-specialists alike will find this book to be a comprehensive evaluation of the potential of the right to health—in view of the challenges of the neoliberal paradigm—to bring about healthier and more just societies in the new millennium.

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LETTER TO THE EDITOR

Lessons from Jonathan Mann: The Ten Commandments on Multidrug-Resistant TB

MICHAEL KIRBY

I welcome the latest issue of the *Health and Human Rights Journal* with a Special Section on Tuberculosis (TB) and the Right to Health. TB is indeed a major challenge to global health. It is one of the most serious impediments to the attainment of the new Sustainable Development Goals (SDGs) that recognise the interdependence of health and development. SDG 3 aims to “attain healthy lives and well-being for all”. As most papers in the Special Issue acknowledged, the statistics are alarming: in 2013 alone, there were approximately nine million cases of TB and 1.5 million deaths resulting from the disease. This means that many people are being left behind so that inclusive and equitable development is not being realised.

The special section drew attention to the extent of multidrug-resistant TB (MDR-TB) and the estimation that 5% of cases of TB worldwide are MDR-TB, that many people with MDR-TB remain undiagnosed. Many of the world’s health systems do not have the capacity to detect and treat MDR-TB. It is a problem that has led UN Secretary-General Ban Ki-moon to establish a High Level Panel on Access to Essential Medicines. He stated,

The availability of health technologies is essential for the achievement of SDG 3. Many of these technologies remain unavailable or inaccessible, such as those needed to treat hepatitis C and HIV, as well as some non-communicable and rare diseases... The [HLP] will comprise eminent leaders from the public and commercial worlds, [be] tasked with making recommendations for how the future of health technologies innovation can be balanced with access for all, so that no one is left behind in the pursuit of a healthy and productive life.¹

In the specific context of TB and MDR-TB, this special issue demonstrated that treatment remains problematic. Most of the people who are ultimately diagnosed as suffering from MDR-TB are extremely poor. Indeed, their poverty has resulted in inadequate or incomplete medical advice. Although there are many and growing numbers faced with this predicament, their poverty is discouraging to the investment of capital designed to find more effective and less expensive cures. New pharmaceutical products, produced by the

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Competing interests: None declared.

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private sector, tend to concentrate on conditions prevalent in middle to higher income countries. There are many neglected diseases. It was, in part, to address this problem as well that the Secretary-General created the High Level Panel.

I have been appointed to serve on the new Panel. Its first meeting took place in New York in late 2015 immediately prior to the “TB, Human Rights and the Law” judicial workshop in New Delhi, India organized by the International Human Rights Clinic at the University of Chicago Law School (UChicago IHR Clinic) and conducted jointly with the All India Institute of Medical Sciences (AIIMS). I attended this workshop, which I reported to the UNDP and the HLP. I first promulgated the following Ten Commandments at this workshop. I also attended a subsequent “TB, Human Rights and the Law” judicial workshop in Nairobi, Kenya co-organized by the UChicago IHR Clinic, KELIN and the Stop TB Partnership. Many of the themes arising at these workshops also featured in the Special Section in the Journal. At the second conference, many of the Ten Commandments were put into practice, including the participation and active engagement with people with TB and survivors. This experience vindicated the wisdom of the Commandments. They are not only right in principle. They improve outcomes.

The Ten Commandments

1. *Empirical Foundation*

It is essential for those who are seeking to establish effective policy for the response to such an epidemic to secure the soundest possible empirical foundations for their decisions. Epidemiological, legal and social decision-making must be founded on a thorough knowledge of the nature of the epidemic, its causes, modes of transmission and trends. These rather than assumptions, prejudice, fear or hype must be for the foundation for all laws and policy. This first lesson was taught to the international community in the earliest days of the HIV and AIDS epidemic by the late Jonathan Mann. It constitutes his vital legacy for contemporary epidemiology, law and social policy. Our duty now is to

extrapolate from our experience with HIV and to spread this message into urgent new health crises, including TB and MDR-TB.

2. *Human Rights Paradox*

Secondly, it is necessary, as in the response to HIV, to address the TB epidemic (especially MDR-TB) in a paradoxical manner. This requires overcoming the ineffective hostile, punitive approach to people living with the condition. It is necessary to adopt a human rights respecting approach to the condition to secure some hope of dealing with it effectively. Guidance is available concerning a human rights approach to TB.² Adopting this approach is in the interests not only of those infected but also of those who are unaffected and governments and institutions that wish to establish an effective strategy for prevention, containment and treatment.

3. *Participatory Approach*

As in the HIV epidemic, it is essential, in responding to the problem of TB, to engage with and involve persons living with TB. This must be done upfront, from the outset and with proper respect and interaction with such persons. In fact, the design of policies should grow out of the experience and demands of such persons. Conferences and workshops should not speak of and to people living with TB alone. They should speak with them and always listen to their voices.

4. *No Time to Lose*

As in the early days of the HIV epidemic, the data placed before the workshop in Delhi and in the papers in the Special Section, frequently stated that there is “no time to lose” in addressing the issues of TB and especially MDR-TB in India and elsewhere. The problem has moved beyond the need for further generalised conferences. The focus of all such meetings and discussions should be the development and follow up of plans for action to address the epidemic quickly and effectively.

5. *Engaging Vulnerable Groups*

It is essential for an effective strategy of dealing

with TB and MDR-TB to engage with groups that are most vulnerable to infection. Those groups have already been identified. Without limiting them, they include:

- Prisoners and detainees
- Children and disadvantageous environments
- People living with HIV
- Healthcare workers
- Hospital treatment officers
- Indigenous peoples
- Particular ethnic groups
- People suffering poor nutrition, lack of adequate housing and basic needs.

6. *International Engagement*

It is essential to avoid reinventing the wheel of responses. Close attention should be paid to engaging with international bodies concerned with the issues of TB, MDR-TB and access to therapy. Engagement with the international community should include: WHO, UNDP, The Global Fund against AIDS, Tuberculosis and Malaria, the STOP TB Partnership, and the Secretary-General's HLP.

7. *Identify Large and Small Strategies*

It is important to identify the large contours of the challenge presented by MDR-TB and TB generally. Some particular strategies may be comparatively straightforward, such as the etiquette of coughing and public spitting. However, other strategies will require nationwide and international initiatives.

8. *Addressing the Triage*

It will be important to face up to the problem of the triage in this as in other instances of disease control and public expenditure. Although to loved ones a human life is priceless, realities oblige governments and health administrators to face the obligation of choosing immediate and long-term strategies most likely to help the greatest number to the greatest degree. Making such decisions can be

difficult, painful and controversial. In a democracy, it is desirable that the choices should be publicly ventilated and that those who make them should be accountable, ultimately through the democratic political process. They should not be unaccountable, secret or unknown. The consequences of attempts to make them thus were revealed in the case of the neglect and indifference to patients in Ekaterinburg.

9. *Pro Bono Lawyers*

It is important to acknowledge the significant and continuing role in human rights and epidemics of pro bono lawyers. This is as much true in the case of TB as of HIV. The work of the AIDS Law Project now (Section 27) in South Africa illustrates the successes that can be achieved. So is the work of Lawyers Collective HIV/AIDS Unit, India, of KELIN in Kenya, and of civil society action from Russia, Kenya and India.

10. *Media Engagement*

The final commandment is that good will and good hopes are not good enough for effective strategies to deal with TB generally and MDR-TB in particular. To raise public knowledge is an obligation when faced with a challenge like this. That can only be done by engagement with the media. Where wrongs (even if only of omission) are occurring, it is essential to raise awareness. That means engaging with the media. This includes newspapers (especially in a country like India); television; cable news; international news outlets; social media; specialist and expert journals. Doing good things in private, cloaked in secrecy, is never going to change public knowledge and promote effective action. Of course, there are dangers in media engagement. They include trivialisation, error, sensationalising topics and creating celebrities. However, only by raising the issue of TB and especially MDR-TB, will political and professional pressure arise. Only then will public funds be deployed. Only then will action be taken to reverse indifference. Only with publicity will the tide of inactivity be turned. Those who are working in this field must become better

at engaging with the media. In the end, it is also good for the relevance of the universities and institutions that are involved. But most of all it brings hope, prevention, and treatment to the aid of people living with TB and especially MDR-TB.

We should spread these Ten Commandments. And in our lives, we should henceforth act accordingly.

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LETTER TO THE EDITOR

Moving the Debate Forward in Right to Health Litigation

OCTAVIO LUIZ MOTTA FERRAZ

The debate on the judicialization of social and economic rights in general, and the right to health in particular, has been beset by polarization between pro- and anti-judicialization supporters and lack of empirical data to allow an impartial analysis of the consequences of that growing phenomenon. The type of empirical study carried out by Biehl, Socal, and Amon, entitled “The judicialization of health and the quest for state accountability: Evidence from 1,262 lawsuits for access to medicines in southern Brazil” and published recently in *Health and Human Rights* (Volume 18, Issue 1, June 2016), is therefore a highly commendable contribution to the debate.¹

As the authors appropriately put it: “The judicialization of the right to health in Brazil is not a single phenomenon, and failing to acknowledge regional differences and attempting to fit all data into one singular narrative may be contributing to a biased interpretation of the nature of judicialization, and limiting the understanding of its drivers, consequences, and implications at local levels.”

Their study, based on a sizable amount of relevant empirical data on the Brazilian state of Rio Grande do Sul, will certainly help to shed light on the still incomplete and fragmentary picture of the judicialization of health in Brazil.

It is important, however, to avoid the temptation to incur the very problems that the authors warn against, that is, to stretch the significance of their findings beyond their appropriate reach and repudiate too quickly the findings of other studies.

I offer the following comments in the spirit of a contribution to move the debate forward.

Myths?

The myths about the judicialization of health in Brazil, according to the authors, are four. Judicialization is driven by urban elites and is not available to the poor (myth 1); is driven by private attorneys specializing in health-related lawsuits and physicians seeking to promote high-cost treatment (myth 2); is mostly used to access high-cost treatments and off-formulary drugs (myth 3); and disrupts health policy making and bypasses administrative procedures designed for appropriate, efficient, and equitable access to medicines (myth 4).

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Competing interests: None declared.

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In my view, none of these positions can be properly qualified as myths (“widely held and false beliefs”).² They are certainly not widely held. There are many, including, importantly, most judges of the country, but also lawyers, scholars, activists, and journalists who actually see judicialization as a positive and much-needed practice with very little, if any, negative consequences.³

Moreover, those who are critical of judicialization ground their conclusions on rather plausible concerns backed by empirical studies conducted in different regions of Brazil at the municipal, state, and federal levels.⁴ Perhaps all these studies are flawed and their conclusions therefore false, but the authors’ data on a single state in Brazil, however important Rio Grande do Sul may be, is not sufficient to challenge these conclusions.⁵

It is also important to avoid oversimplification of the views qualified as myths. Many of the studies cited do not claim that litigation is unavailable to the poor or never driven by state attorneys rather than private lawyers. What many claim, plausibly and based on empirical evidence not directly challenged by the authors, is that at the federal level, and in several cities and states, there does seem to be a social gradient in right to health litigation. In other words, it is easier for the better off—not necessarily the richest, but nonetheless individuals who cannot be described in any sense as poor—to access the courts and demand the right to health.⁶

Rather than challenge myths, what Biehl, Socal, and Amon do is reveal important new empirical data from Rio Grande do Sul that adds an interesting perspective for further reflection on the judicialization of health in Brazil.

Limitations of their data

Their main, and bold, claim is that judicialization “largely serves the disadvantaged [“low-income plaintiffs including the very poor” at page 210] who turn to the courts to secure a wide range of medicines, more than half of which are on government formularies and should be available in government health centers.” (at page 216) They see in Rio Grande do Sul, therefore, “a process of judicialization from

below.” (at page 216)

If this claim is correct, it would not disprove, as already stressed, the studies carried out in other places that found a prevalence of litigants represented by private lawyers, living in places of low socioeconomic exclusion and claiming expensive medicines not included in government formularies. But it would certainly make of Rio Grande do Sul an example of what we could regard as a more benign, legitimate, and progressive type of judicialization.

But the claim seems stronger than the data warrants. As to the socioeconomic profile of litigants, studies in other states have used multiple indicators such as indexes of social vulnerability, the human development index (HDI), and even direct data on a claimant’s income, as well as indirect indicators such as type of legal representation (private lawyers versus state attorneys) and type of health service used (private versus public) to build a plausible picture of who litigates.

The authors’ study would have benefited from using some combination of these indicators, instead of relying solely on type of legal representation. The fact that 57% of claims in their sample are filed by the Public Defensory (PD), which “provides free legal assistance to people classified as low-income (defined as earning three times the national minimum wage or less)” proves only that litigation is not restricted to the richest, but not that it is accessible to the very poor, not even to low-income plaintiffs.

This is because the PD threshold of “low-income” of three times the national minimum wage is rather high, amounting currently to R\$2.640,00 (around US\$760 per month), that is, much higher than the average income in Rio Grande do Sul (R\$1.435,00, US\$420)⁷, and almost 35 times higher than the extreme poverty threshold in Brazil (R\$77,00, US\$22).⁸

Without direct data on a claimant’s income, or other stronger indicators such HDI, it is unfortunately impossible to know if the poor and the poorest are really benefiting from litigation despite all known obstacles they usually face to access justice.⁹

A similar difficulty affects the authors’ conclusion that the majority of the drugs claimed (56%) “are on government formularies and should be

available in government health centers.” The mere fact that the active principle of the drug is on government formularies is not sufficient evidence that the lawsuit is a result of policy failure. Some lawsuits request brand name medicines whose generics are available in the official lists. A good example is acetylsalicylic acid (“Aspirin,” “ASA”) that is part of the official list but is one of the most frequently litigated drugs in the authors’ sample. In the state of São Paulo, where it also generates significant litigation, a more detailed study showed that 1,725 lawsuits in 2014 requested 22 different brand names or presentations of ASA to the ones offered in the public system.¹⁰ Offering a generic version of a drug can be hardly regarded as an obvious policy failure.

There are also lawsuits brought by patients who have private insurance and use the public system exclusively to access expensive drugs not covered in their insurance policies (such as some cancer drugs) that the public system offers in principle only to patients being treated in the system.

These examples show, again, that without more detailed data and analysis, the mere percentage of on-formulary drugs featuring in litigation gives us only limited indication of the possible causes of judicialization.

The way forward?

The brief discussion above shows, I hope, how Biehl, Socal, and Amon’s important contribution could elicit even further and deeper insights into the intricate phenomenon of the judicialization of health in Brazil through more detailed investigation of the socioeconomic profile of health litigants and the reasons so many go to court.

It also reaffirms, in my view, what I called the Brazilian model of right to health litigation, a model that needs to change, even if it may at times lead to positive outcomes of the sort that may have occurred in the case of Rio Grande do Sul. As I argued:

The defining features of this “Brazilian model” are related to the profile of claims (the litigator and the object of litigation) and the outcome of litigation (the rates of success and failure of litigation). As to the profile of claims, the vast majority of right-

to-health cases in Brazil to date have been led by individual claimants and have concerned the provision of curative medical treatment (mostly medicines) which can be enjoyed individually. As to the outcome of litigation, the Brazilian model is characterized by an extremely high success rate for claimants. This model, I suggest, is encouraged by the dominant interpretation of the right to health by the Brazilian judiciary. As noted above, most Brazilian judges and courts, including the STF, see the right to health as an individual entitlement to the satisfaction of all one’s health needs with the most advanced treatment available, irrespective of costs.¹¹

I did not include in the model, deliberately, the socioeconomic profile of litigants, but rather that of the claims: individualized claims for curative treatment (mostly medicines). There may well be, I repeat, cases from several jurisdictions in which these individualized claims do not favor the urban elites represented by private lawyers forcing the state to provide them with off-formulary high-cost treatment. But in many cases they do, as several studies conducted so far have shown.

The challenge ahead for all who support the right to health is to change the Brazilian model so that it prevents this pernicious kind of judicialization and encourages a more positive kind to flourish. A further challenge is to develop more specific criteria to identify what should be counted as positive judicialization, which is much harder and more controversial than identifying the opposite, pernicious kind.

We seem to agree on the general aim: the effective protection of the right to health of the whole population involves an equitable distribution of the necessarily limited resources of the public health system. There is much less agreement, however, on what specific health goods and benefits an equitable distribution would entail. It is towards this consensus that we should, in my view, work. Beyond determining the socioeconomic profile of claimants and the status of the goods and services they claim (on or off-formulary), we need to develop criteria to assess whether these goods and services ought to be part of the coverage in the public health system or not as a corollary of the right to health. This is no

easy task, but it starts with understanding the need for prioritization and a focus on the needs of the worse-off (especially where health inequalities are high, like in Brazil). The current Brazilian model, and that would also include Rio Grande do Sul, is not the most conducive to delivering that task.¹²

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5. Although the authors do qualify the reach of their claims by adding "at least in Rio Grande do Sul" to some of their conclusions, in many other parts of the article they don't, and the general argument of challenging "myths" seems to be meant to apply much more broadly.
6. It is interesting to note that some of the authors themselves have raised these concerns in an earlier article. J. Biehl et al, "Judicialisation of the right to health in Brazil," *The Lancet*, 373/9682, pp. 2182-2184.
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8. It should also be noted that the PD threshold is often not

followed in right to health cases, especially those claiming drugs that are costly, when public defenders tend to relax the admissibility criteria for accepting to represent the litigant.

9. The indicator related to occupation offers little help. If one adds the retired (32%) who can be in any socio-economic bracket to the 26.9% of the sample where no information is available, one has 58.9% of the sample where it is not possible to draw any conclusion about socio-economic status from the sample. The authors remind us that "Brazilian law also allows for individuals without the ability to pay to request that the state pay legal fees. In 91% of the lawsuits (n=1,147) plaintiffs requested this support." Yet as anyone familiar with litigation in Brazil knows, it is extremely easy to get legal fees exempted in Brazil, sufficing to make a self-declaration which is rarely challenged or rejected in court.

10. Secretariat of Health of the State of Sao Paulo, May 2015 (on file with author).

11. See note 5.

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RESPONSE TO *LETTER TO THE EDITOR*

On the Heterogeneity and Politics of the Judicialization of Health in Brazil

JOÃO BIEHL, MARIANA P. SOCAL, AND JOSEPH J. AMON

In response to our article, “The judicialization of health and the quest for state accountability,” in which we examine a systematic sample of 1,262 lawsuits seeking access to medicines in the southern Brazilian state of Rio Grande do Sul, Octavio Luiz Motta Ferraz raises three concerns:

1. that our use of the term “myth” to describe the popular narrative in Brazil about the “judicialization of health” is inaccurate;
2. that our data has limitations, and particularly that our claim that judicialization “largely serves the disadvantaged” in Rio Grande do Sul is not fully warranted; and
3. that our findings “reaffirm” his view of what he calls “the Brazilian model of right to health litigation.”¹

These are curious points.

Rather than simply “widely held and false beliefs,” a myth, and more specifically, a political myth, can be understood as “an ideologically marked narrative which purports to give a true account of...political events and which is accepted as valid in its essentials by a social group.”² Our use of the term “myth” was in this sense, an understanding that Ferraz seems to endorse in the first sentence of his letter, stating that the debate on the judicialization of the right to health has not been grounded in evidence but “beset” by polarization and a “lack of empirical data.” The objective of our study was to expand the empirical base and to challenge—provocatively—polarized positions and the idea that there is a single countrywide “truth” about this complex and heterogeneous phenomenon.

Our article is one of the many outcomes of a larger multi-methods research effort.³ The study examines a representative sample of all medicine-related lawsuits in Rio Grande do Sul, the state that accounts for

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Competing interests: None declared.

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about half of all cases of health litigation in Brazil.⁴ Information on patient-litigant demographics, their legal representation, medical diagnoses, the type and frequency of medicines requested, the legal arguments employed, and the immediate ruling of judges were collected directly from the lawsuits and reviewed and excerpted by research assistants trained in law and pharmacy. While a more detailed understanding of patient-litigants' socioeconomic status would be desirable, we stand by our finding, based upon multiple variables, that in Rio Grande do Sul, "the majority of patient-litigants are in fact poor and older individuals who do not live in major metropolitan areas and who depend on the state to provide their legal representation."

Our finding stands in marked contrast to politicians' statements that judicialization is "Robin Hood in reverse" and a "triumph" of the "haves over the have-nots," and to Ferraz's own claim that "a majority of right-to-health litigants come from social groups that are already considerably advantaged in terms of all socioeconomic indicators, including health conditions."⁵ This claim, based upon a small number of studies circumscribed to a few geographic areas, has been generalized by many public officials and scholars and taken to represent a nationwide pattern.

We struggle to understand how Ferraz can approvingly acknowledge our explicit recognition of the geographic limits of our study, quoting from our discussion that the "judicialization of the right to health in Brazil is not a single phenomenon," while he speaks of a singular "Brazilian model" that "needs to change." Although there may be characteristics of the phenomenon that are similar across geographic areas in Brazil, we do not believe that there is a single "Brazilian model" of judicialization, nor that it is helpful to the scholarly discussion and political debate—in Brazil, or globally—to create a caricature of "positive" versus "pernicious" forms of judicialization.⁶

Moreover, we find problematic Ferraz's call "to develop criteria to assess ... [which] goods and services ought to be part of the coverage in the public health system." While it was not the focus of our article, it is fair to say that we support a right to health

that covers all Brazilians and the principles of participation and equity—in terms of both access to health and access to justice. By contrast, Ferraz seems to be advocating for a technocratic and top-down approach that could circumscribe the object and scope of the country's constitutional right to health.

Just as our findings demonstrate that judicialization in Rio Grande do Sul is a widespread mechanism accessible even to the poor, they also indicate that patients are using the judiciary to obtain treatments that should be available through existing governmental policies.⁷ From this perspective, judicialization exposes the precariousness of public infrastructures while also being a mechanism for state accountability and a potential driver of advancements towards quality universal health coverage and transparent and participatory priority-setting.

In the last paragraph of our discussion, we state: "At the very least, the heterogeneity of right-to-health litigation across the Brazilian states indicates the need for a more nuanced and in-depth analysis of its drivers and implications at local levels." While Ferraz, in his conclusion, seems to fold our results seamlessly into his pre-determined model, we hope that our systematic and comprehensive examination of the judicialization of health in Rio Grande do Sul contributes to less mythologizing and encourages others to more objectively assess the impacts of judicialization on both individuals and policies, as well as its possible role in driving social and political change at local, regional, and national levels. We welcome the attention of Ferraz and other scholars, policy-makers and activists to this task and look forward to further debate and discussion.

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