

Beyond the numbers: using rights-based perspectives to enhance antiretroviral treatment scale-up

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Human rights analyses, concepts, and in particular rhetoric have played a consistent role in the global response to HIV for over two decades. Despite the longstanding recognition of human rights as essential to an effective response, recent global guidance, particularly with respect to the implementation of antiretroviral treatment (ART) scale-up efforts, falls short of meaningfully incorporating human rights norms and concepts. Applying human rights to ART scale-up draws attention to who is gaining access to ART, how they are gaining access, and over what period of time, not just how many people gain access. Deliberate consideration of the human rights principles of the interdependence of rights (including attention to the legal and policy environment), participation, non-discrimination, accountability, and key aspects of the right to health can help to identify and overcome some of the challenges to increasing and sustaining access to treatment and needed services, as well as to promote accountability and transparency for what is done and how it is done. Whereas a need remains to document evidence of the ways in which a lack of attention to human rights negatively influences the long-term outcomes of scale-up programmes, this paper focuses on the positive role human rights can play in ART scale-up efforts, and offers suggestions for research and action moving forward. © 2007 Wolters Kluwer Health | Lippincott Williams & Wilkins

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Introduction

Human rights analyses, concepts, and in particular rhetoric, have played a consistent role in the global response to HIV for over two decades. Many international institutions such as the Joint United Nations Programme on HIV/AIDS (UNAIDS), bilateral cooperation agencies and international non-governmental organizations justified their approaches and based their work on a recognition of the links between human rights and HIV [1]. Whereas organizations incorporated human rights into their activities in very different ways, it appeared that all generally assumed that to do so was a good thing. In the past few years, however, political and technical guidance in the HIV field has been moving away from engagement with human rights, particularly, but not exclusively, in the area of antiretroviral treatment (ART) scale-up. At this time of unprecedented financial and political commitment to addressing HIV, it is vital that the global response not lose sight of the critical benefits that the promotion and

protection of human rights can offer to HIV prevention, treatment, care, and support efforts.

Beyond the moral and legal imperative to pay attention to human rights, rights have provided the basis for more effective policies and programmes. In addition to questions of good governance and equity in the utilization of resources, rights have highlighted the responsibility of all sectors of government for addressing issues of concern, thereby helping to promote responses to HIV that reach beyond the health sector. Furthermore, attention to rights has been shown to help those engaged in policy and programme work better to recognize and address economic, social, cultural and political factors that may influence the impact of the HIV interventions they wish to put in place, including the participation of affected communities. Finally, attention to rights has helped shed light on the processes of programme implementation as well as the immediate outcomes, thus highlighting unintended potential negative effects [2].

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The next section provides an introduction to global ART scale-up initiatives and how human rights are, or are not, included. Following this, to contextualize this discussion, a brief overview is provided of how the inclusion of rights in HIV efforts has decreased in recent years. Attention is then given as to why this trend should be reversed, highlighting some of the different ways in which rights may be used to impact ART scale-up positively. Focusing on the integration of human rights into treatment scale-up policies and programmes, the advantages of systematic attention to rights are explored.

Human rights in global treatment scale-up efforts

The clearest demonstration of the international community's continued interest in incorporating human rights into HIV efforts is the 2001 Declaration of Commitment on HIV/AIDS from the UN General Assembly Special Session on HIV/AIDS, which contains an entire section devoted to human rights [3]. Rights are, however, addressed as distinct from the rest of the document, thus when it comes to areas such as AIDS treatment none of the indicators used to measure progress include human rights considerations [4].

The '3 by 5' initiative, launched in 2003 by the World Health Organization (WHO) and UNAIDS, in part the result of sound human rights advocacy [5], was billed as a step towards ensuring that AIDS treatment was universally accessible to all who needed it as a 'human right' [6]. Although rights existed in the rhetoric, however, they were marginal to its approach. For example, even as 'Treatment and Human Rights' was listed as one of the guiding principles of the 3 by 5 strategy, no specific guidance was provided as to how human rights could be implemented. Human rights were not integrated into any of the main pillars of the WHO strategy, and were entirely absent from the lists of 'Key WHO Actions and Deliverables'. Finally, aside from a brief reference to gender equality, marginalized groups, and the participation of affected communities, rights were also absent from the list of 'Strategies' and 'Action Steps' [6]. In 2005, the global health community established the aim of coming 'as close as possible to the goal of universal access to treatment by 2010 for all those who need it' [7]. Universal access moved beyond '3 by 5' in its integration of prevention with treatment and care and its focus on national level targets. A review of the numerous documents intended to provide guidance to countries on universal access reveals that although human rights are considered important principles in establishing targets (for example, human rights, equity, and the participation of people living with HIV are all listed as significant), guidance on how to integrate them concretely into

target-setting is lacking [8]. In addition, the indicators suggested for measuring progress fail fully to capture whether human rights concerns have been integrated into the implementation of universal access efforts, and it is unclear who should be held accountable for any successes or failures in doing so [9].

To promote the creation of the enabling environment necessary to achieve universal access, UNAIDS has joined with others in 'Uniting for HIV Prevention' [10]. Within this initiative, the need to ensure that human rights are promoted, protected, and respected is recognized as an 'essential policy action' [10]. In particular, the 'Practical Guidelines for Intensifying HIV Prevention' provide some commendably specific suggestions for what should be done in order to integrate human rights into HIV prevention efforts (for example, specifying the importance of zero tolerance for gender-based violence, and calling for legal reform that protects the rights of people living with HIV and vulnerable populations) [11]. These 'practical guidelines' present an example of the specificity that is possible regarding the integration of human rights into HIV guidance, but nothing similar exists in relation to treatment scale-up.

Why this sidelining of rights?

An overview of the broader landscape in which HIV and human rights work is situated, with particular focus on how attention to rights is decreasing, may help contextualize current debates specific to human rights in ART scale-up.

In general, the United Nations and other international agencies appear to be shying away from the use of human rights language and concepts in their work [12]. It is likely that much of this is related to pressure from certain governments, in particular the United States government and its allies [13]. Over the past decade, human rights issues that used to be prominently displayed on the websites of international organizations appear to have been removed entirely, or moved so as to be less obvious (Annotated Bibliography on Rights-Based Approaches, Program on International Health and Human Rights, Harvard School of Public Health, unpublished). Even in cases in which organizations continue to use human rights language openly, the funding for 'human rights' activities is limited. For example, despite a clear commitment to human rights on the part of the Executive Director in 2006, only 2.3% of the UNAIDS budget was designated for human rights activities [14].

This sidelining of rights has been accompanied, in recent years, by an expansion in the use of the language of stigma and discrimination. A number of global documents reduce attention to human rights in HIV to 'combating

stigma and discrimination', but addressing stigma and discrimination is not synonymous with addressing human rights [15,16]. Recent UNAIDS 'human rights-related' recommendations, based on regional consultations on the main obstacles to ART access, focus on eliminating gender inequality and stigma, and provide no concrete advice on actions that must be taken to ensure human rights protection [18]. Although these issues do fit together, governments have specific obligations in the realm of human rights that go beyond the need to combat stigma and discrimination, for which accountability is lost when human rights language and concepts are not used.

More justifiably, perhaps, critics argue that solid evidence of the value of integrating human rights into HIV programming is lacking. Even as the language of 'HIV and human rights' and 'rights-based approaches to HIV' remains omnipresent, a gap in understanding exists as to what role human rights legitimately play in HIV efforts. Possible explanations for this include: insufficient documentation of the evidence of what successfully integrating human rights into HIV programming means; internal organizational and donor agendas driving many documented efforts leading to the presentation of information in ways that are not easily transferable; organizations' adoption of the language of rights to justify their work as it was politically useful to do so without actually clarifying what is rights-based about their efforts; or limited operational guidance as to how human rights are best integrated into HIV Programmes. Even the *International Guidelines on HIV/AIDS and Human Rights*, widely cited by international organizations and civil society groups, do not provide sufficient guidance as to the implementation of human rights in ART scale-up efforts [18]. Whatever the reason, not only does a problematical lack of clarity persist, but it is true that when rights have been integrated into HIV programming, there has been insufficient documentation of the positive difference this has made.

Table 1. Methods of advocacy and legal accountability.

Using human rights in advocacy	Using human rights in legal accountability mechanisms
<p>Human rights groups and HIV activists document human rights abuses related to HIV and call attention to them. This helps to exert pressure on those responsible to change their existing practices. At times, the strict legal interpretation of human rights can be secondary to the use of human rights language as a means of drawing attention to an issue. Advocacy in these cases is used to mobilize community action on an issue of concern, and to change attitudes, actions, policies, or laws for the betterment of individuals affected by that issue.</p> <p>One example of using human rights in advocacy is Médecins Sans Frontières' Campaign for Access to Essential Medicines. This global campaign was born from frustration that in many countries essential medicines are unavailable, inaccessible or of unacceptable quality to the majority of the population, especially the poorest [20]. The campaign has used human rights language to push to lower the prices of medicines and to overcome other barriers to access.</p>	<p>By ratifying international human rights treaties, governments assume legal obligations towards their populations to promote and protect human rights in the context of HIV. Legal mechanisms also provide means of redress for individuals who have been negatively impacted as a result of violations of human rights. Furthermore, they provide standards to hold governments accountable for their human rights obligations and can be the basis for advocacy efforts to effect change.</p> <p>One well-known use of the law for ensuring access to HIV treatment was when committed activists in South Africa succeeded in forcing their government to be legally responsible for making nevirapine available to all pregnant women who needed it for the prevention of mother-to-child transmission of HIV [21].</p>

Human rights in the response to HIV

In the late 1980s, the call for human rights was explicitly embodied in the first WHO global response to AIDS [19]. As an intergovernmental organization, WHO's framing of this public health strategy in human rights terms allowed it to become anchored in international law, thereby helping to make governments and intergovernmental organizations publicly accountable for their actions in the context of HIV.

Over time, human rights came to be used in a variety of ways to facilitate the achievement of HIV-related policy and programmatic goals. In the context of ART scale-up, these uses can be broadly categorized as those relating to advocacy, the use of national and international legal accountability mechanisms, and the integration of rights into programming efforts. Rights-based programming refers to the conscious integration of human rights principles into all aspects of programming, from design through implementation, monitoring, and evaluation. Table 1 outlines the methods of advocacy and legal accountability, whereas the role of human rights in programming efforts is discussed in further detail in the following sections [20,21].

Applying human rights to antiretroviral treatment scale-up

The value of human rights for ART scale-up policies and programmes has not yet been sufficiently taken into account. Integrating key principles into ART scale-up programmes can improve the long-term success and effectiveness of these programmes partly by focusing on the processes by which activities are carried out. Paying attention to human rights may thus improve not only the uptake of treatment, but sustained access and adherence over time.

Moving beyond numbers

Unfortunately, within AIDS treatment efforts, there has been an inordinate focus on numbers, more specifically the number of individuals being placed on ART. The assumption is that programmes can be determined to be successful simply because they result in more individuals being put on ART. This is exacerbated by donors who generally require results within short time frames that show growth in the numbers of individuals receiving testing or treatment. The US government, for example, in reporting on the success of the President's Emergency Plan for AIDS Relief, states that a 'minimum of 30 million people will need to be tested to meet PEPFAR's goals' [22]. Therefore, human rights with their emphasis not only on numbers but on who the people are behind the numbers, and if they are able to sustain access over time, raise uncomfortable questions.

Although it is vitally important that numerical targets exist, when taken on their own they are insufficient. Applying human rights principles to ART scale-up draws attention to who is gaining access to ART (and who is not), how they are gaining access, and over what time period, not just how many. We must ask, for example, whether access to treatment is accompanied by appropriate care and support? How are issues of adherence addressed? Are human rights considerations raised in relation to food, education and non-discrimination taken into account or is the focus simply on medical issues around adherence?

Universal access with its focus on national level targets is in keeping with the human rights concept that governments must set benchmarks and targets to take progressive steps towards their full realization, and regularly assess progress towards meeting these targets; complete and immediate fulfillment of all human rights obligations is impossible. A human rights perspective, however, also points out that it is insufficient to look at aggregate numbers to assess progress; the process of how numbers are reached, as well as the breakdown of the numbers themselves, are equally important.

A successful treatment programme must not only increase the number of individuals on ART, but also ensure that these individuals remain on treatment over time. Indicators, therefore, should include not only how many individuals have been put on ART in a given time period, but also whether they received good quality counselling, whether they are satisfied with the quality of care, whether they received proper information on medications and dosage, and so forth.

Unfortunately, existing universal access indicators do not reveal how scale-up activities are being carried out, or whether attention to human rights considerations is being ensured. Instead they provide us with numbers of testing sites or programmes, with the unstated assumption that if

these numbers are high, the country is more likely to achieve its scale-up goals. Although critically important, indicators such as 'number of voluntary counselling and testing sites in country that serve defined most-at-risk populations' [8] do not reveal the extent to which these services are available, accessible, acceptable and of high quality for affected populations. Even when targets have been set for 'equitable access to key prevention, treatment, care and support interventions for defined vulnerable populations' [8] this does not tell us how the targets were set, or how the participation of vulnerable populations was ensured in the setting of these targets.

In order to monitor the process of scale-up efforts, the challenge is to find novel approaches for analysing existing indicators, to refine current indicators in such a way that they can gather the type of information that is not currently being collected, and perhaps even to propose areas of research to create a better understanding of the success or failure of ART scale-up efforts, and the contribution of human rights to these outcomes.

Integrating human rights principles into antiretroviral treatment scale-up

A review of strategies used by United Nations agencies and other international organizations identified the human rights principles most relevant to HIV programming to be: the interdependence of rights (including attention to the broad legal and policy environment); participation; non-discrimination; accountability [23]; and key aspects of the right to health: accessibility, acceptability, availability, and quality [24]. The value of each of these principles to ART scale-up efforts is briefly explored below in an effort to begin to illuminate a research agenda that brings human rights considerations into play.

Interdependence

In many countries, despite good treatment policies, the broader legal and policy context threatens effective ART scale-up (e.g. spousal and parental consent laws, and criminalization of sex work, drug use, and same-sex sexual activity, all of which limit the usage of HIV-related services by individuals who fear being arrested, reported, or not being able to access services). In 2006, UNAIDS noted that in many countries 'legal, social and cultural barriers are undermining access to interventions for those most at risk of HIV infection and most affected by AIDS' [18]. Furthermore, these legal barriers exist in addition to the already difficult situations that surround HIV services in some countries, where fears of breaches of confidentiality or stigma keep individuals away (see Box 1). Homophobia, gender inequalities, stigma and discrimination against individuals in vulnerable groups have all been identified as major barriers to accessing services [17].

Box 1. Testing as a gateway to treatment

Knowing one's HIV status is important but, from both public health and human rights perspectives, there is an obligation to ensure that if testing is performed, access to prevention, care, support, and treatment is not only a theory but a duly implemented practice. Scaling up antiretroviral treatment requires scaling up HIV testing, but if testing occurs without proper consent, counselling, or with little regard to confidentiality, over time, fewer individuals are likely to desire to be tested, and thus fewer will access treatment. Whereas the push to scale-up HIV testing is to be commended, certain safeguards should be in place, and specific attention should be given to monitoring the effects of different forms of provider initiated testing and counselling in health facilities on informed decision-making, appropriate pre and post-test counselling, patient confidentiality, referrals, and access to appropriate services, all of which are critical components of appropriate HIV testing.

Overall, an analysis of the broader legal and policy context within which ART scale-up work takes place can help to identify crucial obstacles that need to be addressed both in the health sector and beyond. The interdependence of rights means that the fulfilment of one right often depends upon the fulfilment of others, so, for example, in order to ensure that AIDS treatment efforts are successful, a range of rights must be considered, including not only health and information but also non-discrimination, participation, housing, food, transportation, and education. Explicit attention to the relationships between rights in ART scale-up work can bring to light the obligations of various sectors of government beyond only Ministries of Health.

Participation

Recognition of the importance of the participation of individuals living with HIV in designing and implementing the policies and programmes that concern them resulted in the creation of the now widely recognized 'Greater involvement of people living with AIDS (GIPA) principle' [25]. Nonetheless, evidence suggests that decisions about how and where ART is delivered are generally being made without the engagement of affected communities [26]. Despite clear statements that national targets should be set in a transparent, accountable and participatory manner, this is not always the case. A recent publication concluded that: '[i]n many countries, the process of involving the community sector (in national target setting) has encountered significant barriers – in relation to attitudes, methods, resources, and logistics, amongst others... These, in particular, have affected the involvement of people living with HIV and key populations' [27]. The assurance of full participation is vital to the long-term success of ART programmes, and,

despite resource or other constraints, consideration is needed to ensure that mechanisms exist to overcome these barriers.

Non-discrimination

If equal numbers of women and men are accessing treatment but treatment is primarily being provided to women in the context of pregnancy and childbirth, a focus on non-discrimination draws attention to which women in this context are accessing treatment and which are not, what efforts are being made to reach women outside the context of pregnancy and childbirth, and, even for those women who initially access treatment in this context, what efforts are made to ensure their sustained access over time. Discrimination in the form of laws, policies, programmes and practice can heighten vulnerability resulting in individuals engaging in risky behaviors (such as injecting drugs with dirty needles) because they are not provided with the needed information and services, as well as because they are deterred from accessing services even if these are available. Attention to non-discrimination can be used to highlight the myriad interactions between gender, race, sexuality and other forms of discrimination as they impact on access to ART [28]. In drawing attention to vulnerable populations, human rights principles underscore the need for disaggregated data so as to ensure that services are reaching all segments of the population that need them, rather than just those easiest to reach or politically strong.

Accountability

Current practice in many countries appears to be that decisions on how ART will be priced and distributed within a population are not transparent. Investigation is needed as to the extent to which accountability, or lack thereof, impacts upon the long-term success of treatment programmes. In several Latin American countries, governments have been taken to court by people living with HIV claiming their right to have access to ART; almost without exception the courts have ordered the governments to provide ART free of charge [29]. In Venezuela, for example, court decisions have repeatedly upheld national and provincial legal provisions that ensure access to ART and, according to recent estimates, 60–80% of people living with HIV now receive treatment through the public sector [29]. Accountability requires that there be this type of follow-up to such legal decisions, that governments and other actors be monitored for compliance with their obligations related to ART provision, and that, if duties are not met, the possibility of recourse exists.

Ensuring that treatment is available, accessible, acceptable, and of high quality

Strengthening health systems is understood to be an integral part of the response to HIV. This is particularly important in the light of WHO's current push to decentralize ART administration and to 'task shift' in such

a way that allows lower level health professionals to prescribe ART [30]. As these changes take place, efforts are needed to determine the extent to which this impacts on the availability, accessibility, acceptability and quality of services for all sectors of a population, including those most difficult to reach. Even if ART is scaled up, unless individuals can reach the services, afford to access them and feel comfortable using them, uptake and long-term engagement will remain limited. By systematically focusing on what it takes to make services truly available, accessible, and acceptable, and by paying specific attention to the principles of interdependence, participation, non-discrimination, and accountability, human rights may contribute to ensuring acceptable processes by which the scale-up of ART can be achieved.

Conclusion

The move away from human rights discussed earlier in this paper threatens the benefits that attention to human rights concerns has brought to the HIV response to date. Attention to human rights in ART scale-up can 'help the development of more effective means to identify the challenges and overcome the barriers to increasing access to needed services, and to enable people to make informed and appropriate choices' [9]. In addition to the benefits that attention to human rights can bring, however, skepticism towards human rights must also be addressed. We must continue to clarify what 'human rights' and 'rights-based approaches' to ART scale-up are, we must document the benefits of incorporating human rights into ART scale-up, and we must gather 'good practices' on the application of human rights not only to ART but also to HIV prevention, treatment, care, and support more broadly. We must also continue to ascertain the quality of the indicators used to monitor the success of programmes and policies, including human rights considerations. Only accurate monitoring and evaluation will provide us with a true understanding of how effective HIV treatment programmes are, whether consciously integrating human rights principles or not. With ever more resources pouring into the fight against HIV, attention to human rights in the context of ART scale-up is increasingly necessary. The lack of attention to human rights is an omission that, if ignored, may be too high a price to pay.

Conflicts of interest: None.

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