Human rights in an era of treatment as prevention[1]

Respect for and protection of human rights have long been recognized as being essential to an effective response to HIV. Since the outset of the epidemic, fear, ignorance and prejudice have fuelled stigma and discrimination against people living with or perceived to be living with or at risk of HIV. The fear of discrimination associated with the disease has been a significant deterrent against accessing testing and treatment. Therefore, human rights protections for people living with HIV (PHAs) or at risk of HIV are critical, not only to protect their rights but also for the realization of universal access to testing, treatment and care.

International commitment to universal access has been evidenced by the adoption of the *Declaration of Commitment on HIV/AIDS* by United Nations member states in 2001 — goals that would provide HIV care, treatment and prevention services to all who need them.[2] The World Health Organization's (WHO) 3 by 5 Initiative[3] operationalized this goal, which was reaffirmed by the 2006[4] and 2011[5] *Political Declaration on HIV/AIDS*, and unanimously adopted by the member states. At the same time, the Declarations recognized that combating HIV/AIDS was a pre-condition to achieving many of the Millennium Development Goals (MDGs).[6]

To complement these political commitments, funding mechanisms such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) were created. Much has been accomplished: since that first agreement in 2001, more than five million people have gained access to antiretroviral therapy (ART), AIDS-related deaths and hospitalizations have decreased and rates of new infections have been reduced in many countries.[7]

Despite these accomplishments, there is still an unacceptably large gap between the number of people on treatment and the number of those in need of it. With the revision by WHO of its guidelines on the initiation of ART, there are nine million people who should be on treatment, but who are not.[8] The likelihood of reducing this gap has been severely undermined by worrying signs that the donor commitment needed to sustain and increase the current momentum in the fight against HIV/AIDS is waning in the current climate of competing global priorities and a worldwide economic crisis.[9]

This situation has been exacerbated by the recent cancellation of the Global Fund's round 11 funding due to low funding levels, including from a number of unfulfilled pledges as well as lower-than-anticipated contributions. Instead, the Global Fund will provide for a "transitional funding mechanism," whereby countries known to be facing a disruption of programs for HIV, tuberculosis and malaria before 2013 will be offered a chance to apply for funding to cover their most essential needs.

For HIV, this funding can cover medicines for people already on treatment, but does not provide for HIV treatment initiation for new patients. This will have particularly devastating consequences for many of the countries in sub-Saharan Africa that are heavily reliant on donor funding for the provision of treatment.[10]

However, a lack of resources is not the only impediment to reaching universal access goals. Unacceptably high levels of stigma and discrimination and human rights violations against PHAs and key populations, as well as widespread criminalization of key populations and of HIV transmission have often acted as insurmountable barriers to accessing HIV prevention and treatment services. Although it has long been recognized that human rights abuses have an adverse impact on public health, particularly in the context of HIV, funding for interventions that promote a human rights-based response to HIV and address stigma and discrimination and human rights violations against PLHIV and key populations remains limited.

> As the benefits of treatment as prevention have been confirmed, funding for the global HIV response has diminished.

It is sadly paradoxical that dwindling financial support for the HIV response in general and, more specifically, for human rights-based programs is the reality at a time when the benefits of treatment as prevention have been confirmed by the HIV Prevention Trials Network (HPTN) 052 trial, which released its results in May 2011. HPTN 052 compared clinical outcomes and rates of transmission within predominantly heterosexual couples in which one partner is HIV-positive and the other is HIV-negative (i.e., sero-discordant couples). HIV-positive individuals with CD4 cell counts between 350 and 550 were randomly assigned to receive immediate ART or to delay initiation until clinical or laboratory guidelines (usually, CD4 cell count below 250) were met.

The randomized comparison between immediate and delayed ART initiation was stopped four years ahead of schedule due to evidence of overwhelming benefit. Specifically, the trial found that immediate initiation of ART in HIV-positive individuals with CD4 counts between 350 and 550 reduced the transmission risk to the HIV-negative partner by 96 percent.[11]

The significance of these results is illustrated by the modelling of the impact of a new strategic investment framework for the global HIV response that is based on existing evidence of what works in HIV prevention, treatment, care and support, and shows that meeting treatment targets based on current guidelines would avert 12.2 million new infections and 7.4 million AIDS-related deaths between 2011 and 2020.[12]

Human rights concerns

Initial debate on this issue prior to the release of the HPTN 052 results, sparked by the publication in *The Lancet* of a mathematical model for universal voluntary HIV testing with immediate ART as a strategy for elimination of HIV transmission,[13] was punctuated by concerns raised by activists about the human rights implications of the operationalization of this model.

In addition to questions raised about several of the assumptions on which the model was based, concern was expressed about the failure of the strategy to consider the human rights aspects and implications of its implementation, particularly given that any universal testing and treatment model raises fears of coercion and other violations of individual human rights. In particular, there were concerns about the failure of the strategy to address the existing legal, social and economic barriers to uptake of testing and treatment, particularly among women and other vulnerable groups, or the range of human rights violations that fuel HIV vulnerability and impede access to treatment and testing in the first place.[14]

Any strategy for treatment as prevention has to be subject to the same concerns. In addition, some activists have questioned the value of any discussion regarding potential implementation of treatment as prevention strategies while governments, particularly in the global south, remain unable to meet current universal access targets, and in a climate where funding cuts are threatening their ability to initiate treatment for new patients who need it.[15]

Therefore, if HIV prevention and the use of ART as either prevention or treatment are to succeed, it is critical that we interrogate the human rights violations that act as barriers to accessing testing and treatment services as well as those that render people more vulnerable to HIV in the first place, and that we articulate the human rights elements of treatment and prevention interventions. Failure to do so will undermine the potential benefits of treatment as prevention and ensure that universal access targets are not met.

Since the outset of the epidemic, stigma and discrimination — on the basis of real or perceived HIV status, often fuelled by fear, ignorance and prejudice — have been pervasive and widespread. They take various forms and occur within different sectors of society. They include verbal and physical abuse of people infected and affected by HIV and AIDS, denial of employment to PHAs and denial of health care and social services to them.[16]

In a study conducted in 2009 in Namibia and Swaziland, respondents in both countries identified health care facilities as the place at which they most often experienced stigma and discrimination.[17] It is frequently directed at those who already face inequality, prejudice and marginalization, such as those with limited power, people living in poverty and people engaging in criminalized behaviours.[18] PHAs continue to face high levels of stigma and discrimination and other human rights violations in their daily lives. Not only do they undermine the basic human rights and dignity of those affected, they also create barriers to access to HIV-related prevention, treatment, care and support services.

> Failure to articulate the human rights elements of treatment interventions will undrermine the potential benefits of treatment as prevention.

People with limited ability to enforce their basic human rights are at higher risk of HIV exposure.[19] In Southern Africa, where women continue to face gender inequality entrenched in law and practice, as well as high levels of sexual assault and violence, evidence shows that women, particularly young women, are consistently more likely to be infected with HIV than men.[20]

The ability of PHAs and of key populations to enforce their human rights — and, more particularly, their right to health and to prevention and treatment services — is compromised both by stigma and discrimination faced at the hands of families, communities, employers, law enforcement officers and health care workers, as well as by legal and policy frameworks that fail to protect their human rights, criminalize their behaviour and, in many cases, actually violate their human rights.

Role of HIV-specific laws

In Africa, the response to HIV and AIDS has seen the proliferation of an epidemic of HIV-specific laws that have proved to be a double-edged sword. In an attempt to address stigma and discrimination on the basis of real or perceived HIV status, these laws contain provisions that outlaw discrimination. At the same time, however, they often provide for mandatory HIV-testing for members of key populations (e.g., sex workers), pregnant women or those wishing to marry. Additionally, a number of HIV laws provide for mandatory disclosure of a person's HIV status to others, such as a spouse or sexual partner.

Mandatory HIV testing and forced disclosure not only violate basic human rights, such as the rights to privacy and freedom and security of the person, but also have broader public health implications for the HIV response. They target and increase stigmatization against key populations at higher risk of HIV exposure and discourage people from accessing HIV-related prevention, treatment, care and support.

Many of these laws also criminalize HIV transmission and exposure. In several instances, the wording of these provisions is sufficiently broad to criminalize the transmission of HIV from mother to baby *in utero* even in instances where the mother has no access to prevention of mother-to-child-transmission services. There is limited evidence that criminalization of HIV helps to reduce the spread of HIV; evidence suggests it instead reinforces the concept of PHAs as potential "criminals" from whom society needs protection, increases stigma and fear, and deters people from accessing HIV-related health care.[21]

In addition to HIV-specific laws that deter access to testing and treatment, the majority of countries in sub-Saharan Africa have laws that criminalize key populations such as sex workers, men who have sex with men (MSM) and injection drug users (IDUs). The existence of such laws makes it increasingly difficult to reach these groups with HIV services. The legislation reflects and deepens their societal stigmatization and exposes them to discrimination, violence, harassment and abuse, including at the hands of law-enforcement officers.

Key populations express reluctance to use existing HIV-related health care services for fear of victimization and discrimination. This further increases their vulnerability to HIV. Criminal laws prohibiting sex between men create additional barriers to condom distribution in prisons, placing prisoners at higher risk of HIV exposure. Consequently, enabling legal environments need to be created to protect the rights of all populations and to support their access to HIV-related health care services.[22]

For their part, sex workers are often marginalized and face multiple barriers to accessing the health and social services they need, such as screening and treatment for sexually transmitted infections (STIs); HIV testing and tailored counselling; post-exposure prophylaxis after rape; access to male and female condoms; ART; and mental health support and substance abuse treatment. Health care workers with negative or prejudiced attitudes towards sex workers further restrict access to services and drive them away from treatment and support. In Malawi, human rights non-governmental organizations (NGOs) are taking up a case against the police after 14 sex workers were arrested, forcibly tested for HIV and their HIV results reported in the media.[23]

Mandatory HIV testing increases stigmatization and discourages people from accessing HIV-related prevention and treatment.

In most sub-Saharan African countries, drug policy continues to focus on supply reduction and criminalization of users despite the fact that IDUs are at high risk of HIV infection. Since 2008, few additional countries have adopted key harm reduction interventions as part of their HIV response. Mauritius remains the only country with established needle and syringe programs (NSPs). Opioid substitution therapy (OST) is also available in Mauritius and, to a lesser extent, in South Africa, Senegal and Kenya.[24]

Although Mauritius sets an example in the region in terms of NSPs and OST, it has yet to amend its drug laws that make it an offence to possess drug-injecting paraphernalia, and the successful operation of the NSPs is often compromised by the presence of law-enforcement officers at or near needle exchange sites, which obviously deters uptake of these critical prevention services.[25]

The problem goes beyond laws that deter access to testing and, thus, to treatment. Mass testing campaigns that are likely to be a precursor to treatment as prevention strategies can also be problematic. Lesotho's "Know Your Status" campaign offered an HIV test to everyone above the age of 12 years. The testing was intended to be voluntary and confidential, and was offered by trained community counsellors in homes. A study of this model revealed flaws in the training of the community counsellors and, consequently, in their ability to deliver adequate pre-test counselling and to ensure that testing was conducted with informed consent and guarantees of confidentiality.[26]

Similar concerns have been expressed about the mass testing campaign in South Africa in 2011. The Treatment Action Campaign (TAC), an HIV lobby group in the country, has received anecdotal reports of coercive testing in KwaZulu–Natal and Eastern Cape.[27]

If universal access targets are to be met and the promise of treatment as prevention is to be realized, more focus must be placed on and more investment made in programs that place human rights at the centre of the response to HIV and promote the establishment and strengthening of an enabling legal, policy and social environment in which all people have access to prevention and treatment services without discrimination. It is not a question of human rights or public health. Although there may be specific human rights considerations that are of particular relevance to treatment as prevention strategies — such as concerns about the risks of compromised consent and confidentiality that accompany mass testing campaigns — the issues essentially remain the same.

The common agenda for all is earlier and successful uptake of HIV testing and counselling, and earlier, timely and successful access to HIV treatment as part of broader efforts to reach universal access to HIV prevention, treatment, care and support. This can only be achieved if human rights concerns are seriously addressed in national and international responses to HIV, including by funding and implementing a series of programs to reduce discrimination and other human rights abuses and increase access to justice in national HIV responses.

The fears of those who are disempowered and still afraid to take an HIV test or to initiate HIV treatment have to be addressed by investing in dignified health systems and protection from the harmful social and legal effects of one's health status being known. Indeed, the expanded value of ART only heightens the need to find successful approaches to improved HIV service delivery *and* human rights protection.

Programmatic interventions to create and strengthen an enabling legal, policy and social environment in which the human rights of PHAs and key populations are protected — and thereby in which access to and uptake of HIV prevention and treatment services is improved — must be funded and implemented. These interventions take both a "top-down" and a "bottom-up" approach: working from the top in terms of addressing laws that act as barriers to accessing prevention and treatment as well as with law enforcers; and from the bottom within communities with a view to strengthening their capacity to access justice and claim their rights where they have been infringed.

> The expanded value of ART only heightens the need to find successful approaches to improved human rights protection.

Community empowerment

Community empowerment and mobilization to know and claim one's rights is key to this effort. "Know your rights and laws" campaigns that empower those affected by HIV are essential in terms of gender equality; non-discrimination on basis of HIV and other social status; elimination of violence against women; protection of the rights of the child; and access to HIV prevention, treatment, care and support. PHAs and members of vulnerable and marginalized groups must be provided with services in the form of legal aid, community paralegals, dispute-resolution (including working with traditional leaders) and strategic litigation to enable them to enforce their rights where these have been denied or infringed.

Interventions aimed at community empowerment are of particular importance. Among the most significant advances that have been made regarding HIV are in countries where networks of PHAs and HIV legal and human rights groups have mobilized around "know your rights and laws" campaigns and undertaken legal advocacy, including strategic litigation. At the individual level, such mobilization results in individual empowerment in terms of being better able to negotiate safe sex, avoid violence, go through HIV testing and counselling and disclose status, and be treatment-literate and -compliant. This is particularly the case where mobilization and capacity-building include training on rights and laws for providers of key services (e.g., health care providers) concerning non-discrimination, informed consent and confidentiality, and sensitizing police on the rights of PHAs and members of key populations.

Strategies for treatment as prevention raise specific human rights considerations, including the potential for erosion of the rights to autonomy and privacy through the implementation of scaled-up testing and the administering of treatment as prevention for the "public good." In order to address these, it is suggested that the implementation of treatment as prevention strategies be guided by the following principles:

- Guidelines determining the optimal time to start ART must be based on what is best for the individual patient. PHAs should not be expected to begin therapy for the primary purpose of preventing HIV transmission. The primary purpose of treatment is treatment. Patients should not be compelled to risk earlier development of antiretroviral drug resistance or suffer drug-related side effects unless there is clear evidence that earlier use of ART can be beneficial for the patient in prolonging life and improving the quality of life.
- If resources are limited, decisions about who should receive ART must be based on the need to treat the sickest patients first and not based on perceived opportunities to prevent new infections. The best way to address this is to ensure that all those meeting current treatment guidelines have adequate access to ART and other health care services.
- The choice to use ART remains a personal one. Patients have the right to decide not to take ART.
- The availability of second- and third-line treatment combinations is essential to long-term use of ART. This will be especially important as earlier treatment is considered to maximize both treatment and prevention benefits of ART.[28]

Conclusion

An enabling legal, policy and social environment in which the rights of PHAs and key populations are protected and upheld has always been critical to achieving universal access to HIV treatment and prevention. The potential of treatment as prevention does not and should not alter the fact that everyone, regardless of their HIV status, sexual orientation or other status has the right to the highest attainable state of physical and mental health. For this to be realized, their rights to dignity, autonomy, privacy, information and to be free from discrimination must be respected, protected and upheld.

However, the knowledge that attaining high coverage of ART can also reduce HIV transmission in a given population does highlight the need for dramatic scale-up of HIV testing as a step toward treatment. Nevertheless, if human rights protections are not a central and well-funded part of testing strategies, rapid scale-up of HIV testing can lead to widespread infringements of privacy rights, autonomy and the right to information without adequate diagnosis or linkage to HIV care for those who test positive. This will only drive people away from the very testing and prevention services that this strategy seeks to provide.

Paradoxically, funding is being flat-lined or reduced just as science, medicine and programs are providing the tools for success against HIV.[29] This threatens both the response to HIV and human rights imperatives in the response, and may result in countries having to choose between biomedical programs and programs to create enabling legal and social environments that serve to protect the human rights of those living with or vulnerable to HIV, when both are critical. It is therefore essential that programs to create such enabling environments, which serve to protect the human rights of those living with or vulnerable to HIV, be funded and implemented.

— Michaela Clayton, Lynette Mabote and Felicita Hikuam

Michaela Clayton (michaela@arasa.org.na), Lynette Mabote (lynette@arasa.info) and Felicita Hikuam (felicita@arasa.org.na) are with the AIDS and Rights Alliance for Southern Africa in Windhoek, Namibia.

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