



Human Rights of People with HIV and Aids

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Abstract

HIV continues to spread throughout the world, shadowed by increasing challenges to human rights, at both national and global levels. HIV/AIDS had been explicitly embodied in the first WHO global response to AIDS. This approach was motivated by moral outrage but also by recognition that protection of human rights was a necessary element of worldwide public-health response to emerging epidemic. The key human rights document and the cornerstone of the modern human rights movement is the universal declaration of human rights (UDHR). It is a common aspirational document, by and for governments, about what rights should exist for all people everywhere.

Key words: HIV/AIDS, human rights, challenges

Introduction

HIV continues to spread throughout the world, shadowed by increasing challenges to human rights, at both national and global levels. The virus continues to be marked by discrimination against population groups: those who live on the fringes of society or who are assumed to be at risk of infection because of behaviours, race, ethnicity, sexual orientation, gender, or social characteristics that are stigmatized in a particular society. In most of the world, discrimination also jeopardizes equitable distribution of access to HIV-related goods for prevention and care, including drugs necessary for HIV/AIDS care and the development of vaccines to respond to the specific needs of all populations, in both the North and South. As the number of people living with HIV and with AIDS continues to grow in nations with different economies, social structures, and legal systems, HIV/AIDS-related human rights issues are not only

becoming more apparent, but also becoming increasingly diverse. The 1980s were extremely important in defining some of the connections between HIV/AIDS and human rights. By the end of the decade, the call for human rights and for compassion and solidarity with people living with HIV/AIDS had been explicitly embodied in the first WHO global response to AIDS. This approach was motivated by moral outrage but also by the recognition that protection of human rights was a necessary element of a worldwide public-health response to the emerging epidemic.

The implications of this call were far-reaching. By framing this public health strategy in human rights terms, it became anchored in international law, thereby making governments and intergovernmental organizations publicly accountable for their actions toward people living with HIV/AIDS. The groundbreaking contribution of this era lies in the recognition of the applicability



of international law to HIV/AIDS-and therefore to the ultimate responsibility and accountability of the state under international law for issues relating to health and well-being.

What Are Human Rights?

Human rights are broadly concerned with defining the relationship between individuals and the state. International human rights law dictates that governments should not do things such as torture people, imprison them arbitrarily, or invade their privacy. Governments should, however, ensure that all people in a society have shelter, food, medical care, and basic education. The concept of human rights has a long history, but the modern human rights movement dates back about 50 years to when the promotion of human rights was set out as one of the purposes and principles of the newly created United Nations.

The key human rights document and the cornerstone of the modern human rights movement is the Universal Declaration of Human Rights (UDHR). It is a common aspirational document, by and for governments, about what rights should exist for all people everywhere. The UDHR was adopted by the U.N. General Assembly on December 10, 1948. A number of international human rights treaties exist that further elaborate the rights set out in the UDHR, including:

- the International Covenant on Civil and Political Rights
- the Covenant on Economic, Social, and Cultural Rights
- the Convention on the Elimination of All Forms of Racial Discrimination

- the Convention on the Elimination of All Forms of Discrimination Against Women

- the Convention on the Rights of the Child

Each of these documents lays out legally binding obligations for the governments that sign on to them. Countries that become party to international human rights treaties accept certain procedures and responsibilities, including periodic submission of reports on their compliance with the substantive provisions of the texts to international monitoring bodies.

Health and government responsibility for health in the context of the HIV/AIDS epidemics is codified in these documents in several ways. In almost all of them, the right to the highest attainable standard of physical and mental health appears in some form. Even more importantly, nearly every article of every document has clear implications for health and for HIV/AIDS. Everything from the rights to information and association to the rights to social security or to the benefits of scientific progress and its applications has clear implications for HIV/AIDS and for the work of public health.

The relationship between HIV/AIDS and human rights is highlighted in three areas:

Increased vulnerability: Certain groups are more vulnerable to contracting the HIV virus because they are unable to realize their civil, political, economic, social and cultural rights. For example, individuals who are denied the right to freedom of association and access to information may be precluded from discussing issues related to HIV, participating in AIDS service organizations and self-help groups, and taking other preventive measures to



protect themselves from HIV infection. Women, and particularly young women, are more vulnerable to infection if they lack of access to information, education and services necessary to ensure sexual and reproductive health and prevention of infection. The unequal status of women in the community also means that their capacity to negotiate in the context of sexual activity is severely undermined. People living in poverty often are unable to access HIV care and treatment, including antiretrovirals and other medications for opportunistic infections.

Discrimination and stigma: The rights of people living with HIV often are violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatisation and discrimination may obstruct their access to treatment and may affect their employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from contacting health and social services. The result is that those most needing information, education and counselling will not benefit even where such services are available.

Impedes an effective response: Strategies to address the epidemic are hampered in an environment where human rights are not respected. For example, discrimination against and stigmatization of vulnerable groups such as injecting drug users, sex workers, and men who have sex with men drives these communities underground. This inhibits the ability to reach these populations with prevention efforts, and thus increases their vulnerability to HIV.

Likewise, the failure to provide access to education and information about HIV, or treatment, and care and support services further fuels the AIDS epidemic. These elements are essential components of an effective response to AIDS, which is hampered if these rights are not respected.

Government Responsibilities for Human Rights in the Context of HIV/AIDS

As discussed above, with the applicability of international law to HIV/AIDS, governments are publicly accountable for their actions toward people in the context of HIV/AIDS. Given the reality of violations that continue to occur, it is useful to consider the specific human rights responsibilities of governments. Governments are responsible for not violating rights directly, as well as for ensuring the conditions that enable people to realize their rights as fully as possible. It is understood that, for every human right, governments have responsibilities at three levels:

1. They must respect the right
2. They must protect the right
3. They must fulfil the right.

As an illustration, consider governmental obligations in the context of HIV, using one right--the right to education:

- Respecting the right means that states cannot violate the right directly. This means that the right to education is violated if children are barred from attending school on the basis of their HIV status.

- Protecting the right means a state has to prevent violations of rights by nonstate actors and offer some sort of redress that people know about and have access to if a violation does occur. A state has to



ensure, for example, that religious groups are not successful when they try to stop adolescents from accessing reproductive health education.

- Fulfilling the right means states have to take all appropriate measures-legislative, administrative, budgetary, judicial, and otherwise-toward fulfilling the right. If a state fails to provide essential HIV/AIDS prevention education in enough languages and media to be accessible to everyone in the population, this in and of itself could be understood to be a violation of the right to education.

In most countries, resource and other constraints can render it impossible for a government to fulfil all rights immediately and completely. The mechanisms responsible for monitoring governmental compliance with human rights obligations recognize that, in practical terms, a commitment to the right to basic education will require more than just passing a law. It will require financial resources, trained personnel, facilities, textbooks, and a sustainable infrastructure. Therefore, realization of rights is generally understood as making steady progress toward a goal. This principle of "progressive realization" is fundamental to the achievement of human rights. It is critical for resource-poor countries, which are responsible for striving toward human rights goals to the maximum extent possible; however, it is also important because it imposes an obligation on wealthier countries to engage in international assistance and cooperation.

The following section presents a framework for monitoring government action.

Advocacy and Accountability

Governments are responsible for promoting and protecting both public health and human rights.(19) None of the international human rights treaties specifically mentions HIV or the rights of individuals in the context of HIV/AIDS, yet all the international human rights mechanisms responsible for monitoring government action have expressed their commitment to exploring the implications of HIV/AIDS for governmental obligations. This may be of critical importance for fusing HIV/AIDS and human rights in practical and concrete ways. For example, in the past several years, increasing attention has been paid to HIV/AIDS in government reporting regarding their human rights obligations. Of the six human rights treaty monitoring bodies, the Committee on the Rights of the Child and the Committee on the Elimination of All Forms of Discrimination Against Women have been the most active in both their questions and responses in relation to HIV/AIDS. All the human rights treaty-monitoring bodies have expressed general concern at the increasing rates of HIV infection and its impact on the lives of populations. In their interactions with some countries, these bodies have focused specifically on laws and policies that might increase rates of infection, such as the lack of health care facilities available to adolescents without parental consent. A primary focus has been the need for governments to use a human rights framework to enact strategies for HIV prevention realistically targeted to the needs of affected populations, including providing information and education, ensuring care and support for people living with HIV and with AIDS, and taking steps to reduce the social and economic consequences of the disease.



Human Rights in HIV/AIDS Policy and Program Design

Human rights are governmental obligations toward individuals; because these obligations include the protection of public health, they are relevant to the design, implementation, and evaluation of health policies and programs. Based on these obligations, governments can be understood as legally responsible for instituting policies and programs that can reduce the spread and impact of HIV/AIDS. However the respect, protection, and fulfilment of all human rights--civil, political, economic, social, and cultural--are necessary not only because they are the binding legal obligations of governments but also because they are critical to an effective response. HIV/AIDS policies and programs can be improved by a systematic review of how and to what extent interventions are both respectful of human rights and of benefit to public health.

A Framework for Action

An agenda for action can be created by recognizing the convergence of the three situations in which people live in a world with HIV/AIDS--infected, affected, and vulnerable--and the three levels of government obligations that exist for every right--respect, protect, and fulfill. This approach has the power to bring about the incorporation of human rights promotion and protection into the diversity of responses designed to control the pandemic and mitigate its impact

The Basic Rights of people living with HIV/AIDS

People living with HIV infection and AIDS should have the same basic rights and responsibilities as those which apply to all citizens of the country. They are

not allowed to be separated, isolated or quarantined in prisons, schools, hospitals or anywhere else because of their HIV-positive status.

People with HIV infection or AIDS are entitled to make their own decisions about matters that affect their marriage and having children. Counselling about the consequences of their decisions should be provided.

No person may be tested for HIV infection without his or her consent beforehand.

In all other cases – such as HIV testing for research purposes or when a person’s blood will be screened because he or she is a blood donor – the informed consent of the individual is required legally.

Where an existing blood sample is available, and an emergency situation necessitates testing the source patient’s blood (e.g. when a health care worker has been put at risk because of an accident such as a needle stick injury), HIV testing may be undertaken without informed consent. This can only happen after telling the patient that the test will be performed and assuring them that the results will be confidential.

If an existing blood sample isn’t available for testing in an emergency situation, the patient must give his or her informed consent for blood to be drawn for the HIV test to be done.

Routine testing of a person for HIV infection for the perceived purpose of protecting a health care professional from infection isn’t allowed.

A parent or guardian of a child below the age of consent to medical treatment may give consent to HIV testing of the child.



Informed consent (the person has been made aware of and understands the implications of the test) is compulsory before HIV testing may be carried out.

The person should be free to make his or her own decision about whether to be tested or not, and may in no way be forced into being tested.

Pre-test counselling should occur before an HIV test is undertaken.

Post-test HIV counselling should take place when the person is about to receive their results.

People with HIV and AIDS have the right to confidentiality and privacy about their health and HIV status.

Information about a person's HIV status may not be disclosed to anybody without that person's fully informed consent. After death, the HIV status of the deceased person may not be disclosed to anybody without the consent of his or her family or partner – except when required by law.

People with HIV/AIDS have the same rights to housing, food, social security, medical assistance and welfare as all other members of our society. Medical schemes may not discriminate against any person on the basis of his or her state of health. People have a moral and legal obligation to tell their sex partners if they are HIV positive. Insurance companies may not unfairly refuse to provide an insurance policy to any person solely on the basis of HIV/AIDS status. All people have the right to proper education and full information about HIV and AIDS and how to prevent it.

Conclusion

People living with HIV/AIDS, their friends and relatives, their communities,

national and international policy- and decision makers, health professionals, and the public at large all, to varying degrees, understand the fundamental linkages between HIV/AIDS and human rights. The importance of bringing HIV/AIDS policies and programs in line with international human rights law is generally acknowledged but, unfortunately, rarely carried out in reality. Policymakers, program managers, and service providers must become more comfortable using human rights norms and standards to guide and limit the actions taken by or on behalf of governments in all matters affecting the response to HIV/AIDS. This requires genuine attention to building their capacity to recognize and promote the synergy between health and human rights and to appreciate more fully the potential gains when health interventions are guided by human rights principles. Those involved in HIV/AIDS advocacy must become more familiar with the practicalities of genuinely using international human rights law when they strive to hold governments accountable. For human rights to remain relevant to legal and policy work in HIV/AIDS, the contact between the conceptual work being done on the linkage between HIV/AIDS and human rights and the realities faced by those working in advocacy and in policy and program design must be ongoing; it is the mutually supportive--although occasionally mutually challenging--interaction between these groups that will help keep this work vital and useful.

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