HIV TESTING IN THE ERA OF TREATMENT SCALE UP

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The ways in which global responses to HIV/AIDS have differed from responses to other infectious diseases have been extensively discussed in the literature. Bayer proposed the term “AIDS exceptionalism” to refer to the compromises reached early on in the epidemic between civil liberty proponents and the public health establishment, affecting policy and practice concerning surveillance, HIV testing, and contact investigation and tracing.

The international response to HIV/AIDS was initially largely driven by experience and discussion in the United States — the first and most heavily affected country in the industrialized world. The language of human rights was introduced into HIV/AIDS discourse somewhat later, when the World Health Organization’s Special Programme on AIDS (later the Global Programme on AIDS) was being developed. AIDS exceptionalism and an emphasis on certain human rights aspects of HIV/AIDS became the international norm.

Potential Criticism of AIDS Exceptionalism and “Rights-Based” Approaches

Today, it is legitimate to question whether classic public health approaches were adequately prioritized in the global response to HIV/AIDS, especially in the most heavily affected countries of sub-Saharan Africa where the epidemic’s severity and impact were initially underestimated. During the early years of the epidemic, the human rights and exceptionalist approach focused primarily on the indi-
individual, whereas in sub-Saharan Africa, HIV/AIDS has mostly been a disease affecting families and whole societies. Rights-based language initially prioritized concepts such as privacy and confidentiality, which often seemed too theoretical in the face of African poverty and mounting rates of HIV infection. At the same time, practical aspects of preventing transmission of HIV were under-emphasized. Failure to diagnose HIV infection associated with diseases such as tuberculosis led to sub-optimal care. These and related practices may have resulted in an increase, rather than a decrease, in stigma attached to the illness. Although diagnostic tests have traditionally played a critical role in the management of other infectious diseases, HIV testing for prevention and care was not promoted. The global response to the epidemic was largely determined in the industrialized world, rather than in the most heavily affected countries themselves. Those strongly defending what were termed rights-based approaches tended to cite as successes a focus on preventing discrimination, emphasis on individual dignity, avoidance of extreme and ineffective policies, creation of a supportive environment, and development of community-based advocacy.

Whether the exceptionalist and rights-based approach to HIV/AIDS in Africa has saved or lost lives or has strengthened or weakened the ability of communities to deal effectively with the HIV/AIDS crisis could be the subject of debate. However, medical advances and advocacy for the prevention of mother-to-child transmission (MTCT) of HIV and treatment have rapidly overtaken this discussion, with pragmatism toward the use of newly available resources now a dominant attitude.

The Introduction of Biomedical Interventions

HIV/AIDS in the industrialized world has been fundamentally altered since the introduction of effective antiretroviral (ARV) therapy. This intervention has rendered achievable the virtual elimination of pediatric HIV disease and resulted in substantial reductions in AIDS incidence and mortality. The landscape of HIV/AIDS prevention and care in the developing world has now been changed through
increased resources for prevention and treatment delivered through the Global Fund to Fight AIDS, Tuberculosis and Malaria; the World Health Organization’s 3 by 5 Initiative; and the US President’s Emergency Plan for AIDS Relief. These initiatives have set ambitious targets for the prevention of new infections and the treatment of HIV-infected persons, and similarly challenging objectives have been defined in the Millennium Development Goals.

It was belatedly recognized that if we faced a global emergency concerning lack of treatment access then we were also in the midst of an HIV testing crisis: anti-retroviral drugs cannot be delivered to persons of unknown HIV status, and the majority of HIV-infected persons globally have not been tested. Relying on the traditional model of voluntary counseling and testing (VCT) will not result in adequate numbers of people tested to meet treatment and prevention goals because it is client- rather than provider-initiated and is onerous in time and counseling requirements. The ambitious goals defined by the international community would have been doomed to failure without a change in HIV testing policies and practices so that millions of HIV-infected persons can be rapidly identified and assessed.

Revised HIV Testing Policy and Practice

In mid-2004, UNAIDS and WHO issued revised guidance concerning HIV testing.\(^5\)\(^6\) In keeping with earlier suggestions, four different categories of HIV testing were defined: mandatory, routine, diagnostic, and voluntary counseling and testing.\(^7\) Each category has its specific contexts and requirements. Routine and diagnostic testing are initiated by health care providers rather than by clients themselves and depend on informed right of refusal or the so-called “opt-out” approach.

The terms “opt-in” and “opt-out” HIV testing have engendered confusion. “Opt-out” testing is provider-initiated. Clients or patients receive essential information about HIV and are informed they will be tested unless they refuse — the HIV test being considered like any other medical blood test. Emphasis is greater on post-test than pre-test counseling. “Opt-in” testing is client-initiated. The emphasis of
pre-test counseling is on voluntariness and neutrality of advice — the client may wish to consider the test or not and has to specifically agree or request the test, rather than having to decline it. With “opt-out”, the default is to be tested; with “opt-in”, the default is not to be tested. The reason the “opt-out” approach is being advocated by public health and clinical workers is that it increases test uptake and therefore access to prevention and treatment services. Informed right of refusal constitutes a valid form of informed consent.

Routine testing is recommended for pregnant women for whom prevention advice will depend on their HIV status. Diagnostic testing refers to HIV testing of persons seeking medical care whose symptoms and signs might be attributable to HIV infection. In some circumstances, as for tuberculosis patients or in high prevalence settings, diagnostic testing could be indicated universally for all who present themselves to health facilities.

To assure individual rights and ethical standards when using the opt-out approach, patients must be informed of the benefits of HIV testing and told that testing will be performed unless they refuse; the results of tests must be provided; options for follow-up must be explained; and persons diagnosed with HIV must be counseled about prevention of transmission and disclosure to those exposed.

Conclusions

Unless health care providers follow the revised UN-AIDS/WHO guidance, traditional exceptionalist perspectives risk interfering with poor people’s access to life-saving preventive and therapeutic interventions. Human rights attention could usefully prioritize social and economic concerns such as equity of access to therapy. The imminent diagnosis of millions more HIV-infected people in Africa will raise further complex issues with human rights and ethical implications, including prevention requirements for seropositive persons, partner notification, disclosure, and discordant serostatus within couples.
References
3. Ibid.