SCALING UP HIV TESTING: Ethical Issues

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HIV testing is not an end in itself. It is instead a means to an end, in which the ethically acceptable ends are care and access to treatment for people found to be infected and access to adequate preventive means for those who are uninfected. It is obvious that testing is required in order to know who is eligible for treatment. Critical to the testing process, however, is systematically linking testing with existing or planned treatment or prevention programs. Failure to do so would be to treat the individuals tested “merely as a means,” which would be a violation of the ethical principle of respect for persons.

When individuals consent to undergo HIV testing, and their consent appears to be both voluntary and properly informed, the situation seems to be one in which they are serving their own ends by agreeing to be tested. In principle, that may well be true, but additional conditions have to be met. These include adequate information provided in pretest counseling; full voluntariness of consent to be tested; and accurate understanding and expectations on the part of individuals tested. If these conditions are fulfilled, then individuals are serving their own ends in agreeing to be tested. These conditions are necessary for testing to be ethically sound, but they are not sufficient. The major benefit to individuals’ learning that they are HIV-positive is access to anti-retroviral therapy (ART), if they meet the medical eligibility criteria and if ART is available. Without the likelihood of receiving treatment, however, being informed of an

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hoped-for availability of treatment at some unspecified future time cannot transform that burden into a benefit. Individuals who learn that they are HIV-negative benefit from receiving information about preventing HIV and acquiring adequate means to do so.

There is ample evidence that, “where treatment has been made available, this has led to overwhelming demands for testing and counselling.” The World Health Organization’s 3 by 5 Initiative and the Global Fund to Fight AIDS, Tuberculosis, and Malaria are two international efforts aimed at scaling up prevention and treatment in developing countries. Each provides an excellent opportunity to ensure that scaling up testing in an ethical manner is linked to funds received or promised, and that the process by which this is accomplished is accountable and transparent. In its commitment to scale up treatment and accelerate prevention in the 2004-2005 biennium, WHO pledged to assist countries by providing technical guidance, helping to build capacity for health care providers, and intensifying advocacy efforts to encourage high-level political support, among other activities. In their role of submitting grant proposals to the Global Fund, the national level Country Coordinating Mechanisms (CCMs) can recognize and fulfill an ethical obligation to wed HIV testing to current availability of ART, or require compelling evidence of availability in the near future.

One of the guiding principles of WHO’s 3 by 5 Initiative is equity: “The Initiative will make special efforts to ensure access to anti-retroviral therapy for people who risk exclusion because of economic, social, geographical, or other barriers.” This same principle should apply to scaling up testing to ensure that those plans go hand-in-hand with current programs to scale up treatment. There will always be economic pressures to do what is most cost-effective, but doing so is likely to lead mainly to increased testing of populations that are easy to reach — and possibly, also easily manipulated. Here, as elsewhere, efficiency and cost-effectiveness should not take precedence over adherence to ethical principles and human rights requirements.

The need to provide accurate, comprehensive, and medically sound information and services to individuals tested
and found to be HIV-negative is an equally important ethical requirement. An example illustrating the ways in which ethical concerns may be compromised in this process can be seen in a major initiative launched in 2004, the US President's Emergency Plan for AIDS Relief (PEPFAR). This 5-year, $15 billion program for prevention, treatment, and care in 15 of the countries most affected by HIV/AIDS in Africa and the Caribbean focuses prevention efforts primarily on “abstinence and be faithful,” with the distribution of condoms “as appropriate” being a much more limited component. Condom promotion and distribution is only for “those whose behavior or circumstances place them at risk for transmitting or becoming infected with HIV.” PEPFAR will not promote or provide condoms for sexually active youth, insisting instead on “abstinence-only” programs — an approach to prevention that has been demonstrated in numerous studies to be ineffective. In Vietnam, injecting drug users are the key population at risk; PEPFAR does not support needle or syringe exchange, however, so the preventive means known to be the most effective risk-reduction strategy will not be part of the US-funded program. PEPFAR’s first annual report to the US Congress describes the rapid scale up of activities, including “HIV counseling and testing for individuals and couples who do not know their HIV status.” However, by restricting funding to only those groups and interventions approved by the current administration, the program excludes significant populations often most at risk and those interventions often shown to be most effective. People being tested for HIV under this program therefore receive only the information and guidance on prevention and risk-reduction that support specific ethical and political views, which is not necessarily the most medically efficacious. These practices clearly violate the principles of equity and ethics.

In sum, to be ethically sound, HIV testing must remain voluntary, be accompanied by adequate counseling, and be linked to existing or promised treatment and prevention programs that fulfill the requirements of nondiscrimination, equitable access, and proven efficacy.
References

4. See note 1.
5. See note 2, p. 10.
8. See note 6, p. 19.