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Routine HIV-testing policies

The recommendation by Rennie & Behets in the January 2006 issue¹ urging policy-makers and health workers to reflect on the ethical significance of routine testing policies for people where protection against discrimination and stigma-related violence does not exist is well taken but, in certain ways, overstated.

If the testing policy outpaces our capacity to meet the stipulated or implicit ethical preconditions (strict confidentiality, informed consent, competent pre-test and post-test counselling, ensuring that human rights are protected and that negative consequences of being tested are minimized by appropriate social and institutional support services), they argue, "the claim that new HIV-testing practices have a human rights basis [or that human rights are at the heart of the policy] could fail to reflect the reality".

If this is a correct analysis of the ethics of – using their example – Botswana's routine offer of HIV testing, we must react conscientiously. Either the policy was irresponsibly optimistic from the beginning, and should perhaps be recalled on ethical grounds, or we must revise the stipulated ideal preconditions of the policy in order to take better account of implementation realities. (It could also be viewed as a call to service.)

Beyond the ideal preconditions stipulated in the WHO Policy Statement on ensuring a rights-based approach to routine offers of HIV testing,2 which are suspected to be unevenly present if not occasionally ignored altogether in practice, Rennie & Behets are particularly concerned with the threat to human rights posed by stigma-related and gender-based violence and discrimination. In search of practical moorings and consistency, it should be noted that: (i) voluntary counselling and testing (VCT) is ethically suspect for the same reasons, since the essential factor is informed consent, or genuine voluntariness; (ii) gender-based violence is a problem quite apart from the risk associated with testing; (iii) we are morally

obliged to consider also the human rights of others who are affected by the claimed right not to know; and (iv) the effort to address the human rights-based concerns is ongoing though admittedly imperfect because it is overburdened.

Rennie & Behets also stress the need for rapid testing as well as affordable testing and availability of treatment. Because resource-poor countries are suspected to be unable to ensure social and medical infrastructures adequate for safeguarding the human rights of people seeking services, in which case the testing should not be routinely offered, it is odd to insist on quicker results to tests that they oppose in principle. Though testing should be linked to "accessible and relevant treatment," there are other sufficiently compelling reasons to test even if antiretroviral therapy is unavailable: preventing further infection, normalizing the disease and managing the disease with alternative forms of treatment. Access to informed treatment is but one benefit of testing.

Public health policies are imperfect compromises between the moral mandate to attack the removable causes of disease and the ethical duty to protect individual human rights. Erring on the side of protecting individuals against HIV-related discrimination and threat of violence, advocates of an exceptionally vigilant human rights-based approach to HIV testing oppose the application of standard methods of disease control. Failure to apply these standard methods, it is argued, undermines society's ability and responsibility to control the epidemic.³ De Cock et al. argue that the emphasis on human rights in HIV/AIDS prevention has reduced the importance of public health and social justice.4 Beyond public health and social justice, there is also the very personal issue concerning the human rights of seronegative husbands, wives, partners and neonates: these vulnerable people should be at the very heart of a sound human rights-based approach to HIV-testing policies and legislation.

Kwame Ampomah, UNAIDS Coordinator in Botswana, posed an arresting question in June 2003 in relation to the issue of "normalizing" the disease: "Has there been a case in history where a major public health catastrophe was effectively managed and brought under control by placing individual rights above collective rights as public interest?" ⁵ Botswana's voluntary HIV testing programme enrolment numbers are climbing, not exponentially but steadily, and health officials estimate that up to 35% of the population now know their status.⁶

Is it ethically obligatory to insist on human rights protections and other policy implementation ideals at all costs, even in health emergencies? Rennie & Behets worry that advocates of expanded testing "sometimes downplay the social consequences of an HIV-positive status for women and girls in low-income countries to make the policy look more attractive or at least less contentious," and they also wonder whether certain individuals might have been channelled into testing. Though useful, this ethical thought experiment is not yet an argument: routine testing policies are hardly responsible for introducing gender inequalities, domestic abuse, stigmatization or overburdened and underfunded health clinics. While routine testing policies could conceivably exacerbate the situation in certain ways, unwittingly or unintentionally, they also raise awareness, reduce stigma, prevent transmission, expand treatment and empower individuals.

Refusing to be tested (opting out) is ethically equivalent to affirmative consent (opting in) only if the refusal is adequately informed and if the patient has sufficient liberty to say no, according to Rennie & Behets, but they would also concede that even affirmative consent in VCT may fail to meet the ethical preconditions they enumerate. Surely we need to understand more about what conditions are required to ensure that the patient has sufficient liberty not to opt out? Rennie & Behets suggest that it would be premature for us to assume that "voluntariness," which is said to be at the very heart of routine HIV-testing policies, occurs in practice. Empowered voluntariness is elusive in any setting, be it high or low in resources; if a decision is voluntary only when one is fully and equally aware of the benefits and risks, informed consent and robust voluntariness are rare achievements in most health-care

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settings. Further, whereas not opting out during a routine HIV test may demonstrate a certain disempowerment, the decision to opt out might be determined by an equally worrisome form of disempowerment or involuntariness.

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