An epidemic like any other? Rights and responsibilities in HIV prevention

Renée Danziger

Throughout the 1980s and into the 1990s, HIV prevention has been closely associated with the protection of individual human rights. Traditional public health measures such as compulsory testing and isolation have largely been rejected as ineffective in public health terms and inappropriate in the context of human rights protection. HIV prevention has been based instead chiefly on elective measures—information, education, counselling, and voluntary testing. In the past five years there have been important clinical, epidemiological, and social developments in the AIDS epidemic. These changes, combined with a growing recognition of possible weaknesses inherent in a strictly voluntarist approach to HIV prevention, may herald a new approach to AIDS control which places more weight on social responsibility in the context of HIV prevention.

In a thought provoking essay on public responses to AIDS, Nancy Scheper-Hughes describes an “uncanny consensus” among social scientists and the international medical community regarding the best way to respond to the epidemic.¹ This consensus is characterised by its linkage between HIV prevention on the one hand with respect for personal freedoms and individual human rights on the other.

According to this view, AIDS is unlike most other epidemics. The modes of HIV transmission, the stigma attached to the disease, and the absence of a cure all combine to render most traditional public health strategies inappropriate for AIDS control. Instead, effective HIV prevention requires elective measures such as education, voluntary testing, and counselling.^{2,3}

This is not to say that mandatory measures have been eschewed altogether. Russia and the United States are just two of the countries, for example, that require HIV testing of short and long term visitors. By and large, however, there has been widespread international support for a broadly liberal approach that couples AIDS prevention with the protection of individual rights.

This linkage has until now bestowed a special sociopolitical status on AIDS, but the epidemiological, clinical, and social developments of the 1990s may eventually erode this status. In effect, these developments are slowly bringing AIDS into line with other communicable diseases.

The normalisation of AIDS

Over the past 16 years, AIDS has evolved from an acute public health crisis into a chronic public health problem. It is every bit as serious a problem today as it was in the 1980s—indeed, in many respects more so; but epidemiological and clinical developments have

had important consequences for the ways in which AIDS is perceived.

Unlike much of the developing world, most developed countries have not experienced the exponential increase in cases of HIV infection that was forecast in the earlier years of the epidemic. The discrepancy between predictions and actual rates of increase of infection has unavoidably detracted from the urgency with which the epidemic has come to be regarded. Policy makers have turned their attention elsewhere, media interest has dropped off, and financial support for AIDS information, education, and research has waned.⁴

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Other factors have also contributed to the “normalisation” of AIDS. The development of treatments such as zidovudine, dideoxyinosine, and dideoxycytidine, either alone or in combination, has opened new possibilities for delaying the onset of symptoms and prolonging the life of people with HIV related disease.^{5,6}

The development of new treatments has also influenced the debate on HIV testing. Until recently, AIDS was contrasted with other communicable diseases for which routine testing is common, because in the case of AIDS there was no treatment to justify routine testing. With this no longer entirely the case, there have been increasing calls for mass HIV testing.

Routine testing of pregnant women has been advocated, for example, so that those who are positive may be offered treatment with zidovudine (shown in one study to prevent two thirds of expected perinatal infections^{7,8}). Mass testing has also been called for more generally on the grounds that the health benefits of knowing one’s serostatus now significantly outweigh the potential social and psychological harms.^{10,11}

Growing recognition of social responsibility in AIDS prevention

The 1990s have also seen a small number of researchers and commentators beginning to ask whether social responsibility—as against individual rights—should feature more prominently than it has hitherto on the AIDS agenda. Scheper-Hughes, for instance, points to the bias inherent in voluntarism, which she argues ultimately disadvantages the most vulnerable sectors of the population. She describes Brazil’s classically liberal response to AIDS—which rests on education and promotion of condom use—and

Health Services Research Unit, Department of Public Health and Policy, London School of Hygiene and Tropical Medicine, London WC1E 7HT
Renée Danziger, research fellow

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shows how the emphasis on elective measures is dangerously misplaced, not least because poor, working class women are often unable to convince their partners to use a condom to protect them from multiple unwanted pregnancies, let alone from a disease that is viewed as a distant threat. Moreover, "the problems of 'educating' Brazilian men for 'safe sex' are overwhelming in the dominant, masculine sexual culture where 'excitement', 'transgression', 'pleasure', 'dominance' and 'danger' are part of the same semantic network."¹¹

Scheper-Hughes challenges prevailing views on HIV prevention by suggesting that routine testing, followed by notifying the partner, might give more effective protection to working class women than simply promoting safe sex. Unlike Brazil, Cuba has based its HIV prevention efforts largely upon mass screening, contact tracing, medical surveillance, and the partial isolation of infected people.¹² Admittedly,

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the consequences of positive test results in Cuba are "nothing short of draconian," but the AIDS control programme seems justified in public health terms: in sharp contrast to Brazil's tragic explosion of HIV, Cuba's epidemic seems to be relatively small scale. Scheper-Hughes is inspired by her findings to ask whether it may not be both practically and ethically acceptable to compromise certain notions of individual rights in the interests of epidemic control (and the saving of lives).

The eminent American sociologist Amitai Etzioni also departs from the individualist paradigm by suggesting that people with high risk behaviours have a *responsibility* to society to be tested and, in the event of testing positive, to provide the names of previous contacts so that they too can be tested. He acknowledges the risk of discrimination and suffering faced by people who test positive but argues that social responsibility should supersede the urge to protect the individual: "It may be harsh to say, but the fact that an individual may suffer as a result of doing what is right does not make doing so less of an imperative."¹³

Michelangelo Signorile, an American AIDS activist, also explores this theme. A prominent champion of gay rights and the rights of people with AIDS, Signorile reflected recently on rights and responsibilities in the context of AIDS: "After much thought, I realise that I owe it not only to myself but to my sexual partners to

know my HIV status. If I find I am negative, I have a responsibility to keep myself that way. . . . And if I am positive, I have a different but equal responsibility: not to put others at risk, and to understand that not all HIV-negative people are able to deal with the responsibility of safer sex."¹⁴

Signorile says that during the 1980s, the responsibilities of people with HIV were rather neglected, as many AIDS workers placed the burden of HIV prevention principally on HIV negative people. Reviewing the impact of the AIDS orthodoxy that dominated the first decade of the epidemic, Signorile writes poignantly: "Now it seems that some of what we did for those who are positive was at the expense of those who are desperately trying to remain negative."¹⁴

Rights and responsibilities in HIV prevention

As the AIDS epidemic evolves, so too must our responses to it. It is beyond question that protection must be provided—both to HIV positive people (protection against discrimination) and to HIV negative people (protection against infection). Perhaps the best way of affording this protection is by shifting the terms of the debate away from individual rights towards a better understanding of individual and social responsibilities.

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- 1 Scheper-Hughes N. An essay: AIDS and the social body. *Soc Sci Med* 1994;39:991-1003.
- 2 Bayer R, Kirp DL. An epidemic in political and policy perspective. In: Kirp DL, Bayer R. *AIDS in the industrialised democracies*. New Brunswick, NJ: Rutgers University Press, 1992:1-6.
- 3 UN Commission on Human Rights. *Discrimination against HIV-infected people or people with AIDS. Final report submitted by the Special Rapporteur to the Sub-commission on Prevention of Discrimination and Protection of Minorities*. Geneva: UN Commission on Human Rights, 1993. (E/CN.4/Sub.2/1993/9.)
- 4 Berridge V, Strong P. AIDS policies in the UK: a preliminary analysis. In: Fee E, Fox D, eds. *AIDS: the making of a chronic disease*. Berkeley, CA: University of California Press, 1992:299-325.
- 5 Dillner L. Study shows two drugs are best for HIV infection. *BMJ* 1995;311:827.
- 6 Clarke A. What is a chronic disease? The effects of a re-definition in HIV and AIDS. *Soc Sci Med* 1994;39:591-7.
- 7 Minkoff H, Willoughby A. Pediatric HIV disease, zidovudine in pregnancy and unblinding heelstick surveys. *JAMA* 1995;274:1165-8.
- 8 Chrystie IL, Wolfe CDA, Kennedy J, Zander L, Tilzey A, Banatvala JE. Voluntary, named testing for HIV in a community based antenatal clinic: a pilot study. *BMJ* 1995;311:928-31.
- 9 Wilfert CM. Mandatory screening of pregnant women for the human immunodeficiency virus. *Clin Infect Dis* 1994;19:664-6.
- 10 Rhame FS, Maki DG. The case for wider use of testing for HIV infection. *N Engl J Med* 1989;320:1248-54.
- 11 Joseph SC. *Dragon within the gates: the once and future AIDS epidemic*. New York: Carroll and Graf, 1992:82-3.
- 12 Veeken H. Cuba: plenty of care, few condoms, no corruption. *BMJ* 1995;311:935-7.
- 13 Etzioni A. HIV sufferers have a responsibility. *Time Magazine* 1993 December 13:60.
- 14 Signorile M. A cruise on the wild side. *Guardian* 1995: March 1.

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MY MOST UNFORTUNATE MISTAKE

Read the notes

Many years ago, when I was a senior house officer, I was asked to anaesthetise a child who was having a left bronchogram for suspected bronchiectasis. A catheter was passed down the endotracheal tube into the left main bronchus and the dye trickled in. The child then had a cardiac arrest. I cannot remember how I diagnosed the arrest and it was before external cardiac massage had been introduced. With considerable bravado, I grabbed a scalpel and made a sweeping incision through the left fifth interspace as I had seen thoracic surgeons do. Stretching wide the incision with my ungloved hands, I felt for the

heart with the intention of doing internal cardiac massage. The child had no heart—or so it seemed. Certainly, I could not find one. It was only subsequently that it transpired that the child had dextrocardia. A stern lesson to a junior anaesthetist to read the notes.—JOHN S M ZORAB is a consultant anaesthetist in Bristol

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