Aids: Ethics, Justice, and Social Policy

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ABSTRACT  Principles of justice and equality demand that HIV seropositive individuals and those with AIDS should not be discriminated against in any area of social provision. If social policy on AIDS is constructed in terms of reciprocal obligations, that is if obligations to the HIV seropositive individual and obligations of the HIV seropositive individual are given equal weight, the civil rights of HIV seropositive individuals may be secured and this may create a climate in which HIV seropositive individuals will more readily notify partners, and others at risk of infection, of their HIV status. It is conceivable that such a climate could facilitate greater control of the spread of HIV/AIDS.

Like no other crisis humankind has faced, the AIDS pandemic highlights weaknesses in the human psyche. In addition to the physical and mental suffering associated with the virus and syndrome, the person who is HIV seropositive or has AIDS may expect to confront both the rational and the irrational fears of those who are not, or believe that they are not HIV seropositive. These fears are often manifested in suspicion of and hostility towards the former [1].

It is not difficult to imagine how this phobia may actually contribute to the spread of the disease which is its object. The threat of labelling, stigmatisation or ostracism may deter those who consider themselves to be particularly at risk of infection from disclosing their status, undergoing voluntary testing, or altering their behaviour in ways which might decrease the likelihood of passing on the virus [2]. Thus does the psychological foment the pathological.

The AIDS pandemic poses unprecedented ethical challenges and calls into question long established principles, in particular those relating to confidentiality in the relationship between the patient and the health care professional and to an individual’s right of privacy. Whilst much research has been devoted to the obligations of society generally, and health care professionals specifically, toward the individual who has AIDS, little by comparison has been written on the obligations of those with AIDS themselves, which obligations we believe may be the key to the development of an effective and equitable social policy on AIDS. Underpinning an investigation of these obligations are principles of justice and equality, as well as considerations of personal autonomy and human rights.

It is now clear that the HIV seropositive individual has been discriminated against and denied civil rights. It appears likely that the persisting animosity and prejudice shown the HIV seropositive individual could well be defused by the recognition of a duty of all citizens to disclose HIV status under certain conditions. It is our intuition that we should think in terms of a reciprocity of obligations, that is, in terms of a reciprocity between obligations of HIV seropositive individuals and obligations to HIV seropositive individuals. Greater
recognition of responsibility to others on the part of the HIV seropositive individual, if allied to a concomitant firm commitment to equitable treatment, could perhaps result in greater voluntary testing and, conceivably, in a decrease in the spread of HIV among the non-infected population.

**Justice and the Principle of Equality**

However we may like to conceive of justice, many would now recognise that the principle of equality lies at its core [3]. The ethical principle of equality may be stated briefly: each person within a community is entitled to and should be afforded equal respect, concern, and protection. At the basis of this principle is the idea that persons are of equal importance [4]. Justice, construed very loosely as fairness, would lack significance if we did not accept that persons matter equally and hence are equally entitled to fair treatment.

A consequence of the principle of equality is that we should not discriminate unfairly between individual members or groups within a community. In the context of health policy and its reaction to the AIDS pandemic, the principle is vitiated if we do not actively seek to afford all non-infected citizens what protection against infection there exists, or if we do not provide HIV seropositive individuals with adequate care of their symptoms, and therapy, as and when it becomes available, and protection against unfair discrimination.

**The Role of The State**

'The Obligation of Subjects to the Soveraign, is understood to last as long, and no longer, than the power lasteth, by which he is able to protect them', wrote Thomas Hobbes in *Leviathan* [5]. Thus, for Hobbes, the obligation of citizens to obey the rule of law is predicated upon the State's acceptance of the necessity of protecting citizens from threats to life and liberty [6]. It can be argued that this is the essence of the social contract and the sole justification of the State. We will treat the sovereign's acceptance of the necessity to protect citizens as an obligation recognised by the sovereign although for Hobbes, the sovereign had no obligations to citizens — his thesis was merely that citizens had no obligations to the sovereign in the absence of sovereign protection.

Whilst in 1651, when *Leviathan* was first published, the kind of threats to life and liberty against which Hobbes would have 'Soveraigns' protect their 'Subjects' consisted chiefly in those of armed or political aggression from abroad, it appears to be generally true to say that in the 1990s the greatest threats to citizens' lives are borne of inadequate health care provision, famine, and disease at home. Over the past decade, AIDS has assumed a position as potentially one of the greatest threats to humankind, and, without the promise of a 'miracle cure' in the foreseeable future, the State's duty to protect citizens from this aggressor is among its first and foremost obligations.

Concomitant with the State's obligation to protect citizens' lives, and just as important, are its obligations to afford them equal concern and respect. Those citizens for whom protection against infection with HIV has failed should be shown the same concern and respect as other citizens; they are entitled to the same consideration in access to employment, health care, and other areas of social provision, as any other citizen.

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Individual Responsibility And The Duty To Warn

On the other hand, the spread of this virus/syndrome which threatens citizens' lives is not independent of individual citizens' actions. Responsibility for protection against HIV/AIDS cannot be wholly abdicated to the State. The individual has, effectively, the power to protect (as much as it is possible to protect) him-/herself and, if he/she is HIV seropositive, others against infection. Inasmuch as this power lies with the individual, for what, and to what extent, is the individual responsible?

If one is responsible for anything, one is responsible for what one knowingly brings about, whether or not this was a hoped for or premeditated result of the action or inaction, and independent of whether that action or inaction was intended [7]. Clearly, this conception of individual responsibility has severe implications for those who are, or have reason for suspecting that they are, HIV seropositive, or who have, or believe that they may have AIDS. If those who know they are or may be HIV seropositive, or know they have or may have AIDS, choose not to share this knowledge with their sexual partners, those with whom they share syringes in drug use, health care professionals, etc., that is, if they do not forewarn others of the risks they may be taking on, they will be responsible for subjecting those others to the risk of infection, and thus the risk of death, and responsible for their death if, as a result of their actions, the partners contract, and die of, AIDS. Thus:

Even though the seropositive individual may be innocent in two senses, (a) have innocently, not recklessly, contracted HIV and (b) be innocent of any intent to infect others, nonetheless they are fully responsible if they knowingly or recklessly expose others to risk. [8]

It is sometimes claimed that all individuals have the obligation to protect themselves and that there is consequently no duty to warn. This principle has two major flaws. The first is that it assumes that people will actually protect themselves in obedience to the principle. The second is that it assumes that the protective steps that they might take will be adequate.

We will just look a little more closely at both these flaws. It may be the case, for example, that all workers at a nuclear plant should wear protective clothing at all times. It does not follow from the soundness of such a rule that worker A, seeing that worker B is without her protective clothing on this particular occasion, has no obligation not to turn on a machine that emits dangerous radiation or to warn worker B before turning on the machinery. Or, even if all are wearing protective clothing, that there is no obligation not to increase the dangerous radiation above the levels to which the workers have consented to be exposed and are expecting to receive.

The second flaw is equally important. Since there is no such thing as 'safe sex', merely less hazardous sex, it is important that each individual makes his or her own informed judgement about the level of risk they are prepared to run in each particular case. One might, for example, think that the risk that one's partner has AIDS is low and that this combined with the further lowering of the risk by practising protected intercourse was an aggregate risk worth running. One's assessment might be different if one knew that the first of the two risks was not small but, rather, 100%. This is why health care professionals often want to know (and rightly) the HIV status of patients for particular procedures even though they take routine precautions against infection during those procedures. Equally, and for the same reasons, patients have a legitimate interest in knowing the HIV status of health care professionals.

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Transmission And Progression Rates

It could be argued that gaps in the state of the art of the epidemiology of AIDS weaken the case for a duty on the individual to disclose his or her HIV or ‘at risk’ status. In particular, there is currently a less than complete understanding of infectiveness, especially during the interval between seroconversion and the pre-AIDS period. Furthermore, some researchers have questioned the direct relation between infection with HIV and the development of AIDS [9]. However, the vast majority of research into conversion and progression mechanisms and rates seems to indicate very strongly that there exists a high risk of contracting HIV via unprotected sexual intercourse with an infected partner, for example, and that the HIV seropositive individual will develop AIDS and, eventually, die as a result [10]. If we are considering the need to protect individuals from HIV we ought, clearly, to accept the worst case scenario.

Privacy

The typical modes of transmission of HIV involve acts which are at least private, and usually intimate. Thus, it is not unexpected that our thesis regarding the responsibilities of individuals conflicts with social conventions on privacy. Should an individual’s supposed right to privacy be protected at all costs? In the context of AIDS where one person’s withholding information he or she regards as private puts the life of another at risk, the right to privacy of the former must, we submit, take second place to the latter’s right to protection.

However, while, as we have construed it, this right to protection from threats to life is a right both against the State and against the individual, enforcing the right to protection in private relationships between individuals does not appear practicable. Even if the right were enshrined in law, the only feasible way of enforcing it would be by enacting punitive measures against those who neglect their (correspondent) duty to forewarn others of their HIV status and/or compensating those who are the victims of a failure to forewarn. But, from the point of view of the victim, this comes too late.

The alternative we are proposing here might at first blush be interpreted as offering social inducements to the HIV seropositive voluntarily to divulge their status, inducements in the form of guarantees of equitable treatment. That this would be false is a point we will return to shortly.

Privacy And Third Parties

First, let us consider the involvement of third parties. Our focus here will be on the confidentiality of the patient—health care professional relationship. The question we must try to answer here is whether the health care professional should keep information about a patient’s HIV status secret, or, in certain circumstances, be free to disclose it to others. The reasons for confidentiality stem from respect for the patient’s autonomy. There is a quasi-contractual aspect involved in that the patient divulges information to the health care professional on the, at least tacit, understanding that the information will go no further. On this basis, patients who might not do so otherwise present for treatment confident in the
knowledge that they will not be prejudiced in their public life by what they reveal. Furthermore, if there exists a right to privacy, it can be argued that this should extend to control of personal information and access to it [11]. These are strong grounds for the health care professional’s preserving patients’ confidences.

However, in the context of AIDS, the right to privacy and the principle of confidentiality can conflict with the moral imperative to do no harm (or, if one cannot do no harm, to do the least harm). Preserving the confidence of an HIV seropositive patient where he or she is clearly refusing to notify partners and others at risk can do substantial harm. For example, it may endanger the lives of future sexual partners, or keep previous sexual partners in ignorance of their at-risk status and so endanger their future sexual partners. It may, of course, result in loss of life.

How can we resolve this conflict? One way might be to ask: ‘Who has the most to lose?’ We do not mean to play down the importance of consent and confidentiality or of respecting the special vulnerability of the HIV seropositive individual, but when persons’ very lives are endangered by respecting such principles the protection of those persons must be an overriding concern. Notification of partners (sexual or in drug use) is thus a paramount moral imperative. If all attempts to persuade the HIV seropositive individuals voluntarily to disclose their HIV status to those whom they put at risk fail, the health care professional surely has a moral obligation to disclose in order to prevent lives being put at risk. To fail to do so would make the professional responsible for the fate of those at risk [12].

Practical Implications

Lofty rhetoric is all very well. It would be an easy path to take simply to say that this is the conclusion we reach by performance of an ethical balancing act and to leave the working out of its practical implications to others. But one of the jobs of applied philosophy, as we see it, is to take into account the practical difficulties of implementing the recommendations of moral reasoning. A moral principle can have little or no point if its observance is impossible in the real world.

Education

What is needed, we believe, is education. We are not talking about the kind of education via the media aimed at scaring people into changing their behaviour patterns — visual images of icebergs and tombstones seem to have had a limited beneficial effect in any case. Firstly, greater awareness of what actually are the modes of HIV transmission is required so that the popular myths surrounding transmission are dispelled and HIV seropositive persons are not treated as pariahs. Furthermore, if, as we suggest, partner notification is an overarching moral imperative, the best way we can see to it that acting on this is maximised is by making citizens aware of the responsibilities of at-risk individuals to their partners, third parties and society generally.

Social Responsibility

This is a first step, but it is not enough. In the reality of the modern world it is too much...
to expect persons to take on these responsibilities when to do so would likely lay them open

to unfair discrimination. If the individual’s obligation to disclose HIV status is to be taken

seriously, the State’s obligation to show him/her equal concern and respect must be

confirmed and enforced.

These societal obligations can be viewed, and at a practical level should be viewed, not

only as a corollary, but as a *sine qua non* of the individual’s duty to disclose. Whilst the stance

we have taken on the responsibilities of individuals can be interpreted as a strong and

independent ground for a duty on the individual to disclose HIV status, there is a sense in

which the individual’s duty to disclose is also and equally a dimension of the State’s

obligation to protect citizens from threats to life which is the concomitant of the State’s

obligation to show all citizens the same concern and respect.

How do these obligations to the HIV seropositive individual translate into real terms?

Firstly, we should try our utmost to find a cure, or effective treatments for AIDS. The

scientific community has already taken this on and is well supported by the public and

private purse, and we will say no more on this. Secondly, we should afford HIV seropositive

individuals and those with AIDS protections against unfair discrimination. These active

protections should encompass all areas of social provision which bear on their fundamental

entitlement to equal concern, respect and protection. HIV seropositive individuals should

be treated equitably in the provision of access to health care, employment, education,
housing, etc. In relation to the duty to disclose HIV status specifically, it must be ensured,

we would recommend by legislation, that such disclosure does not jeopardise this equitable

treatment.

**Insurance**

There is a particular problem with insurance. Life insurance not only provides security for

dependents, but, because of the link with mortgages, also secures many people’s access to

housing. Something must clearly be done to ensure that the HIV seropositive individual

has reasonable access to housing and can provide for his or her dependents. Two policies

for ensuring equitable provision of life insurance suggest themselves. How viable these

might be will partly turn on the scale of the problem of HIV seropositivity and this will

partly turn on the success we have in using measures like these to encourage responsible

behaviour and control the spread of the disease. Firstly, we could introduce legislation

requiring insurance companies to provide cover for HIV seropositive individuals; the costs

could be equalised by loading premiums generally — this is a classic business practice. A

second alternative is to utilise national resources. That is, the State would make itself

responsible for providing HIV seropositive individuals with mortgages and insurance for

their dependents.

The mechanics of such insurance provision are complicated. It is beyond the scope of

this paper to explore in detail how either might work or how the costs would be offset [13].

Clearly a ceiling will need to be set on the HIV seropositive individual’s ability to obtain

such insurance. It should be sufficient to enable such an individual to enter the housing

market at a reasonable level but not so high as to enable that individual to exploit the

goodwill of society for the personal enrichment either of himself or his family or friends.

We do not believe it to be beyond the wit of man or broker to arrive at some reasonable

parameters for these purposes. It must be borne in mind that there will almost certainly be

gains in public safety and in diminution of personal risk commensurate with the financial

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burden of the provision. Indeed our guess is that it will come to seem a small price to pay for doing what’s right.

This suggestion would hold good for other fatal conditions if it were part of a comprehensive system of health screening of the type we may expect to be available at some time following the successful mapping of the human genome. Then:

Premiums should be set as if there was no information available, as if screening were not a feature of existence. If they were set for average life expectancy or illness, or accident expectancy for a particular age, the risk would even out. We must remember that for every terminally ill 20-year-old who might get ‘unfair’ cover there would be many whom screening and monitoring would protect from disease or premature death and who would consequently balance those who cash in.

Since screening is likely to reduce the vulnerability of the community at large, insurance companies cannot be worse off than they are at present if they are required to set premiums as if no new information existed. For this reason legislation constraining insurance companies might be less controversial than would at first appear. [14]

In effect, what we are recommending here is that the infrangibility of the civil rights of HIV seropositive citizens be confirmed in law. In principle, this may be a truism; in reality, it is a desideratum.

**Mandatory Testing?**

The individual’s duty to disclose HIV status seems to presuppose an individual’s certain knowledge of his/her HIV/AIDS status. If this was the case, the duty to disclose would appear to require mandatory testing for HIV of all citizens as a prerequisite. Ethically, mandatory testing poses many and complex problems [15], not the least of which are the challenge to personal autonomy this represents and the consequent violation of the right of all citizens to refuse medical touchings, a right which is legally protected in many jurisdictions; ethics aside, doubts have been voiced about the practicability and economic viability of establishing a system of mandatory testing [16]. However, our thesis does not imply universal mandatory testing as a direct consequence. What we are suggesting is that those who have reason to suspect that they may be HIV seropositive or have AIDS, as well as those who know that they are HIV seropositive or have AIDS, recognise and shoulder their responsibilities to their partners and relevant third parties. One responsibility of members of the former group is, a priori, to be tested for HIV antibody. This testing we believe should remain voluntary, and should be accepted simply because it is the right thing to do, in short because it is ethical. However it is always helpful if doing the right thing coincides with one’s interests. This we believe, would be facilitated by our reciprocity of obligations thesis.
Reciprocity Of Obligations

To date, it seems there has been no alacrity in the securing of what are, after all, fundamental civil rights for people who are HIV seropositive. The reason for this, we suspect, is that talk of the responsibilities of HIV seropositive individuals and those with AIDS is virtually excluded from the discussion. If the debate is framed in terms of reciprocal obligations, the protection of HIV seropositive individuals against discrimination, and the possible desirable consequences which we have been discussing, may be more easily attainable. These conclusions are, at basis, direct implications of a conception of justice.

Our chief concern here has been to identify the fundamental premises on which a social policy may be constructed which will help create an environment in which HIV seropositive individuals will not be subject to discrimination and fear of discrimination will not deter the individuals who know or have reason to suspect that they are HIV seropositive or have AIDS from forewarning their partners, or other third parties who they consider may be at risk, of their HIV status.

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NOTES


Tragically, fear of discrimination is itself an important obstacle to both greater epidemiological understanding of HIV transmission and implementation of public health measures aimed at minimizing HIV infection.


No moral balancing act can take place among us; there is no moral outweighing of one of our lives by others so as to lead to a greater overall social good.

Also, for Ronald Dworkin (Dworkin, op. cit., p. 199):

The weaker members of a political community are entitled to the same consideration and respect of their government as the more powerful members have secured for themselves.

We are grateful to Stephen Clark for helping to clarify Hobbes's point.


We are assuming the moral symmetry of acts and omissions — see Harris (1980) op. cit. For an alternative discussion (of how this distorts the patient-health care professional relationship), see Anon., ‘Medical confidentiality’, Briefings in Medical Ethics 7 (1990) 2-3.


Harris, (1992), op. cit., p. 223.
