AIDS: THE INDIVIDUAL AND SOCIETY

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Introduction

The ethical issues in AIDS that are of legal interest concern an individual in his relation to society and in his transactions with others in that society (here, as elsewhere, I use he and him because we only have one female AIDS patient in New Zealand). These issues arise from the facts about AIDS. At present we believe that:

1 HIV causes AIDS;
2 HIV is only transmitted by fresh body fluids;
3 Most people who are infected by HIV will develop AIDS;
4 AIDS is a lethal and incurable disease;
5 There is a "window" between infection and the development of detectable HIV antibodies so that an individual can only be found to be infected after he has already become a danger to others.

In the light of these facts I will examine the following issues that arise in AIDS:

1 Protection of society and the rights of individuals;
2 Sanction of criminal activities;
3 Ethical constraints on transactions between individuals where there is risk involved;
4 Confidentiality;
5 Euthanasia.

1 Protection of Society and the rights of individuals

Some claim that there is no case at all for respecting confidentiality with AIDS because, like tuberculosis and other significant public hazards, it ought to be notifiable. If it were notifiable its detection and the use of the information about individuals that resulted would be a matter of public health and not individual discretion or patient choice. It would be fair to say that in the past the public weal has been given inordinate weight in the balance between public and individual good. Even in the United States "[t]he courts . . . proclaimed public health 'the highest law of the land' and announced 'all constitutionally guaranteed rights must give way' to its demands. At the same time, however, courts held communicable disease measures constitutional only if they were"reasonable" attempts to prevent the spread of disease".[1] But it is the very term "reasonable" that indicates the need for

1 Jones Merritt, "The constitutional balance between health and liberty" *Hastings Center Report Supplement*, December 1986, at 3.

careful ethical thought. Justice Kirby has noted "the law does not exist in isolation. It is part of the mosaic of social regulation . . . the perceived needs for law depend upon the perception (and actuality) of the size and nature of the problem being tackled".[2] At last report there had been 126 cases of AIDS reported in New Zealand, which tallies with predictions by Professor David Skegg in 1987.[3] In the same article he made some alarming remarks about the future: "Although we cannot predict what lies ahead with any confidence, we must warn the public that the possibility of a major epidemic is real".[4]

We have a sound ethical and legal basis for compulsory detection and public health measures designed to prevent the spread of a disease wherever the affected persons pose unavoidable risks to the general populace in their normal everyday activities. But we know that AIDS is not highly infective because, in fact, the *only* way to transmit the disease is by direct inoculation of one human being with fresh body fluids from another. Thus it is clearly not the case that AIDS can be inadvertently caught by members of the public dealing with HIV positive individuals. What is more, there is no specific treatment for AIDS so that reporting has advantages for those infected or those at risk. Finally, the window of undetectable infectivity (which may be as long as 14 months) means that eradication based on detecting HIV positive individuals is impossible. Therefore, there is no purpose to be served in terms of keeping the public from harm or of eradicating the disease by detecting and reporting HIV positive individuals. Neither is there any reasoned basis on which employers, associates, or clients of HIV positive persons need to know about their status.[5]

There is, moreover, an added ethical factor: to be told oneself or have others told that one has AIDS is to suffer a major change in one's life. This change is so intrusive and important that there is a strong case for seeking consent to HIV testing. Doctors are professionally dedicated to the ethical principle *primum non nocere* and we do not, in our general practice, risk a significant harm to a patient without explicit consent. We waive this as we waive our dedication to confidentiality when there is a public danger involved. But these conditions do not apply to HIV infection because there is no risk to the general public outside a specific and reasonably avoidable range of situations. Thus there is no ethical justification for testing any individual for AIDS without consent.

It may be argued that there are some situations where the risk to others makes testing mandatory regardless of the individual's wishes. The commonly cited scenario is an at-risk person entering medical care. Here there are two possibilities. First, the patient may be unwell but sentient and competent to act in his own best interests.

2 Justice Kirby, "Legal Implications of AIDS", infra at 1.
3 "The AIDS pandemic: what lies ahead" (1987) 100 NZ Medical Journal 588.
4 At 589.
5 With the exception of clients of a prostitute.

Because of the effects of an HIV test it would seem that if such a patient refuses one we ought to take special precautions as if there were a positive test. Second, the patient may be gravely ill with a brain disorder or other major medical catastrophe that has destroyed, perhaps irreversibly, testamentary capacity. If such a person is HIV positive, a good recovery is extremely unlikely and therefore the test would allow a judicious decision to be made about the propriety of intensive (and futile) treatment. Conversely, if the patient is negative then that not only has therapeutic implications but also means that there is no sinister fact creating an ethical dilemma. Thus the only situation in which testing might be done without consent is where the patient is so seriously ill that he is incompetent to consider the request; in this situation there is no ethical problem whichever way the test result goes.

AIDS and the ethical requirement for consent for HIV testing create a problem for medical science. Any community has a clear interest in obtaining good epidemiological data about the disease for the purpose of health planning and the pursuit of measures which may lead to control of that disease. But the ethical constraints on HIV testing and the hesitancy of many of those at risk about knowing whether or not they are affected together make a mockery of any epidemiological work in HIV infection and AIDS. Thus we need to be clear about those constraints and the requirements for consent and confidentiality.

The patient who is at risk from AIDS rightly feels that he has little to gain and much to lose if he is tested and found to be HIV positive. We have, as I have noted, no effective therapy, so that he loses his normal expectation of longevity, and he is faced with an unenviable choice in his relations with others between candour with the risk of ostracization and deceit with its strain and discomfort. Testing for HIV does not necessarily involve a distinct procedure apart from taking blood for other purposes and therefore there is no requirement based on the physical act of testing that would normally be thought to require specific consent. Thus the sole reason for consent is the consequences of the knowledge that the particular individual concerned is HIV positive and the ethical requirement that we make significant information about a person available to him. This is not avoided by not telling the patient because even the knowledge that there is a card which would enter play at any point and that carries such dire consequences for oneself is a significant thing for any person to have to live with. Once there exists an affirmative answer to the question "Have you been tested for HIV antibodies?" your life can never be the same.

Some would argue that true knowledge can never count as a harm but there seems ample reason to doubt this when that knowledge concerns one's HIV status. Thus it appears that we cannot avoid infringing ethical principles if we screen people for HIV antibodies without their consent but that we cannot get good epidemiological data if we insist on consent. However, there is a flaw in the argument. The harm for patient A arises from the fact that he has a positive HIV test. But what the researcher

wants is a measure of how many unidentified and unnamed human beings are HIV positive. Thus there is no conflict. Any sample she obtains from A need not be identifiable as being from A to serve her purposes. The ethical problems can therefore be "finessed". There is no invasion of A's privacy nor is there a potential harm to A, because nothing is known which can be traced to A.[6] In this way the scientifically useful knowledge that x% of patients in the community are HIV positive could be gained without infringing on patients' rights or extracting ethically problematic knowledge about any given individual. The knowledge about A which we ought to surround with norms of consent and confidentiality would not exist to be notified to or withheld from anybody including A himself.

If this recommendation were put into practice it would be true that blood from patients would have been used for research but the lack of special ethical problems with that research would imply that a very general and non-informative form of consent could be gained to the effect that the patient did not mind some of his blood being used anonymously for research. The lack of any material concern to the patient in the situation makes even this seem a little unnecessary. Thus I do not think that any ethical problem stands in the way of epidemiological research into HIV and AIDS provided that the knowledge gained cannot conceivably be traced to any patient involved.

This conclusion has, however, prompted objections from doctors who have asked what they ought to do if they found, say, that one of a thousand patients tested with HIV positive. Could such a doctor, in all conscience, let this individual go undetected and endanger other potential patients within the community? Must we not, therefore, be able to trace the sample and through it the infected individual. But the arguments already advanced resolve this issue. First, we have not sought permission to gain ethically problematic knowledge about a given patient. Second, we must seek that permission where we want to discover the HIV status of an individual. Third, the population is not really at risk and therefore does not need protecting. Fourth, we have served a research interest which has given us knowledge that we did not have that may ultimately benefit the whole community. If, as a result of such an exercise we feel that a group ought to be tested to see which *individuals* are HIV positive then we must ask each individual we propose to test as to whether he or she will agree. Some may well say "no" and we will, perhaps, fail to find the infected individual, but then we are no worse off than we would have been anyway and as researchers and scientists we (and therefore the members of our community) are much better off. Also we have avoided contravening the requirements of ethical medicine.We may, however, have to live with the fact that among a thousand people we have tested one, we know not who, is HIV positive.

6 An easy method of avoiding duplication of tests could involve testing patients only on their first visit to the hospital after commencing the survey.

2 Sanction of criminal activities

A further ethical problem in public health measures is created by the spread of AIDS in the drug-using community. Here it seems plain that there are two courses open: we could either deny drug users access to needles and allow shared needle use to spread the disease or we could provide exchange needles. The latter measure runs the risk of increasing intravenous drug abuse. The conflict arises from two facts (i) we are committed to rescuing addicts where that is possible but there is no rescue from AIDS; (ii) we treat drug abuse as a crime and do not wish as a society to appear to condone that which we regard as unacceptable.

Perhaps the best we can say is that we obviously do not want more addicts to have to rescue from addiction but neither do we want to turn our backs on one of the genuine causes of mortality among such people. Here we cannot do the ethics without epidemiology in that we need to know whether availability of needles is a genuine factor in the prevalence of dangerous drug abuse and whether AIDS is making a significant long-term difference to its mortality. It seems likely to me that the former is untrue, although I have no evidence to that effect, and that every death from AIDS caught while "in the scene" is a tragedy. For this reason I would support the provision of exchange needles.

A final and broader comment on public health measures to deal with AIDS can be made by drawing on the model of justice developed by John Rawls. On this model, any arrangements in a just society should be acceptable to a group of rational negotiators none of whom know which place in that society they will finally occupy. On this account the resultant constraints on any "marginalised groups" would need to be tolerable to every person whether or not they belonged to such a group.[7] This produces a fine balance between the common weal and minority rights rather than just endorsing the tyranny of a majority.

3 Ethical constraints on transactions between individuals where there is a risk involved.

Justice Kirby raises another important issue: "calls are now being made, and sometimes answered, for the provision of specific crimes to penalise the deliberate or reckless spread of this potentiality lethal virus".[8] I share his reservations about such legislation. "Criminal offences, which have only a minor symbolic value and are rarely prosecuted with success, may actually prove counterproductive because they discourage test-taking".[9] The last worry is consequent upon a clause linking

7 Justice Kirby has discussed marginalised groups, infra at 7-9.
8 At 3.
9 At 4.

culpability to knowledge of one's positive HIV status. We have statutes in New Zealand that could, arguably, be pressed into service in relation to AIDS. "Every one is liable to imprisonment for a term not exceeding 14 years who, wilfully and without lawful justification or excuse, causes or produces, in any other person any disease or sickness".[10]

Now, it seems entirely right to hold a person guilty of a crime who wilfully infects another person with AIDS whether his evil intent is general or focused on that individual. However the first problem in pressing such a charge, as has been suggested, would be to identify the relevant causative act. But I presume it is possible, where one can identify a pattern of actions some elements of which must have been responsible for a harm, to hold those responsible for them responsible for the harm caused. The second major problem would seem to be to prove that the requisite intent was present given the alternative explanations for the behaviour exhibited. It is far more plausible that the infected partner acted with disregard for the foreseeable consequences of his actions or that he was afflicted by *akrasia* (weakness of the will). If the former were true then it might be argued that the individual acted with reckless disregard for the safety of another person and that the act or relevant omissions (not emissions) should have been recognised as likely to endanger the health of other partner. To sustain this argument one would, presumably, need to show that even if the critical course of actions was pursued for acceptable reasons there was both an awareness of the possibility of causing harm and a failure to take any measures to forestall it. It could, of course, be argued that an at risk person has reason to *believe* he may be a danger even if he does not *know* he is. It is likely however, for the reasons already given, that the clear moral duty will remain just and only that — a moral obligation to care for the welfare of those with whom one has to deal in as much as one's dealings with them impinge on their welfare. Legal measures are likely to act neither as a deterrent from the "reckless" behaviour nor as an incentive for desirable behaviour in this area.

The other plausible scenario involves *akrasia* or weakness of the will. Here the individual appreciates that he ought to take certain precautions, and not cause danger to another, but he is swayed from adhering to this intention by the occurrent motivation for sexual gratification and perhaps a fear of its denial if he discloses certain information or acts in certain ways. Humans do get swayed from their reasonable, "all-things-considered", best judgments and what sways them has a far less reflective and even-handed lineage than deliberation. For this reason adding further reflective considerations such as laws or moral maxims is singularly unsuccessful. The fact that reason has already failed suggests that further reason will not fare any better and therefore that we must recognise what Hodgson[11] has called

10 Crimes Act 1961 s201. I was made aware of this by Peter Skegg.

11 "The legal and public policy implications of Human Immunodeficiency Virus antibody testing in New Zealand", infra.

"the inherent limitations of the law in modifying behaviour". We could say that here reason has reached its limits of jurisdication; as Aristotle observes, "if water makes him choke what can you give him to wash it down?".[12]

What is needed to overcome both of these plausible defects in intention is to change the character and dispositions of the agent concerned so that he intuitively acts out of some concern for others and preserves the commitment to so act in the face of occurrent and conflicting desires and fears. This, of course, is a change which goes beyond the rule of any law and concerns what we might call "the settled habits of the human heart".

4 Confidentiality

The human heart is directly relevant to the importance of and our respect for confidentiality. There is a potential conflict inherent in the doctor's duty to protect his patients from harm and his duty to respect confidences. I have explicitly argued that we cannot and need not develop an effective ability to protect the general public or society at large from AIDS. But two cases arise where specific identifiable individuals are at risk of infection: (i) the sexual partner; and (ii) the surgeon or other professsional colleague. In most cases we can, I think, agree with the British General Medical Council:[13]

> Where HIV infection or AIDS has been diagnosed, any difficulties concerning confidentiality which arise will usually be overcome if doctors are prepared to discuss openly and honestly with patients the implications of their condition, the need to secure the safety of others, and the importance for continuing medical care for ensuring that those who will be involved in their care know the nature of their condition and the particular needs which they will have.

In relation to the first possible case the Council states:[14]

> There are grounds for disclosing that a patient is HIV positive or has AIDS to a third party, other than another health care professional, without the consent of the patient only where there is a serious and identifiable risk to a specific individual who, if not so informed, would be exposed to infection.

To my knowledge, the law has set no precedents in this area but lessons may be drawn from some similar situations. In the *Tarasoff* case "an action was brought against a psychotherapist for failing to warn his patient's murder victim of the patient's threats to her life. The majority of the court held that if a psychotherapist determines or should have determined, pursuant to the standards of the profession,

12 Nicomachean Ethics, Bk7, ch 2.
13 The Lancet, August 20 1988, at 464–5.
14 At 465.

that a patient presents a serious danger of violence to another, the therapist incurs an obligation to use reasonable care to protect the intended victim against such danger".[15] This decision affirmed both an obligation to warn and constraints on the fulfilment of that obligation: "The therapist's obligations to his patient require that he not disclose a confidence unless such disclosure is necessary to avert danger to others, and even then that he do so discreetly, and in a fashion that would preserve the privacy of his patient to the fullest extent compatible with the prevention of the threatened danger".[16] It would seem that the latter restrictions were the real reason for an apparently contrary decision in New Zealand medical disciplinary proceedings regarding Duncan.[17] In fact, New Zealand law allows for a breach of confidentiality both where the doctor becomes aware of child abuse and where he believes that a patient is likely to drive while suffering a medical condition which will cause him to be a danger to others. But are we ethically justified in these legally sanctioned actions?

Justification can, I think, be found in the fact that where we have a conflict of duties we appeal to more fundamental commitments to resolve it. We have an ethical commitment to confidentiality on the basis that it harms a person in certain ways for others to be acquainted with facts about him with respect to which he feels sensitive. But the risk of death to another is a more serious harm and justified overriding the conflicting duty. However, there is not only an appeal to relative harms here. I have argued elsewhere that the infected, deceitful individual is "free-loading" on a climate of mutual care and respect by exploiting medical confidentiality and endangering his partner.[18] Thus, in my discussion, I have overturned confidentiality when two conditions hold. First, an unaffected person must be threatened by identifiable or probable harm and therefore have a claim on the doctor's promise that she will keep people from harm where she can. Second, the partner, in his own relationships, undermines the values of mutual trust and "responsiveness to the moral features of human interactions" on which confidentiality is based.

5 Euthanasia

The last issue which I shall address is euthanasia. The fact that AIDS is an unpleasant and fatal disease has led to calls for renewed attention to legislation permitting euthanasia. The legal attitude to euthanasia is, at present, to regard it as assisted suicide. We do not have strong legal sanctions in place to forbid assisting a suicide and the reasons for so doing are obvious (one cannot, for instance, retrospectively discern the true wishes of the victim). But the possibility of malign or reckless action bringing about a victim's death seems remote when this is part of a course of medical

15 *Tarasoff v Regents of the University of California* (1976) 131 Cal Rpt 14; 551 P 2d 334.
16 At 347.
17 *Duncan v Medical Disciplinary Committee* [1986] 1 NZLR 513 at 521 per Jeffries J.
18 "AIDS and confidentiality" (1988) Journal of Applied Philosophy 4.1 at 15-20.

care (Dr Crippen aside). It is just implausible to argue that doctors may be found to have in their ranks a number of closet psychopaths and murders who will begin killing their patients in hospital wards throughout the country if we "take the brakes off". What is more, it is quite possible to accommodate euthanasia within a legal system as a carefully constrained practice. In Holland a doctor who has killed a patient will not be prosecuted under the existing homicide legislation if the following conditions are met:[19]

1 the patient has to be informed about his situation;
2 the physician must have become convinced that the patient's request to terminate his life is the result of careful consideration and that he has upheld his request freely;
3 the physician has come to the judgment that termination of the life of the patient. . . is justified, because he has come, together with the patient, to the conviction that there are no alternative to the untenable situation of the patient;
4 the physician has consulted another physician included in a list drawn by the Minister.

But I have argued elsewhere that the situation is not as clear as it might be in this area.[20] First, I would claim, with the BMA, that the distress of terminal illnesses such as AIDS can be greatly mitigated by good palliative or hospice-type care in which the patient's needs (which are not only physical but also psychological and spiritual) are met.[21] Second, there may be many reasons for a euthanasia request, as there may be for a suicide and, when unfolded, these may not amount to a good reason for terminating the patient's life even though they do express real and unmet human needs. Third, there is a link between our practices and the intentions that we tend to form.

That the link goes both ways should give us some pause. When abortion was legalised it was thought that a number of safeguards had been put in place to check a slide towards abortion for ill-considered reasons. Without taking a moral stance on this issue, one can observe that the practice of performing abortions has changed our conception of what is involved. This has reached the point where the moral significance that was once almost universally read into abortion is now no longer readily discerned so that the intention to abort is no longer seen to be as serious and weighty as it once was. Thus the practice has changed the way in which we view the intention. Without saying anything about the link or lack thereof between abortion and killing one can derive certain thoughts about euthanasia from these well-known social observations. It is not only possible but plausible that euthanasia may go

19 Leenen, "Euthanasia, assistance to suicide and the law: developments in the Netherlands" (1981) 8 Health Policy at 197–206.
20 "Euthanasia, letting die and the pause" (1988) Journal of Medical Ethics 14.2 at 61–8.
21 The BMA Report on Euthanasia (1987).

through the same evolution from a thing that is seen as serious and needing careful safeguards to something which is regarded with much more equanimity. But it seems to me that the decision to kill an adult human being should not be lightened in this way. The murderer, as Peter Winch has observed, is changed by his murder.[22]

Going in the other direction we can consider the effect of endorsing a certain type of intention on the subsequent behaviour of the agents concerned. Aristotle clearly saw that an agent's character is not only the source of her intentions but, in a sense, the sum of those intentions. An agent's character can be regarded as the complex of *hexes* or settled habits of the heart that she has developed. These "habits of the heart" emerge as a person formulates and commits herself to courses of action in various situations and these conceptions and commitments cumulatively build on each other to form her personality. Thus the intentions that we act upon change us as characters as well as expressing our character. I and many others fear the change that would be induced in the deepest intuitive responses should it become acceptable, initially under closely constrained conditions, for doctors to kill their patients. It would be wrong to call this "brutalizing" but it would be right to worry about its effect on an individual for whom a fundamental axiom (or better disposition) of reason and action was to safeguard and help the suffering and helpless.

Lastly, the events at the end of a person's life are complex. If, with Jean-Paul Sartre, we regard each of us as writing an autobiography of deeds and experiences, then the book is not completed until the life ends. The last sentences of many books do change the whole often in unexpected and unmeasurable ways. Thus there is a kind of reverence, a kind of "hands off" humility that many of us consider is appropriate at this point and that is expressed in what Elisabeth Kubler-Ross has called "the silence that goes beyond words".[23] We cannot predict what may happen as death approaches the dying individual. This uncertainty, and the humility which it characteristically occasions, is a further reason why I do not think it right to make the moment of death radically subject to human choice. For all these reasons I would demur from the minority but strident clamour for euthanasia.

Conclusion

I have attempted to outline the points at which law, ethics and AIDS impinge upon one another and to provide an ethical underpinning for the legislative and common law debates that we face in this area. I believe that the ethical arguments critically turn on the uniqueness of each human being and his or her personal engagement and development in relationships with others. If this is clearly kept in mind then we will all act with the humanity that is a *sine qua non* of right thinking on these issues.

22 *Ethics and Action* (1972).
23 *On Death and Dying* (1970) at 9.