

AIDS and HIV infection: ethical problems for general practitioners

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SUMMARY. *AIDS and HIV infection raise a number of important ethical issues and problems for general practitioners. The ethical issues which impinge most directly on the personal relationship between patient and practitioner are duty to care, consent and confidentiality. These issues, and some practical problems which are likely to be encountered by practitioners, are discussed with the help of case studies and by applying fundamental ethical principles.*

Introduction

THE acquired immune deficiency syndrome (AIDS) is a relatively new problem, the full extent of which is unlikely to become apparent in the UK until the turn of the century.^{1,2} To date, only a minority of general practitioners have experience of managing people with AIDS or human immunodeficiency virus (HIV) infection, but as the numbers of infected people increase few general practitioners will remain untouched by this problem.³

Only recently have general practitioners begun to consider what their response should be to this growing problem. There has been some discussion of the demands that AIDS will make on our knowledge, clinical skills, counselling skills and attitudes,^{4,6} and a working party has been established by the Royal College of General Practitioners to examine responses in these areas. In addition, there has been growing discussion of the ethical aspects of AIDS as these influence the choices that we make in dealing with people with AIDS, HIV infection or who are at risk of HIV infection.⁷⁻¹⁰ One example of this was the debate about testing for HIV at the annual representative meeting of the British Medical Association in 1987. A motion was passed stating that 'In certain circumstances doctors should be able to test for antibodies to the human immunodeficiency virus (HIV) without first gaining the patient's consent'.¹¹ This resolution was greeted with alarm and dismay, with accusations that doctors were more concerned about protecting their own interests than serving those of their patients. The original motion was modified by council and later held to be illegal, on the opinion of two eminent lawyers.¹² However, this debate continues, with a body of opinion maintaining that the doctor should have the right to perform the test without the patient's consent.

Patients too are concerned about ethical issues. A recent study of AIDS patients showed that the main reason why they expressed a preference for visiting the hospital rather than their general practitioner was concerns about confidentiality.¹³ Another study demonstrated that over 60% of university students were unwilling for their general practitioner to be informed of the results of a blood test for HIV performed by a sexually transmitted disease clinic, because of concerns about confidentiality.¹⁴ In addition, there are reports of doctors refusing to treat pa-

tients with AIDS, removing them from their lists and testing patients without their consent.

The purpose of this paper is to discuss some of the ethical problems that AIDS and HIV infection present to general practice, and to describe, using case studies, situations that are likely to be encountered in the surgery.

Ethical principles applicable to medicine

Ethics is the study of morals. It is concerned with the rights and wrongs of any particular decision or course of action. For the most part, we are unaware that there is a moral content to a consultation unless a moral dilemma occurs. Nevertheless, moral issues are an important influence in decision making in general practice alongside physical, emotional and psychosocial components.

There are a number of ethical principles fundamental to medicine.¹⁵ These are expressed in ethical codes, such as the Hippocratic oath, and in good conduct guidelines, such as those produced by the General Medical Council.

Respect for persons

Respect for persons means treating patients as having rights and involves finding out what they want and trying to meet these requirements.¹⁶ It recognizes patients' right to know, their rights to privacy and their rights to treatment — and to refuse treatment. From the principle of respect for persons follow two important moral rules — confidentiality and consent.

Confidentiality. Confidentiality can be considered to be respecting other peoples' secrets,¹⁷ and is an extension of the patient's right to privacy. Patients' interests are served by the doctor being better informed but if patients knew that their secrets were likely to be divulged then they would be reluctant to give information to the doctor. Although this is an important moral rule, it is argued that there are situations when confidence can be broken.

Consent. Consent can be considered to be an extension of the patient's right to know and can be defined as 'a voluntary, uncoerced decision made by a sufficiently competent or autonomous person on the basis of adequate information and deliberation; to accept rather than reject some proposed course of action that will affect him or her'.¹⁸ This definition emphasizes two things. First, that the patient has a choice in what happens to him or her, and secondly, that the choice is made after the necessary information has been provided. Consent in this sense is by definition informed consent. Within the consultation the patient can be thought to be disadvantaged because of the doctor's self-interest, by being ill, having limited medical knowledge and power, and by being overawed by the doctor. The application of this moral rule helps to correct any disadvantage by empowering the patient and respecting the patient's rights.

Duty to do good and avoid harm

Benevolence can be considered to be the doctor's duty to put the patient's interest before his or her own. It is counterbalanced by non-maleficence, a duty not to do harm, which is possible with some forms of medical intervention which are beneficial in themselves.

Fairness to all

Justice demands that there is no discrimination on the basis of age, sex, religion, sexual orientation or preferred lifestyle, with equal opportunity of access to resources.¹⁵ In the case of AIDS this principle would demand equal access to counselling, prevention, assessment and treatment services, including treatment with azidothymidine. In addition, resources must be distributed fairly and with the increasing financial burden that AIDS poses to the health service, this is an ethical issue of great practical importance.

While these are the main ethical principles that can be applied to our discussion there are also certain themes which run through any discussion of ethical issues related to AIDS:¹⁹ the rights and duties of individuals versus the rights and duties of society, caring versus judging, and advising and counselling versus adopting a particular moral posture.

Ethical problems related to AIDS and HIV infection

Some issues, such as the rights of people with HIV-related dementia or the mentally handicapped with HIV infection, have attracted little attention from doctors. Other issues, such as making AIDS a notifiable disease, and the anonymous and voluntary screening of the general population and antenatal patients, are vigorously debated. In general practice there are three major ethical issues surrounding AIDS and HIV infection which impinge directly on the personal relationship between doctor and patient — the duty to care, consent and confidentiality.

Duty to care

Case study: John is a 22-year-old homosexual who has recently been diagnosed by his sexually transmitted disease clinic consultant as having AIDS. He agrees that his general practitioner should be informed and within a few weeks receives notification from the family practitioner committee that he has been removed from his doctor's list.

This case raises the issue of the doctor's duty to care for a patient with AIDS. In this situation the general practitioner exercised the right to remove the patient from his or her list and hence avoided treating him. Was this a just and fair thing to do?

The fact that some doctors are unwilling or reluctant to care for people with AIDS, has led to appeals for doctors to realize that they have a duty to care.²⁰⁻²² It is often stated that our predecessors treated people with more infectious diseases, such as tuberculosis, hepatitis B and plague²³ but a closer inspection of history shows that their responses were varied, with some doctors deciding to care for patients so as not to be seen to be cowardly and other doctors, including Sydenham and Galen, fleeing from the epidemic with their private patients.^{24,25} There are three main reasons for this reluctance to care: a fear of infection, a sense of hopelessness and powerlessness, and difficulties in dealing with certain groups of patients.

Fear of infection. Since HIV was first isolated several studies have shown that the risk to health care workers is small.²⁶ The major risk is through penetrating or needle-stick injuries. The risk of seroconversion after accidental exposure is less than 1%, and so far, only a small number of health workers have acquired HIV infection occupationally.

A sense of hopelessness and powerlessness. People who learn that they have become antibody positive often feel powerless or hopeless in the face of the virus.²⁷ A diagnosis of AIDS is associated with inevitable mortality; this is something that we cannot prevent, despite our knowledge and modern technology,

so we can share these feelings of hopelessness and powerlessness in dealing with people with AIDS. AIDS also reminds us of our own mortality, perhaps because many of those affected are young people.

Difficulties in dealing with certain groups. It is important to recognize our own attitudes and prejudices towards people in high risk groups.²⁸ Dislike of homosexuals is common even among those caring for them. A small minority of carers believe that homosexual patients are 'getting what they deserve'.²⁹ Intravenous drug users are often described as manipulative, uncooperative and demanding of prescriptions for drugs. In addition, there has been a tendency to label homosexuals and drug users as 'guilty victims', with children and haemophiliacs labelled as 'innocent victims'. This creates a hierarchy of blame which reflects our attitudes to these groups.³⁰

Can the actions of John's practitioner be justified? The arguments of those who defend refusal to care include a belief that the obligations to self and family override obligations to patients, that treating patients when one is fearful or hostile only compromises their care, and that some doctors are unable to cope emotionally.³¹ If we apply the ethical principle of beneficence and recognize that the patient is dependent on the knowledge and help of the doctor, we see that the doctor must efface self interest and care for patients with AIDS. This decision need not be blind to the real but small risks of infection, which can be minimized by sensible precautions. It is also not invalidated by any disapproval the doctor might have for any particular group of patients.²²

Consent

Case study: Susan is a 24-year-old intravenous drug user. She consents to a blood test for infectious mononucleosis when she develops swollen glands. Her general practitioner, knowing she uses drugs intravenously, decides to test the blood sample for antibodies to the HIV virus. This has not been discussed with Susan and her consent has not been obtained. A positive result is returned.

This case study illustrates some of the difficulties that can occur when a blood test is taken without the patient's consent. She may be angry when she finds out and may react adversely to being told of the positive result. It is recognized that this can result in adverse psychological reactions, even suicide.³²

What reasons can be given for not seeking the patient's consent? It is argued that we already take blood routinely to screen for certain conditions without seeking the patient's consent for each individual test, for example, blood from antenatal patients is screened for syphilis. Few general practitioners seek specific consent for this test and it has been argued that this establishes a precedent which could be extended to the test for HIV. However, the test cannot be considered routine because of the serious implications of a positive result. Furthermore, as consent is such an important moral rule it would seem desirable to extend this to tests where at present specific consent is not sought. Another reason given for not seeking consent concerns the patient's ability to understand what is being said and to make complex decisions. This assumes that the doctor knows what is best for the patient, but why should the doctor take responsibility for this choice and the consequences that arise from it?

Confidentiality

With AIDS and particularly the blood test for HIV there are situations where it can be argued that a breach in confidence

might benefit the patient, the doctor, nursing staff, other people or society.³³ For example: Should a patient's confidence be broken in order to try and prevent another patient from acquiring infection? Should practice and community staff be informed of a positive HIV test result or of a patient with AIDS? Should information about the blood test for HIV and the patient's sexual preferences and lifestyle be made available to insurance companies? Should the results of a blood test for HIV, performed by a sexually transmitted disease clinic, be made available to a general practitioner without the consent of the patient?

Protecting the interests of another patient. Case study: Peter is a 23-year-old intravenous drug user. He is antibody positive for the HIV virus and is having regular sexual intercourse with his girlfriend who is also your patient. She does not know of his positive status. Despite counselling and persuasion he is adamant that his girlfriend 'must not know'. His girlfriend takes the oral contraceptive pill erratically and Peter will not use a condom.

This is not a new dilemma and is similar to the situation where one partner has a sexually transmitted disease, and refuses to tell the other partner so that he or she can receive treatment and advice. Is this a situation where the patient's confidence can be broken in order to benefit another patient?

Initially one should try to help Peter take responsibility for not passing on the infection to his girlfriend or anyone else. If this approach fails, it would be justifiable to break confidence and tell his girlfriend. In this situation, the greater good has been to try and prevent the girl from acquiring the virus, especially as she is not using adequate contraception. Peter should be told of the intended course of action, and given reasons for it. While breaking confidence in this situation can be justified, the rule of confidentiality is still an important ethical principle which should only be broken in exceptional circumstances.

Practice and community staff. In view of the high level of anxiety, prejudice and fear about people with AIDS, only those directly involved in the care of patients with AIDS or HIV infection should be informed. This would include partners, practice nurses and community nurses, but not receptionists and secretaries. The patient should be told which members of staff have this confidential information. Any extension beyond this, for example, to home helps, family members and employers, should be discussed with the patient prior to disclosure.

In general practice it is unavoidable that staff who are not directly involved in clinical care, such as receptionists, will come across confidential information. Therefore, all practice staff should be educated about their duty of confidentiality towards all medical information, including that related to HIV infection and every practice must work out procedures for preserving confidential information, particularly in the written record.

Insurance companies. Currently general practitioners are asked by insurance companies to extract information from medical records about whether patients engage in behaviour which puts them at risk of HIV infection or have had a blood test for HIV. Should this information, which was given in confidence, be released to insurance companies?

While patients give written consent for the company to approach their general practitioner, they are unlikely to be aware that the company is requesting information about their sexual behaviour, intravenous drug use or the HIV blood test. The patient is also unlikely to be aware of the nature and extent of information recorded in the medical record, which may contain impressions about the patient which have no basis in fact.

This is an unsatisfactory situation. The best solution is for the general practitioner to seek the patient's verbal or written consent, and if this is refused to return the form uncompleted. More fundamentally, is it right that information which was collected for medical purposes should be made available for a commercial purpose which may not serve the patient's interests? The company can always protect their investment by arranging an independent medical examination.

HIV blood tests performed by sexually transmitted disease clinics. At present, these clinics do not release the results of blood tests for HIV to general practitioners without the patient's consent, unless the patient was referred by a general practitioner. This is the same as for other sexually transmitted diseases.

It is argued that these results should be made available to the general practitioner regardless of whether the patient has given consent. This would protect against a wrong diagnosis and incorrect treatment. For example, in a consultation for cough and fever in an intravenous drug user, knowing that the person was HIV antibody positive would suggest the possibility of *Pneumocystis carinii* pneumonia, which might be inappropriately managed if the patient's antibody status were unknown. Knowing who was antibody positive might also ensure that general practitioners took appropriate self protective measures during consultations.

There are problems with these arguments. Most importantly they ignore the patient's right to choose for him or herself. There is also considerable anxiety among patients about general practitioners receiving confidential HIV blood test results from sexually transmitted disease clinics,¹⁴ and this might dissuade people from seeking help and advice from these clinics. There are also problems with the result of the blood test, which can be negative in someone who has not developed detectable antibody. The benefits to the doctor in terms of heightening his awareness of risk and taking self protective measures are also doubtful as there will be patients who, unknown to the general practitioner, engage in high risk activities and who have not had a blood test for HIV. It is more logical to employ the same standard of self protection with all patients.

Conclusion

AIDS is likely to become the most serious health problem of this century. The ethical issues described here are not simply academic but affect the very heart of the doctor-patient relationship, with important implications for both doctors and patients. Our response to these issues, both as individuals and as a profession, is crucial and is likely to be seen as a barometer of our personal and professional integrity. It is up to us how we respond; we can either be diminished in our response or reaffirm our commitment to patients and to trying to salve some of the ills and injustices that are associated with this virus.

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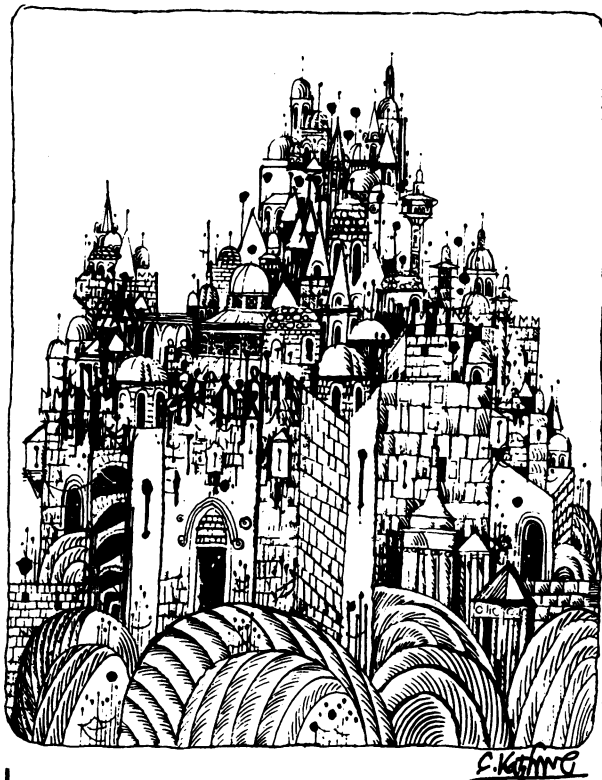


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