

Ethical issues and HIV infection

Three examples illustrate ethical dilemmas in three differing contexts.



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In southern Africa medical practice has changed as a result of the HIV/AIDS pandemic. Old ethical dilemmas resurface in the new disease environment. Three illustrative cases are presented, dealing with confidentiality, futility and resource allocation, respectively.

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CONFIDENTIALITY

Case 1

AM is a 24-year-old salesman. He presents with a short history of dry cough and breathlessness. On examination he has generalised lymphadenopathy and oral thrush. His respiratory rate is increased, but there are no added sounds in the chest. The chest radiograph shows bilateral midzone opacification with a ground-glass appearance highly suggestive of *Pneumocystis carinii* pneumonia.

His general practitioner advises HIV testing, but AM declines, claiming he will lose his job if he is found to be HIV-infected. He also refuses to share the diagnosis of pneumocystis or the possibility of HIV infection with his wife.

What are the doctor's responsibilities to the patient's wife and employer?

Comment

The dilemma arises because of a conflict of duties which the medical practitioner experiences. His primary obligations are to his patient, and he feels that he must comply with AM's instructions. However, AM's wife is either at risk of acquiring the infection and all that it implies, or, if already infected, has an interest in knowing about choices available to her.

The doctor's duty towards AM's wife is an example of a public responsibility. A classic legal case in the USA often cited in this setting is that of *Tarasoff*, where the Supreme Court of California determined that a psychiatrist had a legal duty to warn a person towards whom his (mentally ill) patient had expressed the intention of committing a violent crime.¹ The qualifying phrase used by the court was that the danger should pertain to a clearly identifiable individual or individuals. This judgment has been used many times to justify breaches of confidentiality when public safety has been involved. AM's wife is in danger of contracting a life-threatening disease, if she has not already been infected. Therefore it is important to inform her of that possibility, and to suggest that she, too, is tested. If she has already been infected, she nevertheless has a strong interest in knowing her HIV status to enable her to consider her options in dealing with the infection.

Furthermore, she is not a stranger to AM, and indeed involved in his everyday life. From the perspective of AM's best interests, she will almost certainly be involved in looking after him, both during the present illness and in the future. It is therefore of value to AM that she stays well, and takes every action to do so. AM's doctor has a duty to point this out to him,

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as well as that she has an additional right to know about his possible HIV infection if in future she will be involved in a caretaker role.

What should the doctor do? One approach frequently followed is forceful persuasion. Although AM has the right to decline HIV testing, his doctor could ask him to share all the available medical information with his wife (or offer to disclose it to her on behalf of AM. Frequently the act of discussing being infected with HIV is difficult, and in this way AM can avoid the discomfort and embarrassment of initiating the subject himself). If AM refuses, even after being made aware of all the arguments mentioned above, the doctor could explain that he will go ahead and disclose the information if AM does not. This would be overriding AM's autonomy in order to protect his wife.

The doctor's responsibility to a patient's spouse is different to his responsibility to the employer.

The relationship between AM's doctor and his employer is of a different nature. The employer does not incur a health risk because of AM, and there is no obligation for the doctor to pass on his suspicions. Even if an HIV test has been done, the doctor does not have an obligation to pass the result on to the employer. Doing so against AM's wishes would constitute an unwarranted and legally actionable breach of confidentiality. Conflicts do occur when medical practitioners are employed by companies to examine their employees medically. In this case any obligation the doctor has to provide medical infor-

mation to his employer should be stated clearly before the medical consultation.

FUTILITY

Case 2

RD is a five-year-old girl. Over a period of seven days she rapidly becomes unwell, complaining of headache and photophobia. On the day of admission to hospital she is drowsy and febrile, with prominent neck stiffness. Lumbar puncture reveals *Cryptococcus neoformans* in the cerebrospinal fluid. Treatment with antifungal and antiretroviral drugs is initiated, but she suffers a respiratory arrest within 24 hours and is ventilated in an intensive care setting. On day 4 her urine output falls and she develops pulmonary oedema. She requires high doses of inotropic support, but remains in renal failure. The paediatrician, during a daily consultation with RD's parents, explains that the evidence points to septic shock as the cause of her rapid deterioration, and that RD needs dialysis. In her experience, children with AIDS and multi-organ failure in the intensive care unit have never survived. Her counsel is to withhold dialysis in the knowledge that RD will die. RD's parents are taken aback and instruct her to 'do everything' for their child.

How should she respond?

Comment

This scenario is close to many encountered in the traditional clinical bioethics setting in North America, where conflicts between health professionals and patients (often their families as substitute decision makers) have led to the establishment of clinical bioethics services and the training of bioethicists. The latter employ decision-making frameworks (such as Siegler's²) and conflict resolution skills to seek consensus. In a less developed hospital environment,

without the luxury of specialist bioethics consultants, clinicians can nevertheless use some of these tools to understand the moral problems better and to improve the way they relate to the conflict with others' desires. For example, Siegler's framework includes four categories of considerations in a clinical case:

- medical indications
- patient preferences
- quality-of-life considerations
- external factors.

They are presented in their usual order of discussion, i.e. all the parties must first be aware of the medical facts (diagnosis, prognosis, treatment choices) before invoking patient preferences. When the patient himself is incapable of making judgements about the quality of his life, others must do so on his behalf. External factors such as limited treatment availability and public health risks are discussed last. If a systematic attempt is made to work through the framework with both parents in our case, a number of previously misunderstood or uncommunicated issues may come to light, which may assist decision-making.

In the case of intervention being futile, clinicians may find it difficult to deal with the family's demands.

Similarly, understanding different approaches to resolving conflict³ (avoidance, coercion, accommodation, compromise and collaboration) as well as the variables involved in a particular consultation (commitment to the relationship, level of moral certainty, time available and the cost-benefit ratio of resolving the conflict) will help

clinicians to avoid making harmful errors in dealing with patients and their families. For RD's parents the sudden unexpected advice to terminate their child's life is not surprisingly met by denial and hostility. Often time is needed to allow reality to penetrate — both time spent in consultation with the medical staff, and time between consultations for reflection to occur and grieving to begin. The added burden of having to make decisions for their loved one, and the moral uncertainty that this may involve, can be alleviated partially by allowing a sharing with other respected persons, such as a pastor or social worker. A request for a second medical opinion should not be interpreted as mistrust or prevarication, but rather as an effort to gain personal certitude.

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Compromise in this situation could involve an agreement on the setting of time limits (i.e. dialysis for 72 hours and then reassess) or decisions about specific treatment choices which will be withheld (i.e. antibiotics or surgical interventions). Most frequently, time narrows the gap between physicians' and families' understandings as the case evolves.

RESOURCE ALLOCATION

Case 3

JH is a medical registrar on call in a busy teaching hospital in south-

ern Africa. He is called urgently to see a 30-year-old man in the casualty department. AZ is unresponsive, cyanosed and hypotensive. He has generalised lymphadenopathy and a healed zoster scar on his trunk. There are bronchial breath sounds and coarse crackles throughout his right lung. A chest radiograph performed the previous day demonstrates multilobar consolidation on the right. JH makes a diagnosis of severe community-acquired pneumonia in an HIV-infected individual. He calls the intensive care unit registrar to seek admission to the unit for AZ.

However, the intensivist declines admission, with the comment that 'there are not enough ICU beds for AIDS patients' and 'these patients don't do well, so we have decided not to take them'. JH responds by pointing out that this episode of pneumonia is very likely to be treatable, and that AZ has a good chance of recovering with aggressive therapy — as good as many other non-HIV-infected patients who do gain admission to the ICU.

How can this conflict be resolved?

Comment

The conflict between a physician's duty to a particular patient and his duty to exercise fairness in allocating limited resources underlies this problem, and is given added dimensions by the stigma and special status of HIV infection. Another consideration in attempting to provide guidelines or a framework for priority setting decisions such as these is the fact that there are manifest differences in health care systems throughout the world, both in terms of economic constraints and sociocultural factors. Therefore it is unlikely that universally acceptable rules can be devised — admitting AZ to an ICU may be as right in Canada as it is wrong in Botswana. The rules agreed upon should free individual

practitioners from having to make such decisions for individual patients. If there have to be restrictions on what clinical decisions can be made on the grounds of resource allocation, it is much easier for the clinician (and more equitable for the population as a whole) if rules have already been set up by the time a patient is seen. How can these rules be made, and who will make them? These questions have occupied policy-makers recently, with mixed results.

Rules for policy decisions in medical facilities can remove the onus of decision-making from the practitioner.

One emerging consensus is that the process by which priorities are set will affect the fairness and legitimacy (acceptability) of decisions made. A process labelled 'Accountability for reasonableness', introduced by Norman Daniels,⁴ includes the following four conditions as components of a legitimate process: relevance (reasons), publicity, appeals, and enforcement. There is emphasis on participation by relevant stakeholders, disclosure of reasons for decisions and a functioning system of appeal against them. As regards the question of priority setting for admission to an ICU (including those with HIV), stakeholders might be admitting doctors, intensive care specialists, hospital managers, and representatives from the general public. Such a group of people would then form a committee and arrive at a consensus strategy for priority setting, which would be widely circulated for comments and appeals, and subsequently enforced and monitored.

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The above process would enable numerous variables to be brought to the table, including (under the condition of relevance) evidence for and against ventilating patients with AIDS in terms of improving prognosis. The evidence would need to be related to the conditions of the particular case, i.e. in hospitals, in countries and for people like the ones encountered. For HIV-related illnesses in developing countries there is frequently little published evidence and therefore local unpublished data, including anecdotal case reports, may need to be resorted to when deciding on a policy. It is incomparably more difficult to attempt an objective decision in an individual case without an existing accepted policy.

CONCLUSION

Using case discussions (all of which are based on situations actually encountered), I have attempted

to locate principles and methods suitable for application to a clinical environment. Clearly, more could be said about each case. Interested readers should consult the articles in the reference list, which provide more detailed and authoritative material.

References

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IN A NUTSHELL

Ethical problems are common when dealing with HIV-infected patients.

A doctor's primary responsibility is to his patient, but a conflict may arise when others are at risk.

When an identifiable individual is at significant personal risk from the patient, the doctor has a duty to warn that individual, which overrides his obligation of confidentiality.

In resolving a conflict with a patient or her family, clinicians may use a framework such as the one proposed by Siegler² to analyse and discuss a case.

Understanding some principles of conflict resolution, and allowing time for family members to deal with the emotional impact of the situation, will often enable doctors to resolve difficulties with end-of-life decisions.

Decisions about resource allocation are far better made as rules, rather than *ad hoc*, when faced with individual patients.

'Accountability for reasonableness'⁴ is a framework which describes an ethical process of making such rules, using conditions of fairness (relevance (reasons), publicity, appeals and enforcement).

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