Ethical considerations in the care of the patient with HIV/AIDS

IT GANGAIDZO, J MIELKE, JA MATENGA

These are the proceedings of a hypothetical case presented at the Wednesday Clinical Meeting, by the Department of Medicine, Parirenyatwa Hospital. The case was based on actual life experiences that wer obtained in the care of HIV/AIDS patients. The discussion was guided in such a way as to place emphasis o ethical issues and less on clinical considerations. The aim was to draw on participants' experience and practic of medicine in today's Zimbabwe. For the purpose of discussions, it was accepted that absolutely correc opinions in ethical issues of medical practice in relation to AIDS/HIV may not exist, and that the discussio was as important as any conclusions that may be reached.

Case Report

A 31 year old junior manager, married with two children (three years and nine months), presented with eight days of progressive dyspnoea, chest pain and a cough. He had large bilateral cervical, epitochlear and axillary nodes on examination. BP was 120/70mmHg. He was pyrexial but had a normal cardiovascular system. The chest was clear. The chest X-ray showed bilateral reticular and nodular shadowing ("ground-glass") appearance in mid-zones; sparing apices and bases.

Presumed diagnosis: *Pneumocystis carinii* pneumonia with underlying HIV infection.

Question: As a clinician, what do you tell the patient about his illness at this point? If you strongly believe there is underlying immunosuppression, when do you discuss this with the patient?

Discussion

All participants agreed that the patient should be told he ha a special type of pneumonia. It is whether or not to tell th patient about underlying HIV that pauses problems for th clinician. Two approaches were put forward. The first was t treat the immediate illness and to follow up with delaye introduction of the subject of underlying immunosuppressio on subsequent follow up consultations. The patient is ther allowed to go and think about it and on subsequent visits, the patient is asked about his views regarding HIV testing.

This approach has the advantage of minimising the "shock" and distress during the acute illness. Against this approach is the danger of losing the patient to follow up before he has been informed about his HIV status especially if he gets better quickly as is expected with *Pneumocystis carinii* pneumonia. The question also arises about whether the doctor is putting

Department of Medicine
University of Zimbabwe Medical School
P O Box A178, Avondale
Harare, Zimbabwe

Correspondence to:
Dr IT Gangaidzo

off the unpleasant task indefinately and eventually forgets about it.

The second approach is to immediately hint to the patient during the initial discussion of his illness. Most patients and relatives ask what the matter is at first presentation. A careful and sympathetic but truthful approach indicating possible reasons for pneumonia e.g., exposure, aspiration after excessive alcohol and other unknown reasons would be well taken by most patients. The doctor should also add considerations of weakened immunity due to mechanisms related to HIV infection.

Immediate introduction of the subject puts the doctor and patient at the same level of thinking. Subsequent discussions of the subject becomes easy and less stressful for both parties. Only a few patients are genuinely surprised, as they would have considered this possibility. Both approaches are practiced by experienced clinicians in the meeting with more in favour of the second option.

Progress of the Case.

After adequate pre and post test counselling, the patient consented to serology testing and was found to be HIV positive. He got better on treatment but the wife had never been present during all these proceedings.

The wife phoned at three weeks post discharge to say her husband was still unwell. "He is usually a very healthy man. What is going on doctor? Is he going to get better? Are you sure you have the diagnosis right? He is not discussing what the problem is with me."

Question: What do you tell the wife?

The first issue is that of discussing any confidential medical matter over the phone. It was agreed that this should not be done under most circumstances as no doctor can guess who is at the other end of the phone, or who else might be listening.

Although ethically the doctor cannot divulge the information to the spouse, the welfare of the spouse is an important consideration. Firstly, the doctor should advise the patient to do so himself emphasising that it is in his interest to do so as the wife will need to care for him later. Furthermore the current legislation allows the caregivers to be informed about the patient they are looking after as they incur some risk of infection if precautions are not taken. For a home based patient the spouse is the major care giver. If nurses are routinely informed of the patient's diagnosis then ways to inform the wife must be found.

To avoid this unpleasant situation, the ideal situation is for he doctor to invite the patient and spouse or other interested close members of the family (not a problem to find these in the Zimbabwean African culture) to be present during the pre and post counselling meeting and to suggest HIV testing for both partners.

The spouse and close family must be considered as the first caregivers. The patient must be prevailed upon to discuss the condition with close members of the family. In the case of a patient who categorically refuses to have details of his illness divulged to a third party, then the doctor's commitment to confidentiality puts him in a difficult situation. This issue drew a lot of discussion.

Progress of the Case.

The employer rings, "Mr X was supposed to be back last week. I understand from his wife he is still not well. I have plans for him to go to the UK for a six months training course since we plan to promote him to senior manager. I have great plans for this young man. Can we go ahead with our plans doctor?"

Question: What do you say to the concerned employer?

As with the wife, there cannot be any discussion over the telephone. The serious dilemma is for the doctor not to compromise the patient but equally to find a way out of the situation without misleading the employer by either refusing to advise or deliberately giving the green light on the basis that the patient is likely to survive for a few years anyway.

Clinicians agreed that the only way out is to involve the patient. He should be encouraged to discuss issues relating to his illness and training with his employer. If he agrees, then the two should get together. The practical and common problem remains, if the patient refuses to divulge any medical information to his employer, but at the same time wishes to be considered for promotion. The doctor must consider patient confidentiality very carefully.

It is important to note that in Zimbabwe, in this era of high prevalence of AIDS/HIV, refusal by a doctor to divulge the nature of illness to the employer and especially to advise the company on the future plans is easily interpreted as suggesting a serious illness with poor prognosis - nowadays this often means AIDS. If the patient has conditions which are not stigmatised (diabetes, cancer of the bladder or renal failure) it is often not a major problem to obtain the patient's consent to reveal detailed information to the interested employer.

Development and Treatment of Complications.

The same case developed cryptococcal meningitis and ended up in hospital two months later. The diagnosis was confirmed by lumbar puncture. Concerned relatives visited the doctor and asked the following question "Can't you treat this brain complication? What about the HIV itself? We understand that no one dies quickly from AIDS in developed countries. Don't we have these drugs here?"

The truthful answer is that drugs are available and the quality of life may improve. Improvement of life expectancy may be questionable. It must, however, be pointed out that the cost is prohibitive. Because treatment is for an indefinite period and multiple combinations are more effective, together with the fact that in this country, the medical aid societies do not cover retroviral therapy, treatment is realistically out of reach of most people, even the well to do. It does help for clinicians to have figures at hand to give to the family in order to appreciate the financial implications of therapy (Table I).

An important ethical consideration is the possibility of the patient channelling all his financial resources (including the legacy of the soon-to-be widow and orphans) into anti-cryptococcal treatment. Life expectancy with such a complication is markedly reduced, but the improvement in the quality of life may be achieved at the expense of better provisions for the family. How the patient or relatives consider the options may depend to a large extend to how the doctor answers the questions posed to him. Another consideration is the ethics of giving long term anti-retroviral therapy to the patient without considering the spouse's welfare.

Conclusion. These are practical real life problems of managing AIDS/HIV patients. The process of counselling

Table I: Cost of anti-retroviral agents for HIV and one of the complications.*

Anti-retroviral agents for one month		Cost of treating cryptococcal meningitis for one month	
- AZT 200 mg t.i.d.	$ 6 599.25	- intense regime (200 mg t.i.d. for 2 weeks	$14 970
- saquinavir 800 mg t.i.d.	$18 584.00	maintenance cost per week (100 mg bd)	$ 2 475
- Lamivudine 150 mg t.i.d.	$12 755.00	- typical monthly regime	$19 754
- Hivid 150 mg t.i.d.	$ 5 790.00		
- didanosine t.i.d.	$ 4 994.40	**Fluconazole**	
- hydroxyurea 500 mg bd	$ 1 796.93	- intense regime (two week)	$12 750
		- typical montly regime	$16 256
Typical "optimal treatment"			
AZT + lamivudine + saquinavir = $37 938.25			
The "poor man's option"			
- Didanosine + hydroxyurea = $6 791.33			

**** Costs based on average quotation from local pharmacies for the month of February 1999.***

should start at the earliest opportunity after first contact with the patient. A clinician cannot discuss anything about a patient over the phone as the identity of the caller is always uncertain. Employers should put their requests in writing.

The ideal approach is to pre and post test counsel the couple together to avoid the espionage atmosphere between the patient, the spouse and the doctor. In the event that counselling could not be carried out with the couple for legitimate reasons then the index case should be advised to discuss with or bring the interested third party to the doctor to discuss the conditions with the index case's consent.