

# ETHICAL ISSUES IN HIV INFECTIONS

Garth Brink speaks to Dr Edoo Barker,  
Chairman of the Committee for Science and Education  
of the Medical Association of South Africa

**Dr Brink:** Simply put, "ethics" means what is right and what is wrong. There is nevertheless a lot more to it than that. We hear terms about patient autonomy, patient welfare, paternalism, privacy of the patient and control of information. All this has to be taken into account when we meet our patients and make decisions regarding management. Confidentiality and the patient's right to information further cloud our decision-making process.

Through the doctor-patient relationship, we practitioners have tremendous power over our patients, whether we actually realise it or not. This relationship can be good or bad; it can be very directive or we can sit back and allow our patients to make the majority of the decisions. We can exert power in the way in which we divulge information; whether we tell patients the entire truth or part of the truth, or not at all. We can influence a patient's decision in a preferred direction.

**My first question is: "Why is it that now, with the advent of HIV, we have these ethical dilemmas, when previously we would just carry on and generally not be too concerned so much about the patient's welfare and the patient's rights? In what way do medical ethics differ from ordinary ethics?"**

**Dr Barker:** The power that the doctor wields over his patient is immense. People talk about this beautiful, sacred, holy, lovely doctor-patient relationship. The only relationship that has quality is one between equals and I cannot imagine a more unequal relationship than that which exists between doctor and patient.

A doctor has all the power, the knowledge and the ability, with subtlety or without, to influence a patient's decisions as to what happens. He or she actually wields the power of life and death. Unequal relationships are open to abuse and it is for this reason that doctors should be so conscious of the responsibility that they carry. They must be aware of the power they wield and of the possibility of imposing upon the patient that which the doctor considers to be in the patient's best interest, but is actually not what the patient himself perceives to be what he/she wants.

Ethics have to do with what is right and what is wrong and in every doctor-patient interaction there is a dilemma. In the past it seldom became an issue. We knew what was right for our patient and what was a good thing to do. "Do no harm" was the order of the day. As far as patient autonomy is concerned, I do not believe that we even thought about it.

Above all, a doctor has a crucial need to be aware of the impact of whatever he does in his relationship with his patient or his patient's community in terms of social justice. It is as important as not doing harm and doing good.

Virtually every interaction implies not only an ethical decision, but an ethical dilemma as well. On a daily basis we are faced with these decisions and dilemmas when we come into contact with patients who may be HIV-positive or have AIDS.

The dilemma arises because of the conflict between competing rights. The person who is HIV-positive or who has AIDS has rights. There is also the right of the health worker to a reasonable degree of security in the practice of his or her profession that he or she will not contract AIDS. Then there are the rights of the community. How big a threat is a patient who is now identified as HIV-positive or suffering from AIDS? How great a risk does he or

she pose to the community at large and what are the rights of the community as opposed to the rights of the person himself? This is where the dilemma lies.

This is now changing. The days are gone when one did tests for syphilis without the patient's consent. Things have changed largely because of what has happened since the advent of HIV and AIDS and the development of consumer awareness. Most of our patients are aware that they are not inanimate beings in our hands, but that we are there as professionals to offer them what we have in the way of skills, knowledge and advice. It is they who are responsible for themselves and they are taking responsibility with both hands. People ask, "What is different about HIV, AIDS, syphilis and any of these other stigma-carrying diseases?" The point is that there has never been a disease with all the characteristics of HIV. It is predictably and still today, universally and unavoidably, fatal.

AIDS carries an emotional connotation, more profound and more powerful even than that carried by the word "cancer". The stigma, the inevitable fatality and the actual impact on the patient in terms of his everyday life, are enormous.

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The ability to obtain a house bond, insurance and frequently the ability to gain or retain employment are all affected. For these reasons people who are HIV-positive or have AIDS have joined together into an incredibly powerful lobby group.

**Dr Brink: Why should we treat and manage HIV as something different from other diseases? Why can't we just get rid of the stigma, everybody come out, acknowledge themselves as HIV-positive?**

**Dr Barker:** The only answer to that is to go and talk to the people who are living with HIV and ask them what they think. It's not up to us as doctors to impose. Our role as paternalistic decision-makers has changed. Today we are servants. We can offer, but not impose on our patients. And we have to ask the opinions of those with HIV and AIDS.

**Dr Brink: Initially when HIV first appeared on the scene it was thought that it should be a notifiable disease. There have been lobbyists for and against this suggestion. There was a strong feeling that, in order to be able to put the brakes on it, in order to be able to introduce some form of control, HIV/AIDS should be a notifiable illness. Yet this has not happened. Why?**

**Dr Barker:** If one is going to notify a disease, there are two options. It can be anonymous, where details of the patients are not supplied, or where all the details are provided. If the details of the patient were public domain and accessible to everybody, this would have disastrous consequences for the patient and his family.

To compensate for that, what sort of benefit could we expect from notification of AIDS, especially identified notification? One of the reasons for notifying the disease is that it enables public health officials to try and detect the source and prevent further spread of the disease. Notification, which allows active and positive intervention, is vital for the community. Notification of HIV and AIDS? You are notifying history. The infection occurred somewhere between months and years ago. This is historical information, which, by the time it gets to the epidemiologist, is irrelevant. If you are trying to control transmission of infection, this is pointless.

If we want epidemiological statistics to help keep track of the success of interventions, then we must rely on the non-identifiable methods of notification where the patient is not identifiable as the source of the positive blood. The rights of the community to have epidemiological information, which would allow effective public health measures to be implemented, supersede the patient's right to refuse to have his or her blood tested in an unidentifiable and unlinked way. This is policy throughout the third world today. Notification of HIV/AIDS would do huge damage to the sufferers and would provide precious little benefit to compensate for this.

**Dr Brink: What is the situation in terms of pre-employment medical examinations? Can an employer insist that the employee undergo an HIV test as a condition of employment? Is this an acceptable practice, or is it something that may not be legally enforced? The problem could arise that employment is granted subject to a negative HIV test.**

Dr Barker: Any employer who asks for an HIV test as a condition of employment is in contravention of fundamental constitutional law and could be taken to court. The problem is that there are certain areas where exceptions are made where it would be actually dangerous for an HIV-positive person to be accepted into employment. The risk of an HIV-positive person who is acting as a health care worker, be it doctor or nurse, is almost invisible. Doctors, especially surgeons who are known to be HIV-positive, are allowed to practise in this country.

Pre-employment testing is something that one must not and may not do. If you are going to test anybody, you are going to talk about counselling and consent. Only with the full understanding and agreement of the patient may you test.

**Dr Brink: I think we must expand on that particular aspect. What should we be dealing with in this pre-test counselling session with our patients?**

Dr Barker: Prior to embarking on pre-test counselling, ask yourself: "What am I going to do with this information — will it really alter my management?" There are some patients who are so clearly HIV-positive and when this is confirmed the information makes no difference to the management. Do you really need this information, is it going to be of any interest to the patient, is it going to alter the treatment at all?

You will be surprised how many of the prospective HIV tests you will in fact not do. Having decided there is a good reason to test, then you must counsel your patient, unless you have access to a professional counselling service.

Start by stressing that the test and the results are confidential. Many patients simply refuse because they believe the minute we know everybody else will know. If you are going to stress confidentiality then you have to be sure that your system of confidentiality is secure.

Evaluate briefly what your patient knows or understands about the whole business of HIV and AIDS. It's a useful opportunity to evaluate the patient's lifestyle, including the possibility of promiscuity and drug usage. You need to explain to the patient why the test is necessary, what you are going to do with the information gained and how it will help in the planning of his/her management. Then go on to explain that there are drawbacks to being tested, especially if the test comes back positive.

The drawbacks are self-evident. First of all he/she is going to have a huge psychological shake-up. There will be the need to face up to the reality of a fairly long-term, but irreversible, death sentence. There will be the need to adjust to the total change of the structure of his life and his future; problems of insurance and employment, interpersonal problems, the need to notify close associates, especially sexual partners, the need perhaps to change his whole sexual style, the need to adopt secure, safe sexual practices and so forth.

It is also an opportunity to discuss the coping mechanisms, support and resource systems that are available, so that you, the doctor, can prepare yourself to provide what the patient might need. Probably one of the most catastrophic things that could ever happen to one of your patients is to be told that he is HIV-

positive. Use it as an educational opportunity, education about sex, safe lifestyle and prevention of spread.

**Dr Brink: One of the problems that we deal with is the patient who is informed about the positive test result and refuses to notify the partner. Many feel that we have a moral obligation to society and to the community at large to inform the partner without the consent of the particular patient. So my question would be: When can information be divulged to a third party without the consent of a patient?**

Dr Barker: This question of divulging information to the patient's family is fraught with danger. Do not talk to a patient's wife, husband, or any relative for that matter, without first talking to the patient and explaining what is to be divulged to the partner, relative or other family member. Encourage openness and point out that, if life is going to be lived in an aura of lies and concealment and separation, then the one time when togetherness is absolutely vital will be the time they are separating from each other.

The days are gone when you would first discuss the issue with the partner or relative and ask: "What are we going to tell him?" It is incumbent upon us to talk to the patient and ascertain whether this information can be given to the partner or spouse. If you have established a proper doctor-patient relationship of trust, confidence and working together, it is unlikely that this problem of not being granted permission to inform the partner will arise.

What you do is to offer to your patient: "I am not asking you to go out there and face this on your own. Do you want me to talk to your partner? Bring your partner in, let us sit, the three of us and we will talk this through. I am here as your supporter, as your friend, as your protector. You cannot live the rest of your life in any sort of relationship with your partner with this lie going on between you." The situation can and does arise when you deal with a totally intransigent patient who states quite categorically that the spouse or partner may not be informed. If you know who the partner is, that the patient will not inform the partner and will not take steps to practise absolutely reliable, safe sex, then you are free to inform the partner. However, the patient must be told what you are going to do — do not do it behind the patient's back.

**Dr Brink: Even if he says to you: "I am sorry, under no circumstances may you tell anybody and I will take you all the way if you do"?**

Dr Barker: The INMDC, MASA and the College of Medicine will support your decision to inform the partner, provided the patient has been informed that you will be doing so.

**Dr Brink: Can we consider the following scenario: A 32-year-old male knows that he is HIV-positive. During the various discussions he informs you that the nature of his problem may not be disclosed. He refuses specific treatment for opportunistic infections. He subsequently develops cryptococcal meningitis and is admitted to hospital. His condition deteriorates and he becomes comatose. We know that we can do something that would improve his condition and restore a reasonable degree of quality to his life. The family now come on the scene and want to know what is happening and what treatment is being administered. We are faced with a dilemma. Do we adhere to our patient's request that we do not treat him? We know that if we tell the parents and he does not survive there will be no come back. If he does survive and he finds his family knows about it, we are then in serious breach of patient confidentiality.**

**What is the ethically acceptable approach in this situation? Are we acting in the best interest of the patient? Could this have been avoided in the first place?**

Dr Barker: If you have a patient who tells you, "I am HIV-positive. I do not want anybody to know. If I get an opportunistic infection I do not want treatment. If I become incompetent, this instruction of mine remains." This is like a living will and he must commit this to writing and sign it. The patient's autonomy is total in this regard. You may not intervene under any circumstances whatsoever.

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ever. This document is shown to the family should they knock on your door wanting explanations and this will cover you in your actions. I think that no doctor has a right to interfere, but there is debate on it.

**Dr Brink:** Let us assume that our patient does die and this information has not been disclosed. The death certificate has to be completed. The family has access to this document and it would see that AIDS was the cause of death.

Dr Barker: Justice Edmond Cameron, formerly a judge of the Constitutional Court, currently of the Supreme Court, submitted a legal opinion outlining the legal status of the death certificate. It is not a death certificate — it is a medical certificate relating to the cause of death. He points out that the sole statutory purpose of this certificate is to satisfy the Home Office and Registrar that the death was not due to unnatural causes that need to be investigated. He stated that, where the revelation of a particular disease such as HIV/AIDS could be damaging to the relatives, it was his opinion that it was perfectly legitimate for a doctor to write “natural causes” or “pneumonia” and simply to leave out contributing causes, although he knew HIV/AIDS played its part. Remember that nobody dies of AIDS — they die of the diseases facilitated by AIDS.

My standpoint still is that you are free if it is in your patient's interest and the interest of your patient's family, not to write this down. Remember that this is a public document — on the payment of R5 anybody on the street can walk into the office and pick up that death certificate. There is no confidentiality.

A completely new death certificate will be available, probably within the next eighteen months. It provides the patient's name, age and all the details of whether the death is due to a natural or unnatural cause. Underneath is a perforated page with a most carefully-designed user-friendly form. This form has a small computer number at the top, which is protected by strict access codes that are only available to people who have absolute right to that type of information. This is totally unidentifiable information that tells you everything there is to know about the patient, including his smoking habits.

**Dr Brink:** Earlier you referred to the importance of an equal relationship. There is an excellent book entitled *A meeting between experts*. On the one hand, there is the medical practitioner with the knowledge of medical science and, on the other, the patient with his/her own fears, concerns and needs. When the two experts meet we have to try and find the common path and explore the way in which this can actually be achieved. We need to look forward to avoid some of the problems that could occur.

Many of the issues that could arise can certainly be addressed or pre-empted where there is a sound, trusting, open and honest doctor-patient relationship. This establishes a forum where many of these issues can be discussed openly, where we can at least inform the patient of the consequences of a decision, so there is an understanding by the patient of the road that he/she wants to take. Perhaps our job basically is to return control to the patient, to restore the patient's psychological autonomy.

We also need to be aware of where our patient is in terms of his or her own development and growth. We need to know what he/she is trying to do and what he/she is trying to achieve. We have to have a deep understanding of our patient. But we must also remember for our own part that uncertainty can also effect our decision to reveal information and we must be wary of exercising control of information to minimise our own fear and discomfort. Through being open and discussing things with our patients we will not avoid ethical dilemmas that arise for they are there all the time. We will at least have an open relationship and one where there is trust on both sides; trust in terms of the patient, in terms of ourselves and we with our patient. With that we can address the issues that arise and find solutions together. ●

## HIV AND LIFE: A PATIENT'S EXPERIENCE

*Based on a talk given by Toni at an HIV symposium in Durban, 15th March 1998*

I have been HIV-positive for 8 years. I was 22 years old, living with my boyfriend for two years, when I had a phone call one day at work from my general practitioner. He asked: “Do you know that your boyfriend is HIV-positive, or that he has AIDS?”

I do not think I can ever put into words what I felt that minute. It was devastating. I think that if I could have died right then I would have, but it did not turn out that way. I went for my test but it took two weeks to get it back, simply because the doctor that I saw at that stage had the specimen re-checked just to make sure the result was correct.

I am not sure whether the doctor knew how to handle the situation, or if it was because he knew my family very well, as my mother had worked for him for a number of years. Maybe his reaction was either just that of a human being or he might have been scared for my family as well.

My relationship with my boyfriend started to crumble. I didn't consult the doctor frequently, as I was very healthy then and still am reasonably healthy. My relationship with my doctor deteriorated, as I was upset because of the way in which he told me about my boyfriend. I spoke to no one and my boyfriend did not want me to tell anyone that I was HIV-positive. I think he was scared that all might find out — to him it was bad enough that I knew about it already.

I kept quiet.

Eventually my relationship fell apart. I was not feeling well and I found out that I was pregnant as well. His response was: “This is your appointment for your abortion”. This was about eight months after I had found out that I was HIV-positive and I did not want to have an abortion right away. I was really desperate to talk to somebody. I did not speak to my parents. My father is a preacher and I don't know why I did not then want to tell my parents. It might have been because I did not want to hurt them, as I knew they would be hurt and very sad. I did not know what my family knew about HIV, so I kept it to myself. The pressure on me kept building up. You go to work every day, you smile to everybody, but you have this huge secret and you are just so scared anybody will find out. It causes a lot of stress.

One day, in the newspaper, I noticed ATIC's telephone number. Eventually I got the courage to phone and I had my first counselling session with a lady. She told me a lot about choices, having the baby or not, what could and could not happen. The only thing at the end of the day was that I had to make the choice. I was 23 years old then and I really did not know what to do. I wanted to have a baby and I was supposed to be married by then to this man, but my life did not work out the way we planned it.

The end came a couple of weeks after I saw the ATIC counsellor for the first time. I had a huge fight with my ex-boyfriend as all he wanted to do was get rid of the baby. He did not want to have anything to do with me or the pregnancy. What I did was not his choice, but emotionally everything just crumbled and I phoned my parents in Ladysmith. I told them that I was in a huge crisis and that they would not want to hear about it over the telephone. My father came straight away and we spent the whole day together and we talked about it. I had to tell him everything that happened, that I was going to probably die of AIDS and that I was pregnant.

It could not have been easy for him either. He has certain standing in his community too. My dad is a very strong person and he took it very well and together we went to see Liz, the counsellor from ATIC. I think for the first time in his life he said that I would have to make the decision about the abortion myself. Whether or not I chose to abort the child, he would never hold it against me. All that he wanted was what was best for his girl. When I did choose to have Calvin I think he was quite happy that I made that choice.