

When do we talk to a sick person about AIDS?



Curriculum Vitae

Dan was born in Homer, USA and studied at various institutions mostly in the States: he received a BA from Colgate University (Hamilton), an MD from the University of Rochester (NY), a diploma in Tropical Medicine from Prins Leopold Institute (Belgium) and a Master's in Public Health from John Hopkins (Baltimore, USA). He started at Vanga Evangelical Hospital in Zaire in 1961 where he is still working as a medical missionary appointed by the American Baptist International Ministeries. Dan is married and father of three children.

Matala was born in Zaire and studied in Vanga and at the Institute of Theology at Kinshasa from whom she received a Bachelor of Divinity with specialisation in hospital pastoral counselling. In 1984 she was appointed as Chaplain and Counselor at the Vanga Hospital. She is married and mother of three children.

CBZO,
Vanga BP 4728,
Kinshasa 2
ZAIRE

Summary

Do we discuss the possibility of HIV infection immediately with a sick person? Or do we test him first and discuss it only when the result is positive and he has had adequate counselling? This paper from Vanga Hospital in rural Zaire declares that the informed consent approach adds further stress to a person already ill. Also, if the person refused testing, this diminishes the effect of counselling about the behaviour necessary to reduce possible transmission of the virus. In the Vanga approach, a patient is tested and referred to the counselling team. If the test result is positive, counselling continues until the person seems psychologically able to receive the diagnosis with hope. No serious reactions have occurred after revealing the diagnosis of HIV infection to more than 700 persons. Careful preparation by counselling and a support approach have positive psychological effects, and often physiological benefits.

Introduction

When do we discuss with a sick person the possibility of having AIDS?

1. Do we do it when we first suspect the diagnosis? We must then recommend to the person that he be tested, but leave the decision to him.
2. On the other hand, can we simply order the HIV test along with other appropriate tests without discussing it with him and without asking his permission?

This question has been hotly debated for years. In many countries, because of intense public pressure, national policies require the physician to inform each sus-

Daniel E Fountain
MD; MPH.

Rev Mrs Matala Masieta

S Afr Fam Pract
1996;17:230-234

KEYWORDS

Physician, family;
Ethics, medical;
AIDS;
Informed consent.

pect person of the advisability of the HIV test. The physician can order the test only with his consent. We call this the 'informed consent' policy. If the person agrees, pre-test counselling is highly recommended to prepare him to receive the result of the test with equanimity, whether it be positive or negative. Is this the best approach?

Three years of experience in caring for more than 1 000 HIV infected persons in Zaïre has convinced us that the approach should be flexible and not subject to a rigid national policy or law. The approach must be that which is best for the particular person in the context of his life situation.

The context of this paper is the Vanga Hospital, a 400-bed general hospital in rural Zaïre. The hospital is associated with a rural health zone serving 250 000 persons in 350 villages with a network of 52 health centres. The context is similar to that of many other health programmes in Africa. Furthermore, certain principles of the doctor/patient relationship apply in all contexts. Before we discuss the issues involved, let us look at the background:

1. HIV infection is a chronic, painful and fatal disease for which we have as yet no cure. In a real sense, it is a sentence to a slow death. Learning that one has a positive HIV serology is a stressful life-changing event.
2. Many severe reactions have occurred in persons who have been told they have, or might have, AIDS. This includes suicide, severe depression, anger and revengeful promiscuous behaviour.
3. HIV infection is a transmissible disease. It is therefore a community health problem, for it poses a threat to persons other than the HIV positive person.
4. The principal method of transmission of HIV is through intimate sexual contact. In addition, blood-borne routes exist as well: Transfusions, mother to unborn child and non-ster-

ile injection equipment contaminated by HIV-containing blood. However, because HIV infection is usually a sexually transmitted disease, the infection carries the strong moral stigma of being sexually promiscuous even to those who have acquired the infection by a non-sexual route.

5. The word 'AIDS' provokes fear in multitudes of people. This is mainly an irrational fear, intermingled with other emotions. These emotions strongly influence the reaction of persons and whole communities to the disease, and can make life very difficult for an HIV positive person. This includes rejection, abuse and discrimination of various sorts.
6. The prevention of the spread of HIV infection requires changes in personal behaviour. Helping people change unhealthy behaviour is very difficult. It requires effective communication and a high level of confidence in those trying to motivate those changes.

To do what is best for a person suspected of having HIV infection, we must consider carefully three important areas:

1. What is best for the person involved.
2. The protection of that person's community.
3. The logistics of the care programme.

The person involved

To face, with equanimity, the possibility or the realisation of having HIV infection requires courage, hope, a considerable degree of self-affirmation and a relationship of confidence with the care-giving staff. When sick persons come to the consultation room they are ill. In addition to physical symptoms, they come with emotional symptoms: fear of serious illness, anxiety about the effects of the illness on their future life, often suspicions about the care-givers – 'Will the doctor or nurse listen to me? Will he or she be willing to help me? How much will this cost?' An important part of our responsibility as care-givers is to gain

To hear about HIV infection, is a painful sentence to a slow death.

It carries a moral stigma of being sexually promiscuous.

Adding extra stress to an already sick patient.

When do we talk to a sick person about AIDS?

the confidence of the sick person, allay these fears, convey hope and, by our attitudes as well as our words and actions, diminish the psychological stress of the illness.

However, when the doctor suggests the possibility of HIV infection and the need for testing, he is adding further stress to an already stressful situation. In the initial consultation he cannot adequately assess the emotional symptoms or the psychological strengths and weaknesses of the sick person. Nor can he possibly predict how the person will react to the possibility of having HIV infection and to the advisability of being tested. How will the sick person support this additional stress?

Awaiting the test result is an additional stress, the stress of uncertainty about a possible fatal prognosis. Awaiting the result may require from one day to two weeks or more during which time the person lives with a fearful uncertainty. He now has three sources of stress:

- the original illness;
- the possibility of HIV infection; and
- the uncertainty of waiting.

If the test result is negative, we have put this person, already ill from another disease, through unnecessary stress. Stress itself can have deleterious effects on the immune system. We have added to that deleterious effect by giving unnecessary stress to a person already trying to cope with another illness.

If the result is positive, we have added stress before psychological evaluation and preparation are complete. So it is clear that the 'informed consent' approach adds stress to a person already ill. For his sake, therefore, we do not raise the possibility of HIV infection until we are sure of the diagnosis and until he has benefited from psychological counselling.

On the other hand, we do encounter situations where the person himself raises

the possibility of HIV infection or of being tested for it. Since he is the one who has expressed concern about this, we can now discuss it openly and suggest he be tested. If he accepts being tested, we refer him to the counselling team for psychological preparation while awaiting the test result.

The possibility of HIV infection also comes up in discussions with a couple, one of whom is seropositive and who has either informed the other spouse or given us permission to do so. After discussing the implications of the situation and giving counsel, we recommend that the spouse have the test. Some accept it; others refuse it. In either case we explain carefully how the couple can live together in a healthy and supportive way.

The community

HIV infection is transmissible. At risk are all persons who might have sexual or blood contact with an HIV positive person. The behaviour of an HIV positive person determines the degree of risk for those with whom he is in contact.

The informed consent approach leaves the decision for or against testing to the sick person. Because the possibility of HIV infection has been raised prior to counselling and psychological preparation, he is vulnerable to many different and conflicting emotions. This is not an ideal time to make a difficult decision which may have life-changing effects. In our experience, many informed people are afraid to be tested and so refuse it.

Furthermore, if the person refuses the test, he refuses what the doctor has advised. This raises a certain level of resistance to counselling, especially to that related to the personal behaviour necessary to protect other people. The person may indeed be HIV positive but refuses testing. If he does not respond to behavioural counselling about how to protect others, his family and the community remain at risk.

A suspect person is tested for HIV without informing him, unless he himself talks about it.

An approach which is flexible and not subject to rigid national policy.

When do we talk to a sick person about AIDS?

HIV infection is not only transmissible; it is epidemic. The explosion of HIV infection in many countries and population groups is alarming. Yet the informed consent approach hampers health care workers in their efforts to protect the community. A physician must know who is infected and who is not in order to help reduce the spread of the virus. He is responsible not only for the health of the sick person but also for the health of his family and the whole community. When a suspect person refuses the test, the physician can do nothing to protect the health of others in his family and community.

We have encountered the following examples:

1. For many years the Vanga Hospital has operated a 'walking blood bank'. When a person needs a transfusion, we look for donors among members of the family or among a large number of volunteers (staff, students, residents of Vanga) who are willing to give blood to needy persons. However, when we began screening the blood of donors for HIV, the number of volunteers dropped dramatically; they did not want to be tested for HIV.
2. A school director consulted us about a situation which involved the possibility of HIV infection. When we recommended the test he refused, stating that if he did indeed have a fatal disease, he would prefer not knowing about it now. When we asked about a possible danger to his wife, he simply replied that God would protect her.
3. In an active childrens' hospital in Kinshasa, many sick children are seropositive. The staff discusses this with the parents and recommends they be tested. Many refuse and do not return after their child leaves the hospital. The possibility of their continuing to spread the virus to others is very real, and the medical staff can do nothing to diminish it.

Undiagnosed seropositive persons pose a serious danger to the community. Adequate case-finding is essential to diminish the spread of the infection. For epidemiological reasons, therefore, we do not follow the informed consent approach. We do all we can to detect every HIV positive person. Then, through intensive counselling, we encourage each one to follow behaviour that will not expose others to the virus.

The logistics problem

In most medical centres, the majority of persons tested for HIV infection are negative. In the Vanga Hospital, the rate of seropositivity among suspect persons is 20%.

Counselling persons about HIV infection is time consuming. Psychological preparation for receiving the diagnosis of HIV infection requires from two to six hours of intense counselling. To be effective, pre-test counselling would also require an hour or more of counselling. With 1 500 persons being tested annually in our hospital for HIV infection, this would require up to 3 000 hours of pre-test counselling time per year. For us this would be impossible. With 300 HIV positive persons per year, this requires 1 000 to 2 000 counselling hours. Even this strains our very limited staff and budget. Therefore, for logistical reasons, the informed consent approach with pre-test counselling is not practical for us.

Furthermore, many sick persons who come to our hospital have minimal understanding of the dynamics of disease. Informed consent requires an adequate knowledge of AIDS and its implications for life and for behaviour. In our context, this would be difficult to transmit to the majority of the suspect persons who come to us.

Our approach

In our first article: 'Telling a person: You have AIDS'¹, we have described the

HIV infection is not only transmissible, it is epidemic.

Stress has deleterious effects on the immune system.

Many informed people are too afraid to be tested, and refuse it.

When do we talk to a sick person about AIDS?

Vanga Hospital approach in detail. We will summarise it briefly here.

1. The initial consultation and examination takes place as with all sick persons. A suspect person is tested for HIV without informing him unless he himself raises the possibility of HIV infection.
2. When the test result is positive, the doctor refers the person to the pastoral counselling team for psycho-spiritual preparation.
3. When the team feels the person is able to receive the diagnosis, the doctor and a counsellor meet together with him. Gently and slowly the doctor explains to him that he has the virus that causes AIDS, but emphasises that, in spite of the seriousness of the illness, there is hope. The doctor tells him what he can do to combat the infection and what he must do and not do to protect the health of the others. The vast majority of HIV positive persons accept this know-

ledge and counsel with equanimity. We have encountered no serious negative reactions in over 700 persons to whom we have revealed the diagnosis of HIV infection.

4. Immediate and long-term follow-up by medical and psychological consultations continues through the coming days and months.

We are pleased with the positive results of this flexible and gentle approach. We feel it is the best one in our context for both the person and the community. It strengthens the HIV positive person psychologically and helps prepare him to cope with the infection and the life-changes which will come. It likewise provides an atmosphere of confidence for counselling about behaviour change, thus diminishing the risk to his family and community.

Reference:

1. Fountain DE, Masieta M: Telling a person: You have AIDS. *S Afr Fam Pract* 1996;17(2):56-60.

News

INDUSTRY

Emerging data on Statins: "The most exciting thing in 20 years"

Presenting the preliminary findings of a German pilot study on the use of fluvastatin^a Lescol; Sandoz) in patients with coronary heart disease (CHD), Dr Antonio M Gotto, Chairman of the Department of Medicine at Baylor College of Medicine, USA, told delegates: "The emerging data with statins in the treatment of CHD and the reduction of coronary events is the most exciting thing I have witnessed in this field in the last 20 years". He was speaking at the 'Drugs Affecting Lipid Metabolism' (DALM) meeting in Houston, Texas, November, 1995.

In a 12 week German study of patients with documented CAD, treatment with fluvastatin caused a significant (30%) increase in coronary blood flow.

These findings, said Dr Gotto, are being definitively assessed in the Lipoprotein and Coronary Atherosclerosis Study (LCAS) – a large clinical trial nearing completion at the Baylor College of Medicine. This study, to be completed early in 1996, is examining the benefit of fluvastatin treatment over two and one-half years in patients with proven coronary disease.

In addition to studying the effect of fluvastatin treatment through classic heart catheterisation findings, the LCAS will also provide data from a group of patients examined by position emission tomography (PET) scanning – a technologically advanced, acute, non-invasive method of assessing changes in blood flow to the heart.

Dr Gotto also acknowledged a retrospective analysis of safety data from earlier clinical trials which indicated that serious cardiac adverse events were less commonly seen with fluvastatin than with corresponding placebo – results that are expected to be confirmed studies such as LCAS.

Fluvastatin, the most recently introduced HMG-CoA reductase inhibitor (statin), is indicated for the control of high blood cholesterol and demonstrates potential benefits in patients with cardiac disease. Introduced in over 30 countries worldwide, Lescol is marketed by Sandoz Ltd, Basle, Switzerland.

Issued by Medical & Corporate Communications on behalf of Sandoz Products.

Vitamin Information Centre

Scientific evidence clearly states that folic acid, one of the B-vitamins, found in green leafy vegetables, liver and whole grain cereals, helps prevent neural tube defects and possibly other birth defects. Women can now prevent one of the most common errors in early embryo development by increasing their periconceptional intake of folic acid. The catch is that neural tube closure is complete by 28 days gestation – therefore supplementation is needed even before a woman is aware that she is pregnant.

Enclosed is information which highlights this gap in knowledge amongst women of child bearing age.

For further information contact Heidi-Lee Robertson, The Officer, Vitamin Information Center, Tel: (011) 393-4794/80, Fax: (011) 393-4790.