

Telling a person: You have 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

This paper describes the experience of a counselling team with 400+ HIV positive persons. They have developed a specific process of eight steps by which they prepare the patient and reveal the diagnosis to him in such a way that it is constructive and reinforcing. This process is explained here step by step. Their findings, after having applied this process to about 400 HIV positive persons, are given. There were no suicidal reactions, not immediate nor later on. No immediate nor delayed severe depressive reactions. No serious reactions of revengeful behaviour. Often patients showed gratitude for having been told the truth and expressed acceptance of the diagnosis and courage to do what was necessary. And often considerable (occasionally remarkable!) improvement in the clinical condition of the person.

Introduction

Telling a person "You have AIDS" is a difficult, delicate and very important task. Many care-givers prefer not to reveal the diagnosis at all because of the devastating psychological effects it may have. Others simply announce to the person without prior preparation: "You have AIDS", or "Your serology is positive". Many anecdotal reports exist describing suicide, severe depression, revengeful behaviour, and rapid deterioration of the physical condition of the sick person. It is our impression that such reactions are usually iatrogenic and can be avoided.

Another approach is possible, that of making this announcement in such a way as to convey hope, courage and a determination to cope with this difficult news in the best way possible. This paper describes our experience since January 1993 of presenting this diagnosis to more than 400 HIV positive persons.

Daniel E Fountain
MD; MPH.

Rev Mrs Matala Masieta

S Afr Fam Pract

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You have AIDS

The Vanga Hospital is a 400-bed church-run general hospital in a rural area of central Zaire. The hospital serves a population of 250 000 people in a catchment area of 6 000 square kilometres. However, as a well-known referral hospital, it draws sick persons from a much wider area, including the cities of Kinshasa, Kikwit and Bandundu.

The staff of 10 physicians is supplemented by a pastoral staff composed of two pastors, trained as counsellors. Physicians and counsellors work as a team, with frequent referrals and consultations between them aimed at healing the whole person.

When a physician suspects a person may have HIV infection, he refers her to the counselling team and a serological test for HIV is done. Suspect persons include those with a clinical picture compatible with HIV disease or an opportunistic infection such as tuberculosis, recurrent herpes zoster, or others. Others are suspect because of social conditions – partner of an HIV positive person, or with an occupation associated with a high level of sero-positivity. Anyone requesting HIV serology is also referred to the counselling team and tested.

The counselling process begins with an evaluation of the person's social, psychological and spiritual situation, and the identification of problems in any of these areas. The counselling team aims at helping the person to resolve any social conflicts or stressful emotional problems such as fear, anger, jealousy, guilt, etc. The spiritual evaluation is to ascertain personal resources of faith which the person has and how these can be reinforced. The purpose of this counselling is to help the sick person diminish social and psychological stresses and find the inner strength to cope with the news of having a life-threatening HIV infection.

When the serological diagnosis is confirmed, the physician alerts the counsellor. Counselling continues until the

counsellor feels that the person is sufficiently strong psychologically to be able to cope with the diagnosis. The counsellor advises the physician and a rendezvous is scheduled.

The purpose of revealing the diagnosis

We feel that revealing the diagnosis of HIV infection is important for two reasons. *The first* is for the well-being of the HIV positive person. As persons, we have a need and a right to know the truth about ourselves. An adequate understanding of our condition, even though it may be a difficult one, is the first step in trying to cope with it.

McWhinney states: "Never tell the patient something that is not true ... The truth will come out sooner or later and when it does, patients who have been lied to and misled, feel betrayed."¹ Deception not only damages the doctor-patient relationship, it also stimulates anger and fear with deleterious effects on the immune system, and diminishes hope with its beneficial effects.

Furthermore, "Truth heals. All treatment to succeed permanently must rest its validity on the power it has to inculcate truth."² The person is a complex inter-relationship of body, mind and spirit. Reinforcing the one strengthens the other. "Peace of mind makes the body healthy, but jealousy is like cancer."³

The second reason is epidemiological. HIV infection is a fatal transmissible disease. An HIV positive person needs to know she is HIV positive and what she can do to protect those persons whom she could otherwise infect. Revealing her diagnosis to her is part of our responsibility to others in her family and in the community.

For these reasons, we make efforts to pursue the medical and counselling preparation as quickly as possible. This usually requires from three to seven days and, when completed, enables us to work with the patient in full confi-

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dence and provide maximum support to her.

Revealing the diagnosis

The physician, the counsellor and the patient meet together. The physician begins the discussion by enquiring about how the person feels. Usually some improvement has already occurred due to treatment of other infections and to having been adequately received and cared for by the hospital staff. The purpose of this approach is to put the sick person at ease.

The physician then states: "We want you to know the truth about your medical situation." Our experience confirms what has been stated above, namely that a person can handle the truth much better than uncertainty. We sometimes delay revealing the truth, or reveal only part of the truth at one time. Deception, however, has no place in care-giving with HIV positive persons or anyone else.

The physician explains that one of the laboratory examinations has shown a virus infection to be present. Although as yet, medical science has no cure for this virus, there are measures the patient can follow to combat the infection and even to recover strength and perhaps health. In this way, the physician attempts to create an atmosphere of hope. This initial discussion may take from five to 10 minutes.

In many instances the sick person already suspects the direction in which the discussion is going, so that when the physician explains that the virus is indeed the AIDS virus, some psychological defensive mechanisms are already in place. In no instance, however, does the physician begin the discussion by announcing directly: "You have AIDS". Such a direct approach is brutal and can have devastating psychological effects.

Having made clear the diagnosis, the physician asks the patient if she has

understood, or if she has questions she would like to ask. The physician waits to see her initial reaction. When the team has handled the initial reaction, or answered any questions, the physician then explains what the patient can do to cope with the infection, always assuring her that the medical and counselling staff will help her in every way possible.

Guidance to the HIV positive person

We give the following guidance to each HIV positive person, explaining that these measures can improve her health and well-being. If she takes the initiative and follows them well, improvement in her physical condition often occurs.

1. Good nutrition. The physician explains locally available foods rich in protein which are important for restoring and maintaining physical strength. Referral to our nutrition service is done, if indicated.
2. Avoiding infections. The physician gives simple instructions as to how to avoid malaria, parasitic infections and other common diseases. He advises the person not to visit family members or friends who may have an infectious disease.
3. Early treatment of intercurrent infections. In case of any infection, the sick person should go promptly to the nearest health centre for adequate diagnosis and treatment. Any infection puts further stress on the immune system, but early treatment helps to restore it.
4. Psychological counsel. The counsellor has already discussed measures of how to handle worries, fear, guilt, shame, feelings of rejection and other stressful emotions. The physician reinforces this counsel.
5. Spiritual counsel. We share with HIV positive persons the conviction that life with God is forever and that this life can give meaning and purpose for living in the present. Physical death will come, as it does to every person. Physical death, however, is basically a transition, and can be an entrance

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into a fuller, more meaningful life.

6. A discussion of sexual activities. This varies according to the circumstances of the sick person. In general, single persons are encouraged to avoid sexual relations and marriage. We give two reasons for this. One is for self protection, to avoid any microbial infections which could be acquired from a sexual partner, including further infections with HIV. The other is to avoid transmitting the virus to another person. With married couples, we discuss the options and risks of sexual separation or the use of condoms. Our aim is to give as much information as possible to the person or the couple so they can make a rational decision about the behaviour to follow.
7. Discussion of the future. We encourage each person to try to deal constructively with all social relationships. In many instances, she can continue working, or eventually return to work. We look for personal factors that can give her meaning and purpose to continue living constructively, such as the need to be strong to care for children or to be economically self-sufficient.
8. A time for questions. Hope has physiological effects. Throughout the counselling process, and during the combined consultation to reveal the diagnosis, we emphasise hope:
 - hope for a physical improvement of health;
 - continued hope for new medications to deal more effectively with HIV infection; and
 - hope for life eternal in a personal relationship with God.

Results

Since January 1993, we have counselled more than 500 HIV positive persons and, as a team, revealed to more than 400 of them their diagnosis of HIV infection. We have had no immediate suicidal reactions, nor have we learned of any suicides taking place later. We have experienced no immediate or delayed

severe depressive reactions, nor have we seen any serious reactions of revengeful behaviour. One young woman expressed anger and aggression during the consultation and was unfortunately lost to follow-up.

In 90% of our patients, the persons understood the essential elements of the diagnosis, the disease, and the measures to follow. This varies much with their culture and level of intellectual development. With some persons, an immediate grief reaction occurs. The staff waits for this to pass, often quietly giving words of encouragement.

In many instances HIV positive persons show gratitude for having been told the truth. Many are able to discuss reasonably matters of family, work and future living. The vast majority of interviews terminate with the person expressing acceptance of the diagnosis and the courage to do what is necessary.

In many instances, considerable (and occasionally remarkable) improvements occur in the clinical condition of the person - fever disappearing, appetite returning and weight increasing. On the other hand, when the disease is quite far advanced, there may be no physical improvement. Even these persons are often able to accept the diagnosis and recognise, peacefully, the prognosis.

Follow-up

Further visits with the counselling team take place following the announcement of the diagnosis. One of the counsellors visits the sick person again within a few hours or the following day. More visits are scheduled during the subsequent weeks for further encouragement as well as for clinical evaluation. HIV positive persons coming from a long distance are given a letter of referral to a hospital or health centre near them which is also part of the care-giving network for HIV positive persons.

No announcement made

We do not announce the diagnosis to every HIV positive person. For those

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Reinforcing one aspect of the body strengthens the other.

Deception has no place in care-giving.

You have AIDS

whose disease is far advanced, our primary concerns are comfort, affirmation and support. Often we do not add a further stress by telling them they have AIDS unless they enquire about it.

A few patients do not appear to have the mental or emotional capacity to understand the disease and the measures for coping with it. With some of these we discuss the diagnosis and necessary measures with a responsible member of the family.

Other persons abandon the counselling process before the preparation is complete and they return to their place of origin. If this is far away, as it often is, no follow-up is possible. This is one reason for pursuing the preparation process as rapidly as possible.

Conclusions

It is possible to reveal to a person the diagnosis of HIV infection in a way that is constructive and reinforcing. This

requires psychological counselling and preparation, and consultations between medical and counselling staff. Throughout the process, the team emphasises hope and encourages the person to find meaning and purpose for the remaining months or years of life. This careful and supportive approach often results in emotional stability and/or physical improvement. Although time-consuming, it is cost-beneficial because it avoids difficult psycho-social reactions which can require much time and care. In terms of hope restored and the joy of living renewed, and in spite of the prognosis, it is remarkably effective.

References:

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Hope has physiological effects.

So often HIV positive persons show gratitude for having been told the truth.

Often remarkable improvements in the clinical condition of the person.



News

INDUSTRY

Fluvirin - new flu vaccine

Medpro Pharmaceutica is proud to announce the introduction of a new high quality flu vaccine to the South African market. In a country where flu vaccination is totally underutilised, the time has come to eradicate the misconceptions about flu and flu vaccination.

Influenza (flu) is always a debilitating illness, but the consequences of influenza and its complications are of greater concern, especially in certain high risk groups. The Flu Awareness Campaign, aimed at the general public, backed by the National Institute of Virology and our Department of Health and sponsored by Medpro Pharmaceutica, inter alia, will strive to clear up these misconceptions, emphasise the risks of flu, the impor-

tance of annual vaccination, and the safety, efficacy and cost benefits of flu vaccination to everyone. Pharmaco-economic data have shown alarming winter-absenteeism figures related to flu.

Fluvirin is manufactured by Evans Medical Ltd, UK, a leading manufacturer of vaccines worldwide. It contains the following strains as recommended for the southern hemisphere by the WHO and our NIV: H3 N2 - A/Johannesburg; H1 N1 - A/Texas; and B - B/ Harbin.

Fluvirin multi dose packaging is unique - 10 pre-filled syringes with needles (not a vial): cost-effective;

convenience; no contamination and no wastage.

Fluvirin is a purified surface antigen vaccine - studies confirm least foreign viral proteins and lowest lipid content.¹ The packaging is bio-degradable.

For further information contact Dr Nic de Jong at Medpro Pharmaceutica (021) 99-8268.

References

1. S Renfrey, A Watts. Morphological and biochemical characterisation of influenza vaccines commercially available in the UK. 1993 Vaccine 655.