

UNISA 1991



Living in an
AIDS
culture

Edited by
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Foreword

The Council of Unisa decided at the end of 1989 that it had become necessary to inform all staff members about the nature and transmission of the contagious, deadly and as yet incurable disease, Acquired Immunodeficiency Disease, generally known as AIDS.

In order to give force to this decision of Council, the Registrar (Professional Services) was requested to put together a team of experts who would determine the nature, content and scope of such an information programme and to supervise the programme's implementation.

It was with great pleasure that I witnessed the earnestness, diligence and enthusiasm, and also the compassion and understanding, with which a team from a variety of fields handled this delicate matter. I am convinced that the insights and perspectives derived from disciplines as diverse as Theology and Business Economics, Communications and Law, Nursing Science and Sociology, Psychology and Social Work have given the project a special character.

This book, *Living in an AIDS culture*, is the culmination of many hours of reflection and research and a work of love produced by an expert team who sacrificed their free time for the University. I would like to offer a special word of thanks to Professor Jan de Jongh van Arkel, the chief editor, and his specialist colleagues, namely:

Prof. M. Beukes, Head, Department of Nursing Science

Dr R. McKay, Department of Psychology

Mr G. van der Walt, Department of Social Work

Mrs A. van Dyk, Department of Psychology

Prof. C. van Wyk, Department of Legal History, Comparative Law and Legal Philosophy

This work is only one facet of an extensive information programme which will be developed during 1991, and I would therefore like to express my appreciation to the general project committee under the leadership of Mr D.W. Steyn. I would also like to thank the following members of staff for their contributions:

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The University of South Africa has access to an almost inexhaustible source of knowledge. It gives me great pleasure to know that all our members of staff are benefiting from this expertise.

Prof. J.C.G.J. van Vuuren
Principal

Introduction

AIDS is not only significant to people who engage in sexual promiscuity – it is a reality which affects everyone. There have already been AIDS deaths among Unisa staff members and among the family and friends of University staff. Newspapers report on people who have contracted the disease despite a responsible life style. The question that inevitably arises is: When am I safe, what is allowed and what is not? In this publication we intend to discuss the major issues relating to AIDS.

AIDS has suddenly become a vogue word. While there are those who are not intimidated by the various AIDS scenarios, there are others who are afraid to use public toilets and who use only cups and glasses that they themselves have washed. People feel uncertain when they are suddenly confronted by the disease without having been properly prepared or when they come into contact with someone suffering from it.

The Council of the University of South Africa believes that no one can afford to be ignorant about AIDS or be uninvolved any longer. Hence the decision to discuss the issue openly and honestly. This book contains the results of more than a year's research, study and reflection by a large group of people, of which the authors represent only a small number.

This book has a variety of objectives:

- to emphasise the importance of being informed about HIV/AIDS and, consequently, to provide readers with information about AIDS and related conditions
- to explain what it is and what it is not
- to explain how one contracts the disease and how not
- to foster understanding for people with HIV/AIDS
- to answer questions about possible legal problems
- to explain what constitutes high-risk behaviour and how the dangers can be reduced
- to provide guidance on the course of action to be taken in specific situations, for example, when first aid is required
- to give practical hygiene tips
- to express the authors' thoughts on our responsibilities in this situation

In our discussion of AIDS we need to use standardised terminology. The term “AIDS” (Acquired Immunodeficiency Syndrome) refers to a collection of approximately 70 conditions caused by a virus which attacks the immune system: the Human Immunodeficiency Virus (HIV). People who test positive for HIV (or seropositive) are therefore at risk of developing AIDS although they may show no signs of infection. Before developing full-blown AIDS an infected person displays symptoms related to the disease. These are referred to as the ARC (AIDS Related Complex). In the literature people with AIDS are termed PWAs.

We hope to make a positive contribution by helping to prevent the spread of AIDS and, where possible, to ease the suffering it causes.

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1

The personal challenge of AIDS

Jan de Jongh van Arkel

1.1 THE THREAT OF AIDS

William Amos is a Baptist minister in Plantation, Florida. While visiting one of the elderly members of his church, Amos learnt that the man's only grandson had recently died of AIDS. Amos (1988: 14) suddenly became aware that AIDS had struck his congregation. He had believed that he would have no contact with the disease until a church member contracted it but now realised just how great the impact of AIDS is and that his responsibility was to begin with a family member of one of his congregants.

Like William Amos we can say: AIDS has struck Unisa – not only through the staff members who have contracted it but also through family and friends of University staff. I could have begun with the question: What did we do when AIDS struck Unisa? We can no longer say it has nothing to do with us; all our lives are affected by the disease.

This is the *threat* of AIDS: It is here and we cannot escape it. We read about it in newspapers and magazines, see its victims on television and hear about it in conversations and on the radio. Directly or indirectly, we are all involved. It is affecting countless individuals' personal life styles. Are public toilets safe? Is it alright to drink one's tea from Unisa cups? How do we warn our children? Are there people working with us who are already infected? Have our children's friends been exposed to HIV? In the face of such threatening circumstances we have to guard against "AIDS hysteria" (Amos 1988: 23) which might cause us to reject all people with HIV/AIDS so that they become outcasts in organisations and communities.

According to an article in the *South African Medical Journal* (Schall, Padayachee & Yach 1990: 324), the HIV/AIDS epidemic is the greatest threat to public health in South Africa this century. The control of the epidemic is of national importance since it could become a matter of national survival.

There is no other human condition that has the combination of being an infectious terminal disease with no known recovery from infection, no clearly established mechanism for either individual or herd immunity as well as a host-parasite relationship so cunningly designed as to defy all scientific efforts to date to reach the stage of a realistic blueprint for effective vaccine or curative drug (Schoub 1990: 607).

The AIDS threat has caused us to doubt technology and medicine. Medicine's enormous successes in treating diseases, even cancer, that have threatened human lives for centuries have suddenly been relativised by a deadly disease for which there is no cure and which is expected to take on pandemic proportions. AIDS has shattered people's faith in human knowledge, science and technology. It has unmasked the modern illusion of happiness and success (Louw 1988: 69; cf. White 1987: 65). It will perhaps be the first epidemic to shock twentieth century humanity out of its complacency (cf. Long 1990: 69).

AIDS hysteria is sometimes referred to as *AFRAIDS* (*Acute Fear Regarding Aids*). *AFRAIDS* has been called the second epidemic (Kirkpatrick 1989: 86). Authors such as Croteau and Morgan (1989: 86) use the term "homophobia", which they describe as a constant and irrational fear of homosexuality coupled with a prejudice which incites not only hatred of and discrimination against gay people but also negativity concerning AIDS at all levels. A pertinent example is the suggestion of psychologist Paul Cameron that all HIV infected people be tattooed on the face as a form of "social quarantine" (Croteau & Morgan 1989: 87).

Despite the threat posed by AIDS we must develop moral sensitivity. This we could refer to as the personal challenge of AIDS. The kind of moral sensitivity we are talking about begins with a willingness to learn more about AIDS and to create opportunities for educating people about the disease and how to behave towards its sufferers and their family and friends. The plea made here is that we do more than simply obtain the necessary information; it encourages us to do something to ensure that people receive this information so that more victims suffering in isolation can be helped.

Our reaction to this plea may be at various levels (intellectual, emotional, pastoral) and extends across a wide spectrum (responsibility towards the infected, their friends and family, other people with whom one comes into contact; responsibility towards the community and the children of staff members).

AIDS is not solely a medical problem to which medical solutions must be sought. As long as there is no cure, it is perhaps primarily a spiritual and psychosocial matter (cf. Smith 1988: v); it is a community matter (a community like Unisa); and it is a personal matter to which each and every one *must* react.

1.2 ETHICAL ISSUES AND AIDS

The ethical problems that arise have to do with general attitudes towards people with HIV/AIDS, their responsibility towards others and our responsibilities towards the healthy and the community as a whole.

The ethical issues surrounding HIV/AIDS are rather controversial. The initial conno-

tations of AIDS as a homosexual disease and the subsequent high incidence of AIDS among individuals involved in socially unacceptable activities (such as drug abuse and promiscuous sexual relationships) have resulted in social opposition. AIDS guidance is not a simple matter. To whom should it be directed and what is its objective? How realistic is it to expect people not to become involved in sexual relationships? The tendency today is to give guidance to people displaying high-risk behaviour, the view being that although their behaviour will not change, they can be alerted to the fact that they are exposing themselves to possible infection. It is for this reason that advice on "safe sex" and the use of condoms is considered ethically justifiable.

Whereas the initial ethical condemnation of promiscuous sexual relationships was directed mainly at its destructive consequences, it is now being realised that such relationships can *kill* (Amos 1988: 104). And we are not using the word in its religious sense of sin or spiritual death; we are speaking of PHYSICAL DEATH. As a result of HIV/AIDS, the old belief that a sexual relationship belongs in a monogamous marriage has suddenly taken on new meaning.

The moral questions raised by HIV/AIDS are not purely theoretical: they penetrate as deep as the ethos of the average person (Louw 1988: 70). The problem of the spread of HIV/AIDS is often directly associated with a personal ethical question about the disease. Some maintain that the moral and spiritual defence system is the only means of controlling the plague. Because AIDS puts people in danger of death, it must surely force them to ponder the consequences of their behaviour. But however logical this argument may sound, the fact remains that people's habits and the general sexual morality of the youth, for example, are not changed that easily.

It does not help to invoke the cliché that we hate the sin but accept the sinner. Favourable and unfavourable reactions to a person's behaviour always affect one's evaluation of that behaviour and one's relationship with the person (Shelp 1989: 325). We have to take into account that many people (and certainly the churches) are ambivalent about the matter. We live in a society which is not agreed on morality. Various subgroups in society represent different opinions and points of view. What is good and proper to one person is wrong or even repulsive to another. This moral pluralism makes it that much more difficult to develop a fixed attitude to any issue – and especially the AIDS issue. I could speak my mind on high-risk behaviour. I could also report synod's most recent stand on an issue. But all the churches do not agree on moral issues.

At present the moral debate is focused on certain forms of moral behaviour which are associated with the transfer of AIDS and on the ways in which people are advised to act. Despite the fact that various behaviours are frowned upon and even condemned, the aid that people receive should be in no way affected. The person who shows compassion and acts within the framework of a pluralistic moral order should always bear in mind that there are others who may judge differently (cf. Shelp 1989: 329).

No one can isolate himself from this discussion any longer. The radicalness of AIDS lies in the damning manner in which it makes everyone aware of their insignificance, transitoriness and depravity (Louw 1988: 69). Every one is, in fact, vulnerable. If the predictions and future scenarios come true, every individual will either contract the

HIV virus or have a family member with the disease. Once HIV/AIDS has struck, it cannot be stopped or cured and it destroys one's life at all levels.

The spread of HIV/AIDS has assumed such proportions that we can no longer really distinguish between "carriers" and "outsiders" or between "patients" and "healthy people". In a certain sense everyone has already been affected and all are at risk whether personally or through friends, colleagues or family.

When discussing ethics, we first need to clarify what the framework of our discussion is to be. From a radical Christian perspective I choose *compassion* above condemnation (cf. Amos 1988: 52; Goss 1989: 308; Louw 1988: 66; Shelp 1989: 333). At present a judgment theology with AIDS as its topic is attracting considerable attention. The proponents of this theology claim that AIDS is God's way of punishing certain groups of people who live promiscuous and sinful lives (gays and drug addicts). The current trend is to speak of high-risk *behaviour* rather than high-risk *groups*.

In our spiritual approach of compassion and caring, merciful involvement plays a greater part than condemnation and rejection. This approach ties in with an incarnation theology which emphasises the redemptive coming of God and his identification with humanity.

Besides the question of right and wrong, there is the prominent ethical issue of *confidentiality*. Confidentiality is the basis of trustworthiness (Amos 1988: 44, 45), without which no form of help is possible. People who are informed in confidence that somebody has HIV/AIDS often have to wrangle with their consciences about their responsibility towards others who may be misled or put at risk if the information is withheld.

The fundamental ethical question posed here is a positive one: How does one live responsibly? Thus while the emphasis does not fall primarily on what is wrong, it is made clear that not every form of behaviour is acceptable. This chapter concentrates solely on the love and mercy of God in Jesus Christ and not on divine judgment as such.

1.3 THE APPEAL FOR CHRISTIAN LOVE AND (PASTORAL) RESPONSIBILITY FOR PEOPLE WITH AIDS AND THEIR FAMILIES/PARTNERS

Although I believe that we have a responsibility to educate and give all people guidance on HIV/AIDS, *quality of life* is the focal point when it comes to people with HIV/AIDS and their family (and friends) (Kirkpatrick 1988: 1). Death is not ignored here; after all, the best preparation for death is to refocus on life and to find practical answers to the question "how does one live with AIDS?"

Any attempt to play a part in the lives of people with AIDS and their families must be such that the care provided is based on *their* terms (Kirkpatrick 1988: 2). It is *they* who are trying to give meaning to a life which suddenly has no future. Kirkpatrick (1988: 3) refers, interestingly enough, to two deaths. The first is when the person decides to make public the fact that he or she has AIDS and has to cope with society's disapproval, rejection and condemnation while suffering shame and guilt. Kirkpatrick's second death refers to the gradual decay of the person's physical and mental abilities as the actual moment of death approaches.

Where do people with AIDS find help to face up to their shame and confusion and the

threat to their lives? The church and ministers of religion have traditionally played a significant role during times of illness. But when it comes to HIV/AIDS the situation is sometimes very different. People with AIDS often have no connection with a minister or congregation because of the church's condemnation (Koops 1988: 15). It is therefore not easy to create a space in which they can work through what is happening to them. People need a place where they can talk about their own responsibility, verbalise anger, and confront feelings of guilt in a space in which forgiveness is possible. The tragedy of isolation (both social and spiritual) is never so obvious as when someone is fighting for his or her life.

Social responsiveness and responsibility (Amos 1988: 57) may also be considered ethical issues. Instead of questioning the ethics of another person's behaviour, we are forced to look at *our own behaviour* towards someone in need even if we argue that that person alone is responsible for his or her situation (cf. Shelp 1989: 333).

Service to people with HIV/AIDS includes the following: inclusiveness, consistency, judgment and touch (cf. Amos 1988).

1.3.1 Inclusiveness

Everyone should decide for themselves how they feel about people infected with HIV or showing symptoms of AIDS. The aversion which many people feel may be the result of prejudices formed on the basis of incorrect information. Perhaps it is a little unfair to ask how we would react if we found out that somebody in our family had AIDS. The inclusiveness at issue here goes far further and is illustrated by the following quotation:

Jesus seemed to go out of his way to be involved with persons whom the religious community had either put in their place (i.e. beggars, women, Samaritans, publicans, and tax collectors) or discarded (i.e. lepers, the handicapped, the emotionally and mentally ill). There was bound to have been plenty of need within the more "acceptable" community for Jesus to have ministered there. However, he chose dramatically to go upstream against the norms of society to make the point that *all* people are acceptable. There are no "throwaway people" in the economy of God (Amos 1988: 67).

1.3.2 Consistency

People are often selective when they have to decide where they are going to help and what they are going to attend to. A person who has smoked for years and is dying of lung cancer normally receives help and sympathy, but people are not as willing to react when the disease is associated with sexual promiscuity. Homosexual perversities are condemned in the Bible (I Cor 6:9–10) along with a variety of other sins, and to the same extent. These include injustice, immoral living, idol worship, adultery, stealing, avarice, insobriety, slander and fraud.

1.3.3 Judgment

A noncondemnatory attitude has always been a basic precondition for giving help. It is

impossible to help someone in need properly if one has negative feelings about or judges that person. One of the negative aspects of HIV/AIDS is that a very large group of people have denounced the whole matter and have distanced themselves from it.

Despite Jesus's warnings about how a condemnatory attitude destroys love, there is always a group of people who claim that they are familiar with God's views and they support this claim by citing their own fortunes and misfortunes (Shelp 1989: 333). It is not our duty to condemn people. God himself will judge, where necessary. Our duty is to preach and demonstrate the Good News of redemption and mercy by our acts towards others.

1.3.4 Touch

Touch can play a significant role in our response to people with AIDS because it demonstrates our acceptance of them (Amos 1988: 74). However, we need to consider certain points concerning touch and even our reaching out to these people. AIDS hysteria and AFRAIDS, which have already been mentioned, are pertinent here.

People are inclined to recoil from people with AIDS. Many do not wish to be informed about the matter. They maintain that it does not affect them or that they are not the cause of the problem – people with AIDS are responsible for the situation in which they find themselves. Such isolation and ostracism causes people with AIDS and their families to withdraw from society and they eventually lose contact with others.

Given the extensive stigmatism and the fear, aversion and condemnation of others which people with AIDS experience, touch demonstrates that an attempt is being made to bridge the gulf. According to Goss (1989: 308) help must attest to unconditional acceptance and must be given with compassion.

To reiterate: help cannot really be offered from outside the situation. Those of us who have worked with the dying for many years know that you have to accept your own immortality or you are haunted by your fears every time you visit the dying and in this way you intensify their suffering. In the AIDS situation we have to be comfortable with our own suffering and our fear of infection, contagion, sexuality and mortality (Kirkpatrick 1988: 4). In this situation we are forced to be honest with ourselves about our thoughts, feelings, prejudices, bias and fears (Smith 1988: 17). It is said, for example, that the care givers of people who live with and die of AIDS are confronted by the same issues as those they care for. They live and die with the AIDS (Goss 1989: 297). The term "cohealing" is used to describe this process.

No disease exists in a vacuum, least of all HIV/AIDS. Besides the person with AIDS there is a family – his or her family. In families in which there is a person with AIDS it is, of course, important first to establish whether they are aware of the diagnosis. If not, the news must be broken to them and they will need time to come to terms with the situation. Families who have already been informed of the diagnosis need information and support. Family members' reactions will in all likelihood be determined by their relationship with the sick person. Parents will probably react differently from the children of a person with AIDS, while the spouse will have to face the possibility not only of losing his or her partner but also of having contracted the disease.

Gillian Walker (Simon 1988: 4) has said that people who work with only the individual AIDS patient have to do with only a single death (the threat of a single death would perhaps be more appropriate). But once we involve the family, we are concerned with life and death simultaneously. Although death is definitely a factor, the main objective of being involved with people with AIDS is to help them to live with infection or disease. This means that they also have to be helped to live with losses.

Our responsibility is not limited to AIDS patients and their families – it extends to what has become known as the second epidemic, namely AFRAIDS (Kirkpatrick 1988: 15). To help people with AIDS, we are also going to have to do something about the stigmatism, ostracism, condemnation and accusation. It is not only our own attitudes that are at issue here, but also those of the community in which we live. It is my responsibility not only to improve my own attitude but also to help create a more understanding community. People with AIDS cannot be helped to live if there is no *habitable space* for them in the full sense of the word. If we succeed in changing the attitudes of the community, there is *Lebensraum* (*living space*) for the patient, whom we help with living rather than dying.

Whereas people with a disease like cancer can hope for remission and even healing, there is no hope for AIDS patients and their families (Goss 1989: 297). They experience inconceivable stress, a series of losses and disappointments, and all manner of lesser catastrophes. They are constantly exposed to uncertainty. They cannot even always be sure that they will receive the necessary medical attention. There is an intense, ongoing debate in the medical profession about the “right” of medical staff to abandon a case once a positive HIV diagnosis has been made (Allen 1988; Annas 1988; Freedman 1988).

1.4 LIFE IN AN AIDS CULTURE

“Hello John, it’s ages since I’ve seen you! I hear you’ve got AIDS. Gee, I’m sorry. But how are you managing?” This very ordinary conversation tells us something about the dilemma in which we find ourselves in an AIDS situation. How do I act naturally towards someone with HIV/AIDS? It is clear that we are going to have to prepare ourselves to live in an AIDS culture. This means that we need to be well informed about the course of the disease, how infections occur, what is dangerous and what is not, and how to behave towards people and their families in different stages of the disease. The problem of stigmatism, AIDS hysteria, AFRAIDS, homophobia, ostracism and unfeeling condemnation which results in isolation will have to be resolved by means of education.

Despite the growing incidence of AIDS it is not just another disease: AIDS is characterised by its irrevocableness, by the fact that it is sexually transmitted, by the stigmatism it fuels and by the awareness it creates of the imminence of death (Sunderland 1989: 311–312). The uniqueness of this disease and the proportions it may assume make it necessary for us to prepare ourselves to live with it. This means that we must inform as many members of staff as possible about all aspects of HIV/AIDS and give our support to people, groups and organisations who are directly involved with the disease. Our responsibility to South African society means that we must look further afield than Unisa.

People who are directly involved in support programmes cannot manage on their own and often need to be trained if their help is to be effective. It is simply too stressful for a person to face a trauma of this nature alone and unprepared (Sunderland 1989: 314). For this reason liaison between the various organisations active in this area is essential.

Listening to people who work with AIDS statistics and the frightening forecasts they make, we may be tempted to see everything about HIV/AIDS in a negative light and to experience feelings of despair. I therefore wish to end with the last two paragraphs of Reverend William Amos (1988: 121), whose story I recounted at the beginning of this chapter. In these paragraphs Amos writes about the day of Tom's death. In his youth Tom lived promiscuously and abused drugs for many years. As a result he contracted AIDS. His wife Ruth phoned Amos one morning to say that she believed the end was near and that they wanted him to be with them. As he was driving to their home, Amos saw a beautiful rainbow in the west. It stretched from horizon to horizon and was brighter than any rainbow he had ever seen before. He thought how ironic it was that he should be surprised by a rainbow in the sky on his way to visit somebody dying of AIDS. Then he remembered the story of the first rainbow God placed in the heavens and the irony was replaced by a feeling of perfect harmony.

He felt that the rainbow confirmed that what God metes out to humanity is not destruction and fear and punishment and condemnation. God had once again hung magnificent colours on the morning air. As he turned in at the house and prepared to go into where this person – who had become like a brother to him – lay dying, he was comforted by the knowledge that their journey together had been good. It had been the way of God in struggling for acceptance and love and justice. It had indeed been the way of the rainbow.

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2

AIDS – the modern Trojan horse

Alta Van Dyk

2.1 INTRODUCTION

The Greeks laid siege to Troy for 10 years, but could not take the city. Finally, Ulysses had a huge wooden horse built. He hid Greek soldiers inside the horse, and left it outside the walls of Troy. The rest of the Greeks then pretended to sail away. The curious Trojans dragged the horse inside the city walls. That night the Greek soldiers crept out of the horse, opened the city gates, and let the rest of the Greek forces into Troy. The Greeks massacred the people of Troy and looted and burned the city (*World Book Encyclopedia* 1978: 374).

The story of the legendary city of Troy has us twentieth century individuals smiling knowingly about the naivety of its inhabitants: to drag a gigantic wooden horse into your city is tantamount to suicide. Anyone could have seen that it was a deadly trap! But today there is a Trojan horse waiting outside the gates of *our* city – AIDS. And we have already begun dragging it into our city because this horse, too, appears harmless. It is precisely this attitude to AIDS that is rapidly causing it to become one the largest and deadliest Trojan horses of all time. Connor and Kingman (1988: 1) describe it as follows:

If we could play at being Satan for the day, charged with the task of designing an epidemic to undermine both the developed and underdeveloped countries of the world at the end of the twentieth century, then the blueprint for the design would incorporate many of the features of AIDS.

The defence of our modern Troy requires the cooperation of every inhabitant of the city. But if we are to plan an attack or a defence strategy, we need to know the enemy's characteristics.

2.2 DEFINITION OF AND HISTORICAL BACKGROUND TO AIDS

AIDS is the acronym for Acquired Immunodeficiency Syndrome. The disease is *acquired* in the sense that the infection is not inherited or genetic but is caused by a virus which enters the body from outside; *immunity* refers to the body's natural defence system which protects it against infection and disease; *deficiency* indicates that the defence system is inadequate, that is, that something is amiss; and a *syndrome* is a group of specific signs and symptoms which occur together and are characteristic of a particular pathological condition. Although the term "disease" is used to refer to AIDS, it is in fact a collection of more than 70 conditions which occur as a result of the damage caused to the immune system and parts of the body by the HIV virus. AIDS may therefore be defined as a syndrome of opportunistic diseases, infections and certain cancers which eventually kill the patient (Lachman 1990). This is why AIDS can be compared to the Trojan horse because it penetrates the body and throws open the gates to all types of disease.

The first recognised cases of the Acquired Immunodeficiency Syndrome occurred in America in the summer of 1981 when a very rare form of pneumonia caused by the microorganism *pneumocystis carinii* and Kaposi's sarcoma, a rare form of skin cancer, were suddenly diagnosed in several patients (Adler 1988). The patients had a couple of characteristics in common: they were all young homosexual men with depressed immunity systems. Although the disease came to be known as Acquired Immunodeficiency Syndrome early on, its causes and the modes of transmission were not identified immediately. It was only in 1983 that it was discovered that the disease is caused by a virus which at that stage was known as LAV (*Lymphadenopathy-associated virus*) and HTLV-III (*Human T-cell Lymphotropic virus Type III*). In May 1986 the virus which causes the diseases was renamed HIV (Human Immunodeficiency Virus). At present there are two viruses associated with AIDS, namely HIV-1 and HIV-2. HIV-1 is associated with infections in Central, East and Southern Africa, North and South America, Europe and the rest of the world. HIV-2 was discovered in West Africa (Cape Verde Islands, Guinea-Bissau and Senegal) in 1986. According to all indications HIV-2 is just as virulent as HIV-1 (Sabatier 1988a).

Dr Luc Montagnier of the Louis Pasteur Institute in Paris, France, discovered HIV-1 in 1983. A year later Dr Robert Gallo of the United States claimed that he had discovered the virus first. One of America's largest court cases followed when the Louis Pasteur clinic charged the government of the USA with Gallo's "theft" of Montagnier's virus, which had been sent to him in good faith for research purposes. The conflict was so fierce that it threatened the 1987 talks between the French Prime Minister, Jacques Chirac, and the American President, Ronald Reagan. The issue was resolved at the last minute, and both Montagnier and Gallo are now recognised as the official discoverers of the virus (Connor & Kingman 1988). The dispute continues, however, and during the International AIDS Congress in San Francisco in 1990 newspaper reporters, hearing that both Gallo and Montagnier were to address the congress, joked about "the odds of running into somebody you're avoiding in a crowd of 12 000 people" (Hilton 1990).

There are many theories about the origin of AIDS. The most popular theory is that

people contracted AIDS from green monkeys infected with SIV (Simian Immunodeficiency Virus). Although SIV is similar to HIV-2 and it is theoretically possible for a retrovirus to cross the species barrier, the relationship between SIV and HIV-2 is not yet clear (Roth 1989). Several scientists have, however, rejected the idea of mutual transference between animal and human viruses.

Studies on the different types and numerous mutations of HIV indicate that the virus has occurred in the human body for between 20 to 100 years. Both Montagnier and Gallo believe that the virus has been present in an isolated community in Central Africa or elsewhere for many years. The spread of HIV in such groups was probably very limited because these people had little contact with the outside world. As a result the virus may have lain dormant for a couple of decades. As changes began to take place in Central Africa – for example, migration from isolated areas to the city – HIV began to spread. Transport networks and the general exchange of blood products eventually carried the virus to the corners of the earth (Gallo & Montagnier 1988).

The theory that HIV is not a “new” virus is supported by a case of a 15-year-old boy who died in 1969 from an undiagnosed disease. As is usual in the case of undiagnosed diseases, blood and tissue samples from the boy were retained. Nearly 20 years later, in 1988, the samples were restudied and it was found that a virus closely related to HIV had been responsible for his death. His symptoms were also identical to those of AIDS as we know it today. For example, during the autopsy a pathologist, Dr William Drake, observed small purple marks which he identified as Kaposi’s sarcoma (Connor & Kingman 1988; Roth 1989).

2.3 THE EFFECT OF HIV ON THE IMMUNE SYSTEM

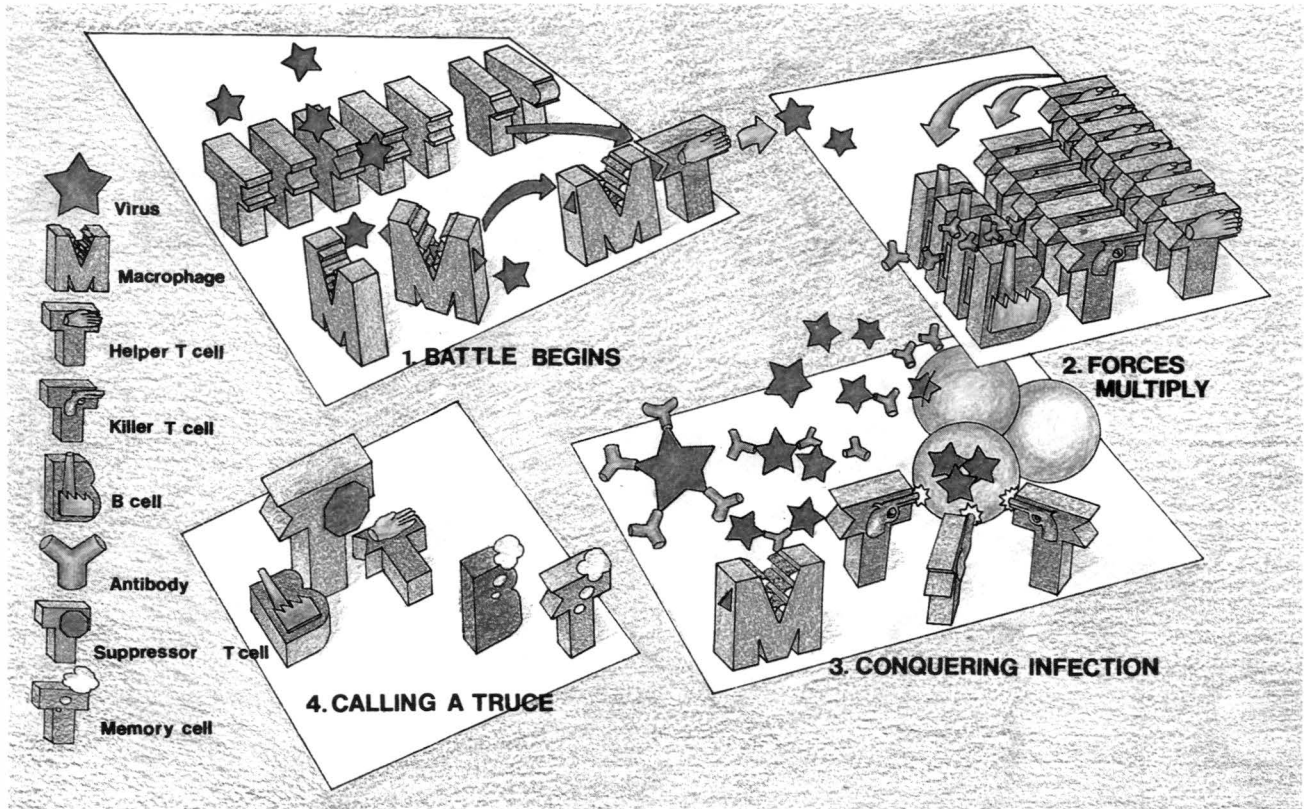
HIV is unique in that it directly attacks and destroys the immune system, which prevents the body against viral, bacterial and parasitic infections. To help you understand fully the danger of AIDS, the functioning of the immune system is briefly explained with reference to the publications of Jaret (1986), Levy (1990), Selwyn (1986a), and Weber and Weiss (1988).

2.3.1 The functioning of the immune system

The functioning of the immune system may be described metaphorically as a war within the body. Such a method is useful since it provides a concrete explanation for people with little or no knowledge of the immune system. This method can also be used in AIDS education. Figure 2.1 represents the immune system graphically. The explanation below follows the numbers in the figure.

The body’s immune system (or defence system) is a complex system of blood proteins and white blood cells which work together to repel attacks by invading organisms. The *white blood cells* (which are formed in the bone marrow) form three different “regiments”, namely:

- (1) *phagocytes* (cell eaters and macrophages)
- (2) two types of *lymphocytes*, namely:



Adjusted from Jaret, P (June 1986). Our immune system: The wars within. National Geographic, 169(6), p. 708-709.

Figure 2.1 Functioning of the immune system

- (a) *T cells*
- (b) *B cells*

Each of these regiments has its own defence strategy but they all have the same objective: to identify and destroy all substances which do not form part of the body. There are four phases to each immune response:

- (1) recognition of the enemy
- (2) strengthening of the defence
- (3) attack
- (4) end of attack once the battle has been won

The functioning of each regiment during the four phases of the immune response may be described as follows:

[1] THE BATTLE BEGINS (See corresponding number in figure 2.1)

Phagocytes, which may be called the spies of the immune system, are constantly sweeping the terrain of the body (bloodstream, tissue and lymphatic system) for anything that appears foreign. They then surround and destroy these foreign bodies. The phagocytes are usually effective in destroying chemical poisons and environmental substances such as dust, smoke and asbestos particles. However, organic invaders such as viruses, bacteria, protozoa and fungi set the entire immune response in motion.

If the ordinary phagocytes are unable to destroy the “enemy” (such as a flu virus) before it attacks surrounding cells, a special type of phagocyte, the **macrophage**, comes into action. The macrophage surrounds the virus and captures a special particle, an antigen, from the invader. The macrophage now displays this antigen on its own cell surface as a “captured banner of war” (Jaret 1986: 716). This banner (antigen) plays a critical role in the immune system’s response: it warns the next regiment, the **T cells**, to attack.

The **T cells** are preprogrammed in the thymus to recognise the antigen (carried by the macrophage). In the thymus the T cells “learn” to recognise all the antigens that nature may create – and there are millions in different forms. One T cell may learn to recognise the antigen of the hepatitis virus while another may recognise a certain type of flu antigen. There are even T cells which can recognise artificial antigens manufactured in laboratories – antigens which the body has never encountered in millions of years of evolution.

The type of T cells which recognise the antigen (or the banner displayed by the macrophage) are known as **T helper cells** or **T4 cells**. The T helper cells now combine with the macrophages and the next phase of the war begins.

[2] THE FORCES MULTIPLY

Once the T helper cells have combined with the macrophages, they activate the rest of the defence system to multiply its forces: T helper cells begin to multiply, they activate more phagocytes and send chemical messages to the **B cells** and **killer T cells** (T8

cells), which are sensitive to the invading virus, to multiply. The **B cells** (or third regiment) occur in the lymph nodes, which may be compared to small munitions factories. The B cells multiply and divide into two groups: plasma B cells and memory B cells. The plasma B cells manufacture antibodies which render invading organisms harmless by clinging to their surfaces.

[3] THE ATTACK AND VICTORY

As the immune system prepares its forces, some viruses penetrate body cells (the only place where they can multiply). The killer cells (with the aid of certain T helper cells) destroy these infected cells by chemically piercing their membranes so that the contents spill out and the multiplication cycle of the virus is disturbed. Antibodies now neutralise the viruses by attaching themselves to their surfaces to prevent them from attacking other cells. This slows down the passage of the invading organisms and makes them easy victims for the phagocytes. Antibodies also produce chemical reactions which can kill infected cells.

[4] THE ANNOUNCEMENT OF A TRUCE

Once the attacker has been vanquished, a third member of the T cell family takes control: the “**suppressor T**” or the peacemaker. Suppressor T cells release a substance which stops B cells doing their work (the manufacture of antibodies). They also “order” the killer T8 cells to abandon the attack and the T helper cells to stop their work. Memory T and B cells “remember” and they remain in the blood and lymphatic system, ready to act should the same virus invade the body again.

The war has been won and the person is immune to the virus in question.

2.3.2 The effect of HIV on the immune system

Like other viruses, HIV lives and multiplies solely in human cells, which offer a perfect hiding place from the body’s defenders. Unlike other viruses, HIV has a special affinity for the main lymphocytes in the immune response, namely the T helper cells. By attacking the T helper cells, HIV cuts short the total immune response. Although several antibodies are formed, they are completely powerless to stop the infection (Jaret 1986; Lachman 1990; Levy 1990; Selwyn 1986a; Weber & Weiss 1988).

When HIV invades the body, the macrophages attempt to do their job and surround the virus. But it is when the macrophage attempts to make contact with the T cells that the problem begins (see [1] in fig. 2.1). A protein on the virus’s outer layer (gp120) attaches itself firmly to the outer layer of the T helper cell (CD4 receptor). The virus sheds its outer layer and infects the T helper cell by injecting its genetic material (RNA) into it. Instead of helping in the fight against the virus, the T helper cell is thus infected and becomes a carrier of death (Jaret 1986; Weber & Weiss 1988).

HIV is a retrovirus. “Retro-” indicates that it does the “reverse” of other viruses. The normal transcription of genetic information in cells is from DNA to RNA to proteins. But the genetic information of HIV is contained in RNA (rather than DNA as in ordinary viruses). When HIV attacks a cell, its RNA invades the cell. In the cell an en-

zyme (Reverse Transcriptase, which is supplied by the HIV) helps to transform the RNA into DNA, which then fuses with the cell's own DNA (or genetic material). The virus may lie dormant for months or even years before it begins to use the cell to multiply. It is not known precisely what reactivates the virus, but as soon as it is, the HIV (like any other virus) uses the cell material to manufacture new viruses instead of proteins. When the virus begins to multiply, it breaks through the cell wall and the infected cell usually dies (Roth 1989).

HIV infects and multiplies in not only T helper cells but also other body cells such as monocytes, macrophages and tissue dendrite cells present in mucous membranes, lymph nodes, the skin, liver, spleen and brain. Scientists were initially astonished by the presence of the virus in the brain because the blood-brain barrier usually filters out all foreign substances such as viruses and prevents them from entering the brain. Since macrophages are among the few cells that move through the blood-brain barrier, researchers later realised that HIV enters the brain by hiding in these cells (Levy 1990).

As if the virus were not already "perfect" in its deadliness, it has another property which makes it virtually untraceable by the immune system. HIV is able to mutate or change very rapidly. This change not only occurs from generation to generation but the virus is also able to change within the host in the course of time. The virus which is identified in a person's blood in the early stages of infection often mutates into another strain displaying different characteristics by the time that AIDS develops (Levy 1990).

The body's immune system relies heavily on its ability to recognise microorganisms by their outer layer. Because HIV mutates so rapidly, it is extremely difficult to identify any similarities between the outer layer of one virus and the outer layer of another virus. As a result the body is unable to vanquish a target which is constantly changing (the virus can be compared to a thief who leaves different fingerprints every time).

Because of the unique way in which HIV attacks and disarms the immune system, the body has no remaining defence mechanisms and no protection against other diseases. All types of bacteria, fungi and viruses are able to invade the body. The AIDS virus is therefore a Trojan horse not only in the way it is threatening our society but also in the way it invades the body: it penetrates to the heart of the city and when the horse is emptied and the gates of the city thrown open in the night, Troy is unable to defend itself.

2.4 THE THREE STAGES OF HIV INFECTION

HIV infection can theoretically be divided into three stages. The **first stage** is the **asymptomatic carrier stage** in which a person infected with HIV develops antibodies, is a carrier but displays no symptoms. This is the period in which the virus lies dormant in the body but can still be transmitted to someone else. An HIV positive person can remain healthy for a long time, display no symptoms and be able to do his work. Some people remain HIV positive for as long as 12 years without any manifestation of clinical disease, whereas others may deteriorate rapidly and die soon. This is partly attributable to the differing virulence of variants of the virus (*AIDS Conference Bulletin* 1990: 7; Levy 1990).

The **second stage** of infection is referred to as ARC (AIDS Related Complex) and

commences when people with HIV antibodies begin to display symptoms. One of the most common symptoms is **general lymphadenopathy** or swelling of the glands in the neck, arms and groin. Other physical symptoms which may appear during this stage are fever, night sweats, diarrhoea, weight loss (at least 10 percent of body mass), general malaise or fatigue, infections such as oral candidiasis (thrush) and herpes zoster (shingles). These symptoms may be constantly or intermittently present and are usually not lethal (Lachman 1990; Pfäffl 1988; Yarchoan & Pluda 1988).

Only when a person enters the **third stage** of HIV infection can he or she be said to have AIDS. As the ARC becomes more serious, the immune system deteriorates increasingly, and more persistent, untreatable opportunistic conditions appear. **Kaposi's sarcoma**, a rare form of skin cancer, is very common during this stage. It is characterised by a painless bluish-purple colouring or swelling of the skin which occurs on different parts of the body such as the mouth, glands and gastrointestinal tract. Kaposi's sarcoma reacts well to chemotherapy but can result in death if not treated.

The AIDS patient is usually thin and emaciated as a result of **diarrhoea** which may last for weeks or even months. **Thrush** in the mouth may become so painful that the patient is no longer able to eat. It is these characteristic symptoms that have resulted in the name "slimming disease" in Africa. The patient is also exhausted and this can result in multiple infections such as shingles, herpes and tuberculosis (Krigel & Friedman-Kien 1988).

One of the diseases that most commonly affects AIDS patients is **pneumocystis carinii pneumonia**, a parasitic infection of the lungs. It is characterised by a continual cough and laboured breathing. This type of pneumonia is difficult to treat and is the most common cause of death in AIDS patients.

AIDS dementia is also common. As mentioned, HIV, unlike most other viruses, can pass through the blood-brain barrier. When this happens, it destroys certain brain cells and gives rise to symptoms which may vary from slight confusion, memory loss, deterioration of thought processes and inappropriate behaviour to personality change, premature senility, loss of muscle control and incontinence (Brew, Rosenblum & Price 1988; Lachman 1990; Pfäffl 1988).

Not every infected person goes through all the stages. Some people show no signs of disease (such as ARC) before they develop full-blown AIDS. Others live for years without any symptoms or only with enlarged lymph glands. There are many questions to which medical science still has no answers. All that can be said with any certainty about full-blown AIDS at this stage is that it always results in death – usually within two to three years.

2.5 THE CURRENT AIDS SCENARIO

AIDS has already taken on epidemic and pandemic proportions in 176 countries worldwide. The World Health Organisation (WHO) reported 68 217 cases of AIDS across the world in November 1987 with 2 000 new cases every month (Lachman 1990). This figure increased to such an extent that just 30 months later, during the Sixth International Congress on AIDS in June 1990, the WHO reported that between 300 000 and

600 000 people worldwide already had full-blown AIDS. This represents an average increase of more than 14 000 new cases per month. The AIDS mortality figure is at present approximately 65 percent. However, more than 90 percent of the people infected in 1982 have already died.

According to WHO estimates there are about 10 to 15 million people who are infected with HIV but have not yet developed full-blown AIDS. Because AIDS is not a legally notifiable disease, some countries – for example in Africa – refuse to publish their figures. This means that international statistics do not reflect the actual extent of the problem. The Medical Research Council estimates that only 10 to 40 percent of all AIDS cases are reported in South Africa. What we are seeing worldwide is therefore the proverbial tip of the iceberg (Oosthuizen 1990a: 4). So dramatic is the increase of AIDS across the world that authors and scientists are referring to it as “the disease of the century”, “the modern Black Death” and even as a “Countdown to Doomsday” (Edelston 1988).

In South Africa a total of 665 cases of full-blown AIDS had been reported to the South African Institute for Medical Research by March 1991. Approximately 60 percent of these people have already died. Statistics indicate that thousands of South Africans are infected with the virus. The infection rate is currently doubling within a period of 8,5 months (*Transvaler*, 18 April 1990: 4; Oosthuizen 1990a; *Nursing RSA* 1990 5 (no. 3): 30; *Beeld*, 10 April 1990).

The Department of National Health and Population Development warned in July 1990 that heterosexual individuals in South Africa had become the primary group at risk of contracting HIV. Up to the end of 1987 it was mainly white homosexual men who contracted AIDS. Since 1988 more and more heterosexuals, and particularly black heterosexuals, have begun contracting the disease. In South Africa the change in the distribution pattern from homosexual to heterosexual over a period of 27 months may be illustrated as follows:

	December 1988	June 1990	March 1991
Homo/bisexual:	66%	56%	41%
Heterosexual:	23%	32%	37%

Although the heterosexual distribution of HIV was initially limited to Africa, this pattern is now recognised internationally (Alvarado 1990: 1A; *Pretoria News*, July 3 1990: 2; Oosthuizen 1990a; Van Ammers 1990).

Figure 2.2 depicts graphically the number of AIDS cases reported in South Africa up to 4 March 1991. The cumulative distribution per annum is also indicated.

2.6 DIAGNOSIS OF HIV INFECTION

HIV is currently diagnosed by means of blood tests. Two of the best known are the ELISA (enzyme-linked immunosorbent assay) and the Western Blot tests. These tests cannot trace the virus itself in the blood, but react to HIV antibodies which are formed in an unsuccessful attempt to protect the system against the virus. However, it takes an

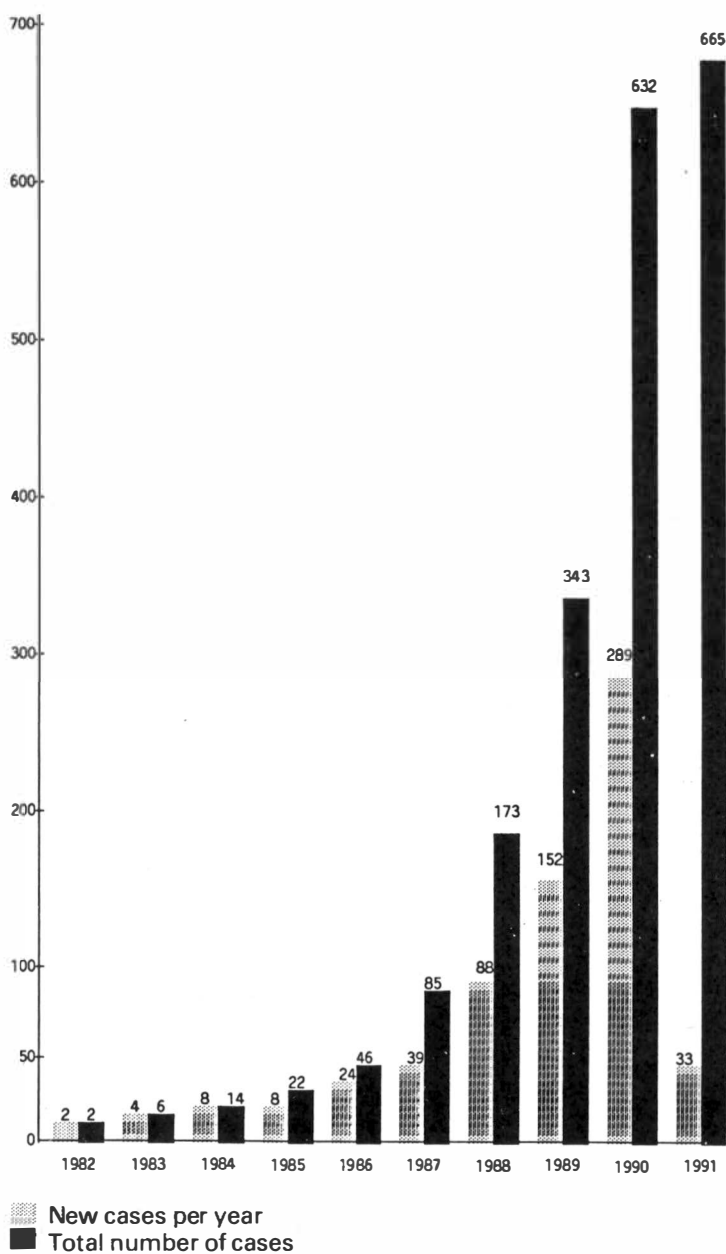


Figure 2.2 AIDS in South Africa: number of new cases per annum/cumulative number of cases (reported up to 4 March 1991)

average of six weeks to three months, or even longer, for infected individuals to develop antibodies to the virus that is already present in their blood. Blood tests performed during this period – which is known as the “window period” – may therefore give falsely negative results. There is even a very small group of people who apparently never develop antibodies despite HIV infection (Sabatier 1988a).

There is a technique by means of which the presence of the virus itself in the blood can be established, namely the polymerase chain reaction technique. It is not commercially available at this stage because it is expensive, complicated and not very accurate as yet.

A promising new development is a urine test (the Calypte EI HIV EIA test) which traces HIV antibodies in urine. Although the virus itself does not occur in urine, antibodies do. At present the test is available only for research purposes but the indications are that it is very reliable. A urine test has many advantages, especially in developing countries in which the lack of facilities makes blood tests a problem. Such a urine test might easily become available on supermarket shelves as a do-it-yourself home test – a possibility with advantages as well as disadvantages, particularly if one bears in mind that testing without counselling is undesirable (James Nicholson, personal communication, June 22, 1990; *Science* 1990: 101).

Coates (1990: 1) notes that testing for HIV antibodies is a useful aid in, and an important part of, a preventive AIDS programme. He warns, however, that the success of a testing programme can be seriously prejudiced if the results are used to facilitate discrimination and stigmatisation or to deny human rights. He writes: “HIV testing is only a tool. That tool is blunted to the degree that it is used to harm other people.”

2.7 THE TREATMENT OF AIDS

There is as yet no cure for AIDS. Nor is there an anti-AIDS vaccine. At the Sixth International Congress on AIDS in San Francisco (1990), scientists from all over the world agreed that a cure for AIDS is not even visible on the horizon. Dr Jonas Salk – the father of the polio vaccine – and other scientists are making good progress and Salk believes that a vaccine should be available by the year 2000. The vaccine will protect healthy, noninfected individuals against the virus, but will of course offer no protection to those already infected (*San Francisco Examiner*, June 24 1990: A1, A2; Levine et al. 1990). The rapid mutation of the virus is one of the reasons why scientists are battling to develop a cure or even just a vaccine.

Time and again the media report on all types of “alternative” treatments for AIDS. For instance, a Dr Alonso of Atlanta, USA, caught the world’s attention when he claimed that he had changed two patients’ serostatus from positive to negative with his hyperthermia technique, which entails heating the patient’s blood. Other researchers emphasise the healing properties of fungal extracts, electromagnetism and self-healing. It appears that none of these “alternative” treatments have a lasting effect and they have been sharply criticised as unethical and immoral because they engender false hope in thousands of ill people while making their propagators rich (Davidson 1990).

The current emphasis in AIDS treatment is on strengthening the immune system so

that the infected individual can be kept as healthy as possible, and on the treatment of opportunistic infections. One of the best known and most effective drugs being used today is AZT (Azidothymidine or Zidovudine). This drug delays the reverse transcriptase process, which must occur before the virus can begin multiplying in the cells, and in some patients it improves immunological functioning. But AZT is very expensive and can have serious side effects, such as bone marrow toxicity which may lead to severe anaemia, constant nausea, heart palpitations and dizziness (Krieger 1990a; Lachman 1990).

Research in the nineties will concentrate on the development of a vaccine and antiviral therapy. Scientific endeavours will focus on the blocking or suppression of viral multiplication in body cells, and attempts will be made to make mutations or genetic changes of the virus in the host less virulent. Much interest is being shown in the genes of the HIV virus, in particular the NEF gene (also known as the silencer gene). Researchers like Levy believe that the key to controlling the spread of HIV in the body is to be found in the NEF gene. The function of this gene is to suppress HIV multiplication. According to Levy it functions in the same way as the stop button on a cassette recorder: it can switch off another gene, namely the "virulence gene", whose function it is to make the virus more virulent. If this does not happen, the virulence gene immediately makes the virus deadly. One of the great tasks of researchers in the nineties will be to learn how to control the NEF gene (Dinchuk et al. 1990; Krieger 1990b).

It appears that the only treatment for AIDS at present is prevention. The Trojan horse must be kept outside the city walls at all costs because once it has invaded the body, there is no defence.

2.8 THE SPREAD OF HIV INFECTION

HIV has been identified in various body fluids but it is especially concentrated in blood, seminal fluids and cervical secretions. Although it is present in saliva and tears, large volumes are apparently necessary to transmit HIV. The virus is also present in the breast milk of infected mothers (Lachman, 1990; Roth, 1989). Although HIV antibodies have been traced in urine, the virus itself does not occur in urine.

A person may be infected with HIV in the following ways:

2.8.1 Intimate sexual contact with an infected person

AIDS is primarily a sexually transmitted disease and is transmitted through penetrating, unprotected vaginal, anal and possibly oral sexual contact. HIV is transmitted only if the virus enters the bloodstream of a person from the body fluids of an infected individual. In sexual contact the delicate membranes lining the body cavities are usually torn as a result of friction. The virus is easily able to enter the other person's bloodstream through the tear or to mix with blood from the tear. Although it appears that women (as the passive recipient) are more easily infected than men, HIV positive women are highly contagious during menstruation. The passive partner (or recipient of semen) in anal sex runs a greater risk of infection than the active partner. A single instance of sexual contact with an HIV carrier is often sufficient for the dreaded virus to be transmitted.

2.8.2 Exposure to contaminated blood and blood products

All donors' blood is tested for HIV antibodies and infected blood is destroyed. Blood products, such as Factor VIII which is used for haemophiliacs, are heated to 60°C to destroy the virus. It is unfortunately not possible to heat whole blood. Although blood is currently far safer than in the past, the window period (the period after infection but before antibodies are formed) creates problems. Infected blood donated during this period cannot be identified as HIV positive and then eliminated. It is the moral and ethical responsibility of people who engage in high-risk sexual activities not to donate blood. It is disturbing to note that in America people donate blood with the express purpose of obtaining a free HIV antibody test.

2.8.3 Intravenous drug users

People who share syringes and needles to inject themselves with drugs run a significant risk of being infected with HIV. The HIV virus is easily transmitted when needles are shared because drug users inject drugs directly into the bloodstream. To ensure that the needle has struck a vein, they draw blood into the syringe and then inject the drug. A drop or two of blood always remains in the needle and is injected directly into the bloodstream of the next user. The virus is highly concentrated in blood and these "mini blood transfusions" are all that are necessary for HIV transmission. In various countries teenagers are taught that ordinary household bleach (diluted 1:10) will kill the virus if they clean their "works" with it. But the objective of this controversial approach to drug abuse is to save lives and slow the spread of AIDS, not to encourage teenagers to become drug addicts.

2.8.4 Accidental exposure to the blood of an infected person

HIV can be transmitted through contaminated needles and instruments if medical standards are low, through tattooing and ear piercing, and through contact with infected blood at accident scenes.

2.8.5 From infected mother to her baby

Although not always the case, HIV can be transmitted from an infected mother to her baby before, during or after birth. The virus may be transmitted through the placenta and blood and also in some cases through breast-feeding after birth. It is estimated that there is approximately a 50 percent chance of an HIV positive mother infecting her baby. It is only at the age of about eighteen months that it is possible to establish by means of blood tests whether the child is infected. Before this age it is impossible to determine whether antibodies in the blood are the child's own or those of the mother.

Although there is a possibility that HIV can be transmitted through breast-feeding, the World Health Organisation recommends that infected mothers who cannot afford alternative nutrition – especially in Third World countries – should be encouraged to continue breast-feeding to prevent their babies dying from malnutrition.

Russian researchers have recently described cases in which babies infected through

syringes in hospitals have transmitted the virus to their healthy mothers through breast-feeding. Bleeding mouth ulcers or thrush in babies and cracked nipples in mothers increase the chances of transmittal (Pokrovsky, Kuznetsova & Eramova 1990).

2.8.6 Infected organs, tissue or semen

The virus is also transmitted through the organs, tissue or semen of an infected donor. All donor products are therefore tested for HIV antibodies. HIV positive people should be encouraged not to carry donor cards.

2.9 MYTHS ABOUT THE TRANSMITTAL OF AIDS

Numerous myths about how AIDS is transmitted are circulating. AIDS is not a highly contagious disease since, unlike many others, it is not transmitted by droplet infection, insects, contaminated water or food, or skin contact. The HIV is very weak and soon dies outside body fluids. Despite all kinds of theoretical arguments, practical experience has shown that HIV is not transmitted through:

- social contact
- blood donation
- toilets and showers
- coughing or sneezing
- public swimming pools (Chlorine destroys and water dilutes the virus.)
- mosquitoes (Distribution patterns show that children who are bitten by mosquitoes do not contract AIDS. Furthermore a mosquito obtains its entire meal from a single person. If the mosquito is disturbed and flies to another person, it sucks out blood rather than injecting it.)
- utensils such as knives, forks and teacups
- restaurants and cafeterias (Even if the chef has AIDS, exposure to heat, air, salad dressings and gastric juices will destroy the virus.)
- holding hands
- physical contact with an AIDS patient such as hugging and comforting (Research shows that the people living with an AIDS patient do not contract the disease if they take the necessary precautions – e.g. adhering to the rules of basic hygiene. Razors and toothbrushes should not be shared and contact with body fluids must be avoided.)
- contact with colleagues
- contact between schoolchildren (provided practices such as the mingling of blood by gang members are avoided)
- kissing (The virus occurs in very low concentrations in saliva and, although researchers differ, kissing appears to be relatively safe. There is no risk in a dry kiss or a kiss in greeting. As far as can be determined French kissing or deep kissing is not dangerous either, but many counsellors warn people to be careful, especially if there are sores or punctures in the mouth cavity. An interesting piece of research showed that at least two litres of saliva are required for the virus to be transmitted in this manner!)

It is unnecessarily stressful to live with all types of fears about AIDS. The virus is transmitted only in an exchange of body fluids as in sexual intercourse or blood transfusions.

2.10 THE PREVENTION OF AIDS

Since there will be no treatment for or vaccine against this deadly disease in the foreseeable future, prevention is our only weapon against AIDS. The most basic means of preventing HIV infection is to ensure that body fluids – whether blood, seminal or cervical fluids – do not enter the bloodstream of a noninfected person. Infected people have a moral and ethical responsibility to protect their sexual partners against infection and themselves against reinfection. Some HIV positive people mistakenly believe that there is no need to protect themselves against further infection. But because there are so many mutations of HIV and some are more virulent than others, protection against reinfection is essential.

Since HIV is transmitted mainly through sexual contact, the following preventive measures are emphasised:

- Total abstinence from sex is, of course, the surest means of not contracting the disease.
- A mutually faithful relationship with an uninfected partner is the ideal. It seems that in the end this will be the only way to vanquish HIV.

If people choose to have more than one sexual partner, **SAFER SEX PRACTICES** are essential:

- The number of sexual partners should be limited.
- Sexual partners should be aware of each other's sexual history. (This is however not a reliable practice since people tend to be dishonest in order not to lose a potential sexual partner.)
- Condoms should be used. (The use of condoms is one of the most effective means of curbing the spread of the disease. Laboratory tests have shown that the virus cannot pass through rubber latex condoms. Various researchers have reported a significantly lower incidence of HIV and sexually transmitted diseases among people who insist on the use of a condom. It is, however, important to remember that condoms are not always 100 percent safe and that they may leak or tear. Condoms tear more easily if used incorrectly.)
- Spermicidal cream should be used with condoms. (Research has shown that the spermicide Non-oxinol-9 kills HIV. People who display allergic reactions to Non-oxinol-9 should not use it since an allergy often results in broken skin, which increases the likelihood of the virus being transmitted.)
- Only lubricants with a water base (e.g. KY Jelly) should be used. (Lubricants with an oil base such as Vaseline and cooking oil damage latex condoms and make them ineffective.)
- All high-risk sexual practices such as vaginal, anal and oral sex without a condom should be avoided.

- Semen, vaginal fluids, blood or menstrual blood should not be allowed to enter the vagina, anus, mouth or broken skin.
- Alternative practices should be adopted. (Mutual masturbation and skin-to-skin contact have become common among gays internationally.)

The whole of society will have to fight together to drive this modern Trojan horse as far as possible from our city limits. The greatest danger we must guard against is division in the community which leads to hate, mistrust, stigmatisation and rejection. Mathilde Krim (in Selwyn 1986c: 164) has the following to say about the great challenge of AIDS to society as a whole:

The challenge to scientific and medical institutions is an enormous one, but so is the challenge to the psychological, ethical, legal and social fabric of societies. How these societies will deal with the threat of AIDS will measure to what extent they have the right to call themselves civilized.

2.11 THE COMMUNITY'S REPLY TO THE CHALLENGE OF AIDS

One wonders whether the chapter on AIDS that might one day appear in a history book on epidemics through the ages will be any different from current ones on the same topic. Will it be said that we learnt from our past mistakes and dealt with AIDS in such a humane, compassionate and responsible manner that we have the right to call ourselves civilised?

The history of epidemics through the centuries is full of examples of fear and panic which overshadowed a more reasonable social response. The bubonic plague in fourteenth century Europe (the Black Death) was initially characterised by mass exoduses from the city and widespread persecution and torture of Jews and other minority groups who were made the scapegoats. The yellow fever epidemic in the late 1770s and early 1800s in America was marked by large-scale social shifts; the wealthy fled from the cities, leaving behind the poor with no food or other essentials. They were placed in quarantine in the cities and did not have access to outside supplies. In Baltimore in 1800 only two members of the city's health board remained with the poor and ill. The cholera epidemic of the mid-nineteenth century was blamed on the depravity and immorality of the poor until sanitary reforms stamped out the disease in 1860. The realisation that even the upper classes were not immune to the disease apparently contributed to the evolution of disease theory and the social intervention which ended the epidemic (Selwyn 1989c).

There are also similarities between the history of syphilis and the current AIDS epidemic. Syphilis, a chronic and sometimes deadly sexually transmitted disease for which there had been no treatment before the discovery of penicillin in 1943, was blamed on blacks, profligates and the lower classes. The discovery in 1905 that the disease was caused by a spirochaete and that it might lie dormant while middle-class men who regularly visited prostitutes transmitted it unknowingly to their wives and ultimately their children, resulted in intense social debate. The implication was that the lowering of sexual morality was responsible for the spread of the disease to all levels of society. In 1915

compulsory testing for syphilis was introduced in various American states – not to help victims, but because policy makers and politicians wished to determine who were the innocent victims and who were to blame. This threatened the individual's right to confidentiality. Some doctors stressed the importance of confidentiality and requested that the identity of asymptomatic infected individuals should be protected to avoid unnecessary social stigmatisation. Others insisted that the names of infected individuals should be published and curtailment programmes were proposed “for the public's health and protection” (Clarke & Potts 1988a; Selwyn 1989c).

It was said that people with syphilis and other sexually transmitted diseases had brought these on themselves and had only themselves to blame. However, the double standards that are so often associated with sexual behaviour resulted in the “innocent victims” of the disease being placed in a special category. A whole fantasy pathology of “causative transmission” was created and hysterical doctors reported that anything from pens to toilet seats could spread syphilis. In 1918 the American Navy removed the door knobs from all its warships because it was believed that touching a knob was one of the ways in which syphilis was transmitted to innocent victims (Clarke & Potts 1988a).

The similarities between the way in which epidemics have been dealt with through the centuries and the way in which AIDS is being dealt with today are striking. AIDS was also initially attributed to the socially unacceptable and it was even welcomed in many circles. AIDS is seen as “the broom that would sweep society clean”, and at racist meetings in Georgia pamphlets were distributed with the words “Thank God for AIDS” (Clarke & Potts 1988b).

On 14 March 1983 an article by Larry Kramer (a founder of the AIDS activist group ACT UP) entitled “1,112 and Counting” appeared in the *New York Native*. In his article Kramer expresses his anger and anxiety about his friends dying around him while the American government, the CDC (Centers for Disease Control) and the National Health Institutes do nothing. He attributes their disinterest to the attitude that the disease is killing “kinky gays” and that it does not really affect them. He pleads for politicians and society to become involved and warns that all control will be lost over the disease if action is not taken immediately.

Kramer's warnings are tragic because he was absolutely right. In January 1988 Clark and Potts published an article entitled “50,265 and STILL Counting”. And during the Sixth International Congress on AIDS in San Francisco in June 1990 activists gave vent to their frustration about the international incidence of AIDS and President Bush's uninvolved involvement with the slogan “300,000 dead of AIDS, where is Bush?”.

The fact that AIDS has been allowed to get out of hand can indeed be blamed on governments worldwide. Although the disease was diagnosed in America as early as 1981, it was only in May 1987 that Ronald Reagan scraped together the political courage to discuss AIDS in public. It was some time before educational programmes aimed at preventing AIDS were launched, and in many countries these programmes remain inadequate. Government and private institutions are more inclined to give financial support to research on diseases which threaten the “innocent” than to research on diseases associated with stigmatised homosexual and promiscuous groups. Even after an HIV test

became available, the blood industry in many countries refused to use it and thousands of haemophiliacs were consequently infected (Clarke & Potts 1988b; Connor & Kingman 1988; Neuberger 1986; Sabatier 1988b).

In his work *The Betrothed* Alessandro Manzoni describes the effect of the Black Death on the inhabitants of a small Italian village in 1682. The following extract from the work displays so many similarities with the assault of AIDS on modern society that it might well have appeared in one of today's newspapers:

Anyone in square, or shop, or home who threw out the hint of the danger, anyone who mentioned the word plague, was greeted with either incredulous jeers or angry contempt. The same incredulity, or it would be truer to say, the same blindness and obstinacy, prevailed in the Senate, in the Council of Ten and throughout the whole of the magistrature ... We have already seen how indifferent the government had been at the first announcement of the plague, both about acting and even about keeping itself informed ... the decree about quarantine which was decided on the 30th October, was only drawn up on the 23rd of the following month and was not published until the 29th. The plague had already entered Milan (Clarke & Potts 1988c: 67).

Aids, like the epidemics of old, engenders fear and panic, which cause people to think and act irrationally. Scapegoats are sought – people who can be blamed for bringing the disease on our society. The mass media are helping in the hunt for a scapegoat by referring to AIDS as the “gay plague” and as an “African” – and therefore a black – disease (Chirimuuta, Harrison & Gazi 1988). This incites prejudice against homosexuals and other minority groups associated with AIDS, such as drug abusers and blacks. The impression is often created that it is the victims' own fault that they have contracted the disease, in other words, that it is their just deserts. Categorisation is the name of the game and people are divided into “risk groups” – the feared outsiders who must be avoided – and the “innocent victims” – the insiders. Misconceptions about how “innocent” people can contract AIDS give rise to all kinds of myths and behavioural regulations. Prejudices and harmful practices, such as compulsory testing and isolation of infected individuals, are common. For example, testing is compulsory for all inhabitants of Cuba and HIV positive people are incarcerated permanently (*San Francisco Examiner*, June 22 1990: A10).

The prejudices, stereotypes and stigmatism resulting from ignorance about AIDS have given rise to worldwide confusion, fear, mistrust, hate and panic. AIDS has created a social apartheid which is as harmful and ineffective as its political equivalent. It divides communities into “them” and “us”, and the destruction of this social apartheid may extend over several generations.

The medical community does not have a solution to AIDS. It is up to us to find one. And we will be able to control AIDS only if it is no longer defined as a *medical problem* but as an *educational and behavioural problem* which we can control.

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3

AIDS in the workplace: legal aspects

Christa van Wyk

3.1 LEGAL PROBLEMS RELATING TO AIDS

AIDS is beginning to have repercussions not only in the socioeconomic sphere but also in the South African legal system as is illustrated by the following examples:

- The possibility of antiselection (the tendency of people with poorer than average health to take out more than average insurance) has necessitated adjustments in the insurance business.
- The claim of third parties to an interest in confidential information given to doctors by their patients has led to a relaxation of the obligation not to divulge confidences.
- People with AIDS may be prevented from attending school.

One of the tasks of the law is to weigh up conflicting interests in society. On the one hand there is the individual with AIDS who wishes to maintain his or her right to privacy, and on the other hand there are the members of society who demand that their health and safety be protected. Regulations were enacted in October 1987 under the Health Act, 63 of 1977, and the Admission of Persons to the Republic Regulation Act, 59 of 1972, with the very objective of protecting society's interests. The regulations under the Health Act (GK R.2438) stipulate that in certain circumstances individuals may be compelled by a public officer of health (a medical officer of health of a municipality) to undergo a medical examination (which may include a blood test for AIDS). The regulations also provide for the compulsory treatment, quarantine and isolation of seropositive people (i.e. people carrying HIV – the virus that causes AIDS – and whose blood samples test positive. "HIV carriers", "AIDS carriers" and "anti-HIV-positive people" are alternative designations). The regulations further stipulate that the principal of an

educational institution who knows or suspects that a pupil or staff member has AIDS or has had contact with a person with AIDS may not allow that person to enter the institution unless a certificate of admission has been issued by a medical doctor. The regulations pertaining to people entering the Republic (GK R.2439) stipulate that a foreigner with AIDS or infected with HIV is a prohibited person who may be deported. (It must be pointed out that these regulations have been severely criticised and have not as yet been applied in South Africa.)

As concerns insurance, the Life Offices' Association of South Africa agreed in 1988 that blood tests would be made compulsory for all new life policies over R200 000 and for disability policies over R2 000 per month. If applicants have not had a negative AIDS blood test within three months before their application (and even in some instances if they have been tested negative), cover is excluded if death or disability is caused directly or indirectly by AIDS or HIV infection. If the insured contracts the disease through a blood transfusion or his work, payment will be considered.

With regard to confidential information, the South African Medical and Dental Council decided in May 1989 that doctors have an ethical duty to inform other health workers that a patient is infected with HIV (SAMDC guidelines: *Ethical considerations in the management of patients with HIV infection*). The Council further decided that where there is a serious risk of a specific individual (e.g. the patient's spouse) contracting the virus, the doctor is ethically obliged to inform that person even if the patient has not consented. Such an ethical obligation is admittedly not a legal obligation but would in my opinion be sufficient justification for a doctor held legally liable for infringing a patient's right of privacy.

3.1.1 The workplace

AIDS causes serious problems in the workplace, and most employers will at some time or other have to make difficult decisions in this regard. In the United States of America surveys have shown that between 10 and 20 percent of all businesses had at least one employee with AIDS by 1988, but that fewer than 10 percent had a written AIDS policy (*AIDS Policy and Law*: 11).

In addition to their concerns about productivity, increased medical expenses and the payment of benefits, employers may have to deal with healthy employees who refuse to share toilets, restaurants and even offices with infected people. How do employees handle such a situation? If they try to ensure in advance that they have a healthy corps of employees by testing all applicants, they find themselves facing certain questions: How reliable are the tests? Can they refuse to employ HIV carriers? Can prospective employees, or even existing employees, be forced to have blood tests? Can provision be made in the contract of service for the dismissal of an employee who tests HIV positive, or would it constitute an unfair labour practice in terms of the Labour Relations Act, 28 of 1956?

Employers can no longer afford to be indifferent to AIDS. All organisations should develop a corporate AIDS policy, preferably before the first AIDS case manifests itself in the organisation. A set of guidelines must be drawn up in order to establish a corporate policy on the procedures applying to AIDS sufferers and seropositive employees.

(An AIDS sufferer is a seropositive person who contracts serious opportunistic diseases – such as pneumonia or tuberculosis – and who faces death within two years. By contrast, a seropositive person may remain asymptomatic for long periods although he or she is carrying the virus and can infect other people. It is reckoned that a seropositive person will develop full-blown AIDS within approximately seven years, although some infected people have remained asymptomatic for as long as 14 years. A seropositive employee may therefore remain healthy enough to do his or her work properly for several years. The expression “employees with AIDS” is used for both asymptomatic seropositive people and AIDS sufferers.)

Guidelines should be provided on how managers and supervisors should approach employees with AIDS and their healthy colleagues, and information should be made available to management and employees at all levels. Management should also keep abreast of the latest legislation and case law applicable to AIDS. At the same time they should look ahead and research how their organisations would be affected if AIDS continued to increase at the present rate. Studies have, for instance, already been undertaken on the expected change in consumer patterns and the composition of the labour force. (A decrease in skilled labour, which will result in increased mechanisation, is expected.)

3.1.2 Specific legal problems associated with AIDS in the workplace

3.1.2.1 Questions relating to the recruitment policy of the organisation

Should tests be a precondition for appointment?

To begin with it must be pointed out that a definite distinction must be made between the legal position and the ideal, most accommodating position. In South African law employers have the right to decide whom they wish to employ. (In the USA the Vocational Rehabilitation Act of 1973 and Americans with Disabilities Act of 1990 prohibit discrimination in the workplace, and this applies to the selection of applicants as well.) South African employers have the right to decide not to employ seropositive people and may ask applicants to undergo HIV tests and to answer questions about their life style in order to identify and keep high-risk cases out of their organisations. Responsibilities to the employee in terms of the Labour Relations Act come into force only when a labour relation is established between employer and employee.

An employer's decision to test may be based on one of the following considerations:

- (a) *To protect the health of coworkers or clients of the organisation.* In the ordinary workplace there is no significant risk of the virus being transmitted and there is little reason why AIDS carriers should not be treated in the short term like other applicants (*Morbidity and Mortality Weekly Report*: 681). Such people are usually able to perform their jobs for an indefinite period and the most sympathetic approach would be to employ these people. Infected persons should not, however, take part in invasive procedures of a medical nature; they are also not suitable for employment in emergency services. Infected health workers should not be involved in pro-

cedures in which there is a danger of their infecting other people if they cut or injure themselves. This approach is in keeping with the guidelines adopted by the South African Medical and Dental Council in 1989. In terms of these guidelines seropositive doctors are required to obtain expert advice on how to adjust their practice to protect their patients. Employers who employ health workers should follow these guidelines. AIDS dementia (infection of the brain and central nervous system at an early stage which results in a variety of neurological and psychiatric aberrations) can be dangerous when an AIDS carrier has to make critical decisions, as in the case of pilots and heavy truck drivers.

- (b) *To promote the health of the worker corps, particularly of seropositive people.* Early diagnosis can benefit an infected employee because good results are being obtained with the early administration of AZT. (Azidothymidine, also known as *zidovudine* and *retrovir*, is the drug which to date has been used with the most success in the treatment of seropositive people.) The immune system is protected for longer, secondary infections are prevented and lost mental ability is sometimes regained. Steps can also be taken to protect infected employees against other contagious diseases in the workplace. These considerations apply not so much to applicants as to existing employees.
- (c) *To win economic advantage in, for instance, cases involving long-term contracts or long training periods.* Other employees' interests in pension funds and medical schemes also come into play. This consideration is probably the most important one.

In addition to their legal position, employers should also take note of the unions' views on this matter. The standpoint of the National Union of Mineworkers (NUM) is briefly as follows (as set out in the *IBP Journal*: 25): NUM holds the hostel and migrant labour system along with the unnatural circumstances it generates responsible for the incidence of AIDS on the mines. It therefore finds the Chamber of Mines' policy of testing applicants and rejecting seropositive people unacceptable. The union has requested that living conditions be improved (by providing family housing, for example) and that a compassionate attitude be adopted to those who are too ill to work. It is also demanding that discrimination at the job application stage and dismissal on the grounds of HIV infection be eliminated. The union's claims are based largely on principles spelt out by the International Labour Organisation and the World Health Organisation.

It is often said that employers should follow a policy which promotes good labour relations but which at the same time is based on good business principles. But things are not quite as simple as that. As mentioned, there is no legislation in South Africa which prohibits discrimination against seropositive job applicants. Nor is there a "right to work" because it is commonly assumed that the free market system and minimal intervention by the state are the best means of addressing the needs of our economy. It is unlikely that the views expressed by organisations such as NUM will carry sufficient weight to eliminate discrimination in practice.

Employers who adopt a compassionate approach and do not reject applicants on the grounds of their seropositivity may eventually be forced to do so by economic

considerations. They may become the target of antiselection by seropositive employees with associated increases in expenditure for themselves and healthy employees. It is probable that uniform guidelines on this matter will be adopted in the future.

On the other hand employers must decide whether testing is worthwhile given the following disadvantages:

- (a) The test is not 100 percent reliable, should ideally be performed regularly and is fairly expensive. (Although testing does not ensure an AIDS-free worker corps, it can limit the rate of infection in an organisation.)
- (b) The employer who obtains confidential information of this kind must handle it as such. The acquisition and possession of personal details of such a sensitive nature imply certain obligations. A breach of confidentiality may give rise to civil liability and even a defamation action.
- (c) Applicants must be informed that AIDS tests are going to be performed on them, even if such tests are carried out under the guise of a general medical examination. If they are not informed, applicants may bring an action for damages on the grounds of breach of privacy. (AIDS tests are not yet routine tests. The more routine they become, the less important it may become to specifically obtain the patient's informed consent for an HIV test.)
- (d) The company doctor must inform the applicant of the test results and provide the appropriate guidance. Precautionary measures to prevent further transmission of the disease should be discussed with the applicant.
- (e) The applicant must agree to the test results being made available to the employer. If the applicant has given his informed consent for the test to a doctor in the employer's service, it may be assumed that the necessary permission has been given.
- (f) The organisation should take note of the unions' possible opposition to AIDS testing. It must, however, be emphasised that the standpoint of NUM referred to above is not necessarily shared by all the unions. It can perhaps be stated in general terms that the new (black) unions are opposed to testing but that the traditional (white) unions may support testing.

Although job applicants can be legally requested to undergo a medical examination, employers may decide to forgo this formality given the problems sketched above. It also does not seem ethically correct to drive *all* seropositive people out of the workplace. Unemployed people are usually not insurable which means that their medical and living costs are borne by the public sector and, in the final analysis, the taxpayer. It also seems counterproductive not to employ asymptomatic seropositive people who are well trained and still productive. Opportunistic diseases which are easily transmitted would justify exclusion from the workplace.

3.1.2.2 Questions about the policy on existing employees

(1) Can existing employees be compelled to undergo AIDS tests?

In some cases the contract of service states that employees have to undergo periodic

medical tests. Depending on circumstances, the addition of an AIDS test to this general medical examination may amount to a unilateral, unfair amendment to the provisions of the contract. Such an amendment is tantamount to an unfair labour practice in terms of the Labour Relations Act. Provision for an AIDS test can, of course, be made by means of an agreement (with the worker corps as a whole or with their representatives) and the employer can emphasise that early diagnosis is to the employee's advantage. Employers may make provision for employees with AIDS to be given flexible work schedules, less demanding work and protection against contagious opportunistic diseases. New contracts of service can naturally stipulate an AIDS test.

(2) Can the contract of service be terminated once a blood test is positive?

The dismissal of an HIV employee who is capable of doing his work would in all probability be judged an unfair labour practice in terms of the Labour Relations Act by the industrial court. This court has developed a body of case law based on fairness. Even if the contract of service provides for dismissal in the event of seropositivity, the industrial court may find that the dismissal was unfair (though legal) and constitutes an unfair labour practice. The court investigates whether the employer had the right to dismiss and whether he exercised this right fairly in the circumstances. It also investigates the facts on which the employer's case rests and considers whether these facts justify the dismissal (which would be difficult to prove in the case of an HIV carrier who is still fit and where there is no likelihood of an exchange of body fluids between employees). The court also establishes whether a fair dismissal procedure was followed. In other words, the employee must have been informed of the reasons for his dismissal, must have heard testimony against him and must have received appropriate warning to improve his performance; alternatives such as moving the seropositive employee to another section of the business must also have been considered. However, the Labour Relations Amendment Act, 83 of 1988, introduced new regulations which resulted in conflicting decisions by the industrial court and contained numerous obscurities. At first glance it appeared that in the absence of a collective agreement or wage regulation measure, employers could dismiss an employee on the basis of the contract of service as soon as he tested HIV positive. If this occurred within the first six months, he could be summarily dismissed. After this period the employer would have to give notice and consult with the employee or his representatives. At the demand of some unions which were discontented with these amendments, the Labour Relations Amendment Act, 9 of 1991, was accepted by parliament in April 1991. This latest amendment returns to the definition of an unfair labour practice as it was before the notorious 1988 amendment. The requirement of a fair reason for dismissal, as described above, will once again apply. The dismissal of an employee solely on the grounds of HIV infection, that is, of an employee whose abilities are not affected or who has not been proved to represent a significant risk to his colleagues or other people, will probably be considered an unfair labour practice.

If the AIDS sufferer is too ill to work, the contract of service will normally provide for termination of service in the usual manner after the necessary notice has been given.

(3) What can be done if other employees refuse to work with an AIDS carrier?

Employers have a duty to inform employees about all aspects of AIDS and to call in experts if necessary. Labour unrest (which in itself may constitute an unfair labour practice) must be prevented, and employees need to be convinced that they are working in a safe place. It should be pointed out that under normal circumstances there is no danger in working with a seropositive person. Employees should be informed about special preventive measures to be implemented if, for instance, first aid is required. (They should be supplied with the necessary preventive equipment and it is the employer's duty to ensure that such equipment is used. Preventive measures should be routinely applied.) If employees still refuse to cooperate, disciplinary action may be taken against them. If large numbers are involved, it may be easier in practical terms to move the infected person to another section within the organisation. As a final alternative and if the contract of service makes provision for it, the employee with AIDS can be dismissed. Dismissal under such circumstances will in all likelihood not be considered unfair by the industrial court.

(4) What are the obligations of the ill employee?

Employees have a common law obligation to act in good faith towards their employers. This means that they have to inform their employers if they contract a serious illness which prevents them from performing their jobs satisfactorily. It may be years before a seropositive employee becomes too ill to work, and during this time he is not obliged to inform his employer unless his seropositivity poses a threat to health in the workplace (e.g. in medical and related professions). If his health deteriorates to such an extent that he is unable to do his work, he has to inform his employer. Should he fail to inform his employer, it may in the final analysis convince the industrial court that his dismissal was fair.

(5) What are the obligations of the employer?

Employers have a common law obligation to take all reasonable steps to ensure safe working conditions for their employees. The premises should be safe and staff should be trained and competent. Employees who contract AIDS through their work have a common law claim for damages against their employer if they can prove that the damage they have suffered resulted from the employer's negligent breach of his duty to take care. Some classes of workers can also invoke the provisions of the Workmen's Compensation Act, 30 of 1941, if they can prove that they contracted AIDS (an unscheduled disease) as the result of an accident which occurred while they were on duty.

It is also possible for employers to be held indirectly responsible for the actions of their employees. If a member of the public is infected with AIDS by an employee in the course of his duties, the employer can be held vicariously liable if the actions of the employee (e.g. an emergency worker) fall short of those of the reasonable emergency worker. It would be wise to withdraw infected employees from procedures in which there is a possibility of their infecting colleagues or members of the public.

(6) What is the policy on sick leave and pension funds?

The manner in which a person with AIDS contracts the disease is usually of no importance in the workplace. An exception is the Basic Conditions of Employment Act, 3 of 1983, which stipulates that an employee shall not be entitled to sick leave if his incapacity is the result of any disease or injury caused by his own misconduct. The question arises of whether an employee, who contracts AIDS because of a promiscuous life style has a claim to sick leave. It is debatable whether promiscuity or homosexuality would be considered "misconduct" today.

In an AIDS case the employer should follow the same policy on sick leave and disability benefits as applies to any other chronic or terminal disease. The impact of AIDS on group insurance should be relatively small since the fact that everyone in the group is usually insured ensures that the risk is spread evenly. This type of insurance will probably become more expensive as time goes by. Medical funds also pose a problem since treatment and hospital costs may be high. This may give rise to stricter underwriting principles and limited cover, especially in the case of small groups.

The liability of pensions funds may decrease since there will be fewer surviving members to claim the benefits. The costs associated with widows' pensions will probably also decrease since the life expectancy of widows may be reduced by their exposure to the virus. It is, however, likely that there will be dependents since AIDS attacks people during their most productive years.

Benefits payable on death and retirement owing to poor health may result in higher medical costs, and it is here that a disability ruling will have a significant effect. The earlier a person is declared disable, the higher the costs may be.

3.2 CONCLUSION

It is clear that AIDS is making new demands on the law and on society. No other modern disease has stirred people's feelings as AIDS has done. A sympathetic, balanced and responsible approach to the disease is possible only if sufficient information is available. Ignorance in the case of AIDS can literally be deadly.

The most acceptable attitude would be to continue to employ people for as long as they are willing and able to work. This is justifiable (especially in economic terms), it is the most compassionate approach (because the mere fact that they are still employed improves their state of mind and their health), and it helps to spread the costs of AIDS more equably over the population. The ultimate question is: Who is going to bear the costs – employers, society or the state?

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4

First aid and health hints

Margie Beukes

4.1 INTRODUCTION

Infection with HIV and AIDS has given rise to an urgent and international problem which has taken on broad social, cultural, economic, political, ethical and legal dimensions and which is having a significant effect on these areas.

National and international AIDS prevention programmes and efforts to control the disease extend across the entire spectrum of social and health services. These efforts to prevent and control HIV/AIDS and their consequences have led to careful scrutiny of the deficiencies, weaknesses and imbalances in existing social and health care systems in many countries. The necessity of dealing with AIDS has therefore created opportunities to reevaluate and reconsider existing systems, assumptions and relationships.

At present there are about $2,3 \times 10^9$ economically productive people in the world. The working environment therefore plays a central role in people's lives everywhere. Anxiety about the spread of AIDS has made it necessary to reevaluate the working environment as a safe place to work. In this way an environment which protects and promotes the health of employees, employers and their organisations and (where applicable) authorities and other organisations can be created. The reevaluation of a working environment covers a wide range of issues, including individual behaviour and responsibility. It also creates opportunities to study working relations which uphold human rights and human dignity, which eliminate discrimination and certain stigmas, and which improve practices and procedures.

HIV infection and AIDS are universal problems. The majority of people infected with the AIDS virus initially feel well. In time they may develop AIDS or HIV related conditions or they may remain healthy. It is estimated that approximately 90 percent of the five to ten million people infected with HIV throughout the world are in the economically productive group. This underlines how important it is that employers attend to the problem.

HIV positive employees who remain healthy should be treated in exactly the same

way as any other employees. The same applies to employees with HIV related diseases or AIDS: they should be treated in exactly the same way as any other employee with a pathological condition.

Most people with the AIDS virus wish to continue working, and they should be encouraged to do so, since it is beneficial to both their mental and physical wellbeing. They must be given the opportunity to make productive, creative contributions in a supportive working environment.

If this principle is to be applied, it is essential that all medical information, including the HIV/AIDS status of the employee, should remain confidential.

4.2 FIRST AID TO PERSONS INFECTED WITH THE AIDS VIRUS

People are often anxious that they will be infected with the virus when administering first aid at a road accident, for example. If an infected person has injuries with bleeding, the area can be effectively disinfected with ordinary household products such as Milton or Savlon. Dishwashing liquid in hot water is also an adequate disinfectant. Infected blood actually has to enter the first aider's blood stream for him to be infected with the virus.

The main problem areas in administering first aid are mouth-to-mouth resuscitation and bleeding. In both situations first aiders may come into contact with the body fluids of an infected person.

4.2.1 Mouth-to-mouth resuscitation

An unconscious person who stops breathing spontaneously (for instance as the result of a heart attack, electric shock or head injury) may require mouth-to-mouth resuscitation. This is a life-saving technique and should be applied immediately without fear of HIV or any other type of infection.

Instances of HIV being transmitted through mouth-to-mouth resuscitation have not yet been reported. Although the AIDS virus does occur in saliva, it is in such small concentrations that it has not yet been proved that it can cause HIV infection. Theoretically, however, there is a risk of the HIV being transmitted if the unconscious person is bleeding through the mouth. In such a case it is essential that the first aider first wipe the blood out of the person's mouth with a clean cloth or handkerchief (if available). Medical personnel with the necessary training can use mouthpieces or resuscitation or other ventilation apparatus. Since such apparatus has more disadvantages than advantages in the hands of the untrained (e.g. in the case of local injury and bleeding), it is not recommended for use by them.

4.2.2 Bleeding

Employees who are bleeding require immediate attention. Quick and effective action by the first aider can save a life (e.g. in the case of an artery which is bleeding profusely).

If the person is conscious, the first aider can ask him to apply pressure to the blood vessel using a thick, clean pressure bandage. If the person is unable to cooperate or is unconscious, or if the wound is too large or cannot be reached by the person, the first

aider should apply pressure with a clean pressure bandage or any other suitable buffer bandage (e.g. a tennis ball) in such a way as to avoid direct contact with the source of the bleeding. If available, rubber gloves should be used; if not, any other buffer material can be used to avoid skin contact with infected blood. Special care must be taken to ensure that blood does not come into direct contact with broken skin or the mucous membranes. If the first aider's hands are covered with blood, he should be careful not to touch his eyes or mouth.

The hands should be washed with soap and water as soon as possible after first aid has been administered.

4.2.3 Snakebite

First allow the affected areas to bleed freely and then, if it is really necessary, suck blood from the wound (this procedure should be avoided if there are open wounds in the first aider's mouth). Rinse immediately with a disinfectant. If there are no open wounds in the mouth but the virus is swallowed, there is no reason for anxiety since it cannot survive in the acid environment of the stomach.

4.2.4 Cleaning soiled areas

Infected blood should be wiped up with absorbent material such as paper towels, a clean cloth or a face cloth, which should be placed in a plastic bag and then burnt or buried. The polluted area should be treated with a disinfectant (e.g. household bleach). Rubber gloves should be worn if possible and hands should always be washed with soap and water afterwards.

Bloodstained clothes and cloths should be handled as little as possible and should be soaked in a disinfectant before being washed.

4.2.5 Additional measures

First aiders should handle broken glass and other sharp objects at the accident site with care. To avoid contact with infected blood, they should also ensure that all wounds or cuts on their hands are covered with a watertight plaster before rendering assistance.

4.3 MEASURES TO LIMIT EXPOSURE

The application of the following guidelines should greatly reduce the possibility of HIV infection. There is, however, no guarantee whatsoever that preventive measures will totally eliminate the danger of exposure. It is therefore the employer's responsibility to formulate a policy which provides for situations in which first aiders may be injured or exposed to infected blood. The policy should include the following:

- Broken skin which comes into contact with blood should be washed immediately with soap and water. Mucous membranes should be washed or rinsed with water or a disinfectant.
- If a first aider is injured by a sharp object (e.g. a used needle), the affected area should be allowed to bleed freely and then be washed with soap and water. A dress-

ing may be applied if necessary. Further measures will depend on the type and seriousness of the injury, and the degree to which the injury and the mucous membranes are exposed and the said areas contaminated with blood.

It follows that the more serious the wound, the greater the danger of infection – not only by HIV but any infection transmitted through the blood. In exceptional cases in which the first aider is seriously wounded, it may be necessary to conduct further examinations, including the testing of blood samples for the AIDS virus or other infections such as Hepatitis B.

- If the first aider insists on HIV antibody tests, these should be performed as soon as possible after exposure. If the initial tests are negative, follow-up tests should be performed three and six months later. In the interim the first aider may require counseling to allay his fears and anxieties.
- Other issues which should receive attention in this interim period are the possibility of the AIDS virus being transmitted through sexual intercourse, the use of intravenous drugs and pregnancy. Positive test results directly after exposure indicate that the person was already HIV positive and that the virus was not contracted through rendering assistance.

4.4 TRAINING IN FIRST AID FOR EMPLOYERS

First aid training in the workplace should include explicit information on how the AIDS virus is transmitted and **how it is not transmitted**. The latter is particularly important, since current myths about the transmission of the virus may cause people to withhold life-saving first aid because of their fear of infection.

It is important to point out in first aid training that the chances of infection are relatively small (approximately 1 in every 250 cases), even if first aiders are exposed to infected blood. Measures preventing contact with infected blood and body fluids should be included in the training. Such measures can drastically reduce the risk of infections transmitted through the blood.

It must be emphasised that first aid should be rendered compassionately with the object of relieving suffering. The first aider must weigh up the life that is at risk against the very negligible, and as yet theoretical, risk that he or she may be infected with AIDS.

Internationally, first aid training is presented both inside and outside the working environment by organisations such as first aid leagues and certain ambulance services. Employers should be encouraged to use the expertise of such organisations in planning first aid training for their employees.

It is essential that emergency equipment should include rubber gloves, disinfectants and watertight plasters or bandages as standard items.

4.5 PRACTICAL HEALTH HINTS AND GUIDANCE FOR CHILDREN, TEENAGERS AND DOMESTIC WORKERS

4.5.1 Essential basic knowledge

- Emphasise repeatedly and appropriately the ways in which AIDS is transmitted (i.e., mainly through sexual contact).

- Be careful not to engender panic.
- Emphasise the importance of basic hygiene.
- Emphasise safe sexual practices.
- Emphasise the fact that the HIV virus may remain virulent for 24 hours.

4.5.2 Measures in the home

- **Blood on floors** – use any household disinfectant or bleach; it kills the virus immediately.
- **Open wounds** – wear rubber gloves when working with blood or bloodstained clothing.
- **Razors** – everyone in the house should have their own.
- **Toothbrushes** – they should not be shared with friends or family members.
- **Children's gangs** – discourage practices in which blood is mingled.

4.5.3 General information

- **Ear piercing** – insist on a new, sterile needle in the apparatus. Discourage the trying on of earrings in shops.
- **Immunisation** – insist that a sterile syringe and needle are used.
- **Tattooing** – discourage where possible. Otherwise ensure that the apparatus is sterile.
- **Breast-feeding** – this is still to be encouraged, as the AIDS virus is very seldom transmitted through breast milk.
- **Birth process** – the AIDS virus is transmitted through the placenta and the babies of infected mothers probably contract the disease in the womb. During birth, the mother's blood inevitably enters the baby's eyes, nose and mouth. However, not all infected mothers give birth to infected babies.

4.5.4 Practices among the black population

- **Circumcision** – traditional doctors must be trained to sterilise instruments and razor blades by soaking them in disinfectant for a couple of hours.
- **Rituals** – the instruments used in rituals (e.g. the making of slashes on the faces of the women of certain tribes) must be sterilised.
- **Safe sex** – the importance of safe sexual practices should be emphasised repeatedly.

4.6 CONCLUSION

A recent study in New York followed up on 101 people who share homes with HIV infected people. The researchers studied contact in the form of shared cutlery and crockery, shared bath towels, baths, toilets, kitchens, beds, physical contact, such as hugging, and exposure to the coughing and sneezing of the infected person. Not one of these people has contracted the virus.

This confirms that AIDS is preventable. By following a number of basic guidelines and acting responsibly, the terror of AIDS can be greatly reduced.

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5

Living with AIDS

**Gawie van der Walt &
Robert McKay**

5.1 INTRODUCTION

Rarely has silent frustration been as eloquent as in the AIDS crisis. Reporting on the Sixth International Conference on AIDS in the San Francisco Bay Times, July 1990, Tim Kingston had this to say:

That morning, June 24, the Moscone center was a perfect metaphor for the state of AIDS in 1990. Leading scientists and researchers are stymied and frustrated by the federal government's reluctance to offer any leadership in the epidemic, its discriminatory immigration policy that penalizes people infected with HIV and a growing fear that AIDS funding may come under attack, and ... they watch with silent anger.

Lars Kallings, president of the International AIDS Society has underlined the frustration and anger that characterise the fight against AIDS:

How can we expect the private person to behave in a rational and responsible way to prevent HIV infection or to reject prejudice when States set a bad example by instituting irrational laws, and then, even worse, after realizing that the laws are unscientific and useless, through political bigotry do not change them?

The AIDS epidemic is having a profound impact on society and is evoking social, political and economic responses. The magnitude of this response is largely due to the disastrous effect of the disease on the social, political and economic sectors and the poor prognosis for the infected person.

In the political arena, government and politicians have deliberated at length to determine the official course of action to contend with the epidemic. The inevitable delays have been highly frustrating for both patients and care givers.

Economically the disease has created a new pool of patients requiring public assistance because of the astronomical medical costs and the victims' inability to continue working as the disease progresses. Those who have lost their homes because they cannot work or have been abandoned by lovers and family members have few places to go as the resources are simply insufficient and therefore not available to many who desperately need them.

AIDS has affected medicine in that the severity of associated illnesses and opportunistic infections represents a serious drain on hospital resources and staff. The disease is not only stretching medical resources to their physical and economic limits, but is also having a profound effect on hospital staff working with seriously ill AIDS patients.

Society's response to the AIDS crisis ranges from denial to punitiveness, discrimination, hysteria and scapegoating. Historically these have been common social responses to epidemics. Society may, however, choose to deal with this crisis differently – if irrational fears about AIDS are to be reduced, the public must be educated by mobilising scientific research resources in a focused manner, by implementing large-scale prevention programmes selected for their effectiveness in changing high-risk behaviour rather than for their conformity to narrow social agendas, by protecting public health without impinging on the rights of individuals, and by treating patients with compassion.

5.2 WESTERN SOCIETY'S ATTITUDE TOWARDS AIDS

AIDS forces people to face the demons they try to repress. Because AIDS is often sexually transmitted, it exposes some of humanity's worst fears and prejudices, as well as unresolved questions about the complexity and mystery of sexuality (Agape 1987). AIDS forces us to face up to many taboo subjects like sex, death, promiscuity, homosexuality and drug abuse. According to Witt (1986), people have always attached moral significance to illness and particularly to incurable and probably highly contagious diseases with an unknown mode of transmission.

AIDS also highlights the basic dualism which pervades much of Western thinking: there are sick people and well people; there are bad people and good people; there is proper behaviour and there is improper behaviour. We hear a whole series of comments, questions, judgments and analyses which obscure the fundamental reality. Many regard AIDS as a punishment for sinning against God and the law of nature, but the AIDS crisis cannot be oversimplified in this way. Christie (1988) of the Johannesburg Medical Institute has stated:

AIDS was viewed as a new broom which would sweep society clean, until hemophiliacs became infected through blood transfusions and the horrible truth dawned that AIDS was a disease for everybody. There was a wave of sympathy for victims of infected blood transfusions, but stigmatization and condemnation was still upheld for people who got the virus by sexual transmission.

For Manning (1987), AIDS has unmasked a headlong flight from reality in the name of decency, belief and order. AIDS forces people to confront the depth of their own lack of decency, their unbelief and their confusion. AIDS is a gauge of how people respond

to the outsider, to sex, to mortality; in other words, how they respond to the human condition.

Society has responded to AIDS by creating an atmosphere in which patients find it extremely difficult to cope. AIDS is the new leprosy. AIDS victims have become the victims of a plague – the gay plague, the result of promiscuity. The notion of high-risk groups has been used to stereotype and stigmatise people and has cut them off from human concern and responsibility. “When I met other PWA’s (People with AIDS) – a genteelism for AIDS victims like myself – I saw what was happening. They were sick, sad and alone, rejected by their friends, lovers and families. As the disease destroys the body, so people’s ignorance destroys the soul” (*Cosmopolitan* 1988). How different the sentiments expressed by Camus in his book *The plague*: “No longer were there individual destinies; only a collective destiny, made of plague and the emotions shared by all.”

5.3 WHAT HIV INFECTION ENTAILS

If AIDS is an evil, then society must fight it by declaring war on this enemy. But the danger of the war metaphor in the AIDS context is that it transforms the person harbouring the enemy – the virus – into the enemy. The word “harbouring” suggests that AIDS victims have evil intentions in deliberately concealing the disease and they have thus come to be regarded as criminals (Visser 1990). People with AIDS have become scapegoats comparable with the Wandering Jew of the Middle Ages. As Manning (1987) puts it: “No one will use street language to describe blacks, Jews or women these days if they want to be taken seriously. But it is still open season on faggots.”

AIDS patients are aware that a positive diagnosis is a serious threat to life. This awareness is heightened by previous contact with people who have died from AIDS. This may cause intense depression, anxiety and anger, and patients commonly begin to contemplate their lives, the significance of death, and the meaning of life itself.

5.3.1 Anxiety

The diagnosis of AIDS or an HIV seropositive test (testing positive for the virus) is often interpreted by the patient as a death sentence. William, aged 33, says: “The experience of AIDS is supposed to be a death sentence, and that’s how you feel – How long do I have to live? – with all those thoughts about dying, and being in hospital and just wasting away. When I first heard, I wanted to close up and not talk to anyone” (Watts 1988). Support groups are difficult to establish since infected persons prefer to remain anonymous.

Forstein (Witt 1986) indicates that anxiety is one of the most common reactions to HIV seropositivity. In addition to having to come to terms with a potentially fatal illness, patients are faced by the prospect of variable physical health, pain and death. Infected people are afraid to expose themselves for fear of losing their jobs, discrimination, shame, judgment and rejection. Some fears are general, while others are highly specific. General fears concern developing AIDS, the stress of coping with uncertainty about one’s future health and loss of control over a future orchestrated by an unseen vi-

rus. Specific fears include that of becoming ill, anticipation of future pain and disfigurement and concern about the possible loss of supportive relationships, whether personal or social.

A telephone call is not contagious and no one will die from visiting me occasionally. I'm not going to infect anyone if they hug me once in a while. I'm not asking for miracles, or approval, or sympathy. I'm not asking anyone to lie to me. Let's be practical ... (*Cosmopolitan*, September 1988).

This is only the beginning of the nightmare. What will happen when I get seriously ill? When I am in hospital, too weak to help myself, emaciated, fighting for life, and scared? I'm going to need friends. Damn it, don't let me die alone! (*Cosmopolitan*, September 1988).

The fears described here are realistic. Isolation, both physical and emotional, may be experienced.

I started telling people indiscriminately. I wanted to see their reactions – to use them as though they were my reactions. When they cried, I cried; when they were reasonable, I was reasonable; when they ran (and many did), I tried to run as well. I had nowhere to run to. I get lonely; I get depressed; I get angry. But it's the isolation that really hurts – knowing that you're all out there and too afraid to touch me or hold me or even reach out to me as a human being. To know that because I am ill I'm an outcast, no longer socially acceptable. You can't imagine what it's like to sit and weep or laugh alone. I remember the good times and find it hard to understand why they had to stop. I have the facts and I'm still frightened. But don't I mean enough to someone for them to be there now when I need help? (*Cosmopolitan*, September 1988).

One HIV positive person has said:

It [AIDS] is the stuff of all our nightmares, triggering many of our deepest fears. In contracting AIDS we lose our physical immunity, but we may also have to face equally painful losses – of a job, an income, a home. Of mental equilibrium or physical beauty. Of a partner or a family. No one knows how many are infected: most sexually active people have never taken the HIV test. And those who know they are HIV positive, remain unclear what their chances are of developing full-blown AIDS. People with ARC (AIDS Related Complex) do not inevitably contract it. Equally, people with AIDS may live for years after the diagnosis. A positive diagnosis can actually be a relief; at least the sufferers have something definite to tackle. And knowledge can change some lives for the better, bringing the realization that every moment is precious (Watts 1988).

Hospitalised patients are often admitted to private wards and are visited infrequently by family and friends. Some sufferers may have engaged only in anonymous sex and therefore find themselves alone and bereft of intimate relationships during their illness. In some cases gloves, masks and gowns are worn by hospital staff caring for these patients. Each personal contact is kept brief. Patients may also isolate themselves because

they anticipate negative reactions from others and act defensively to avoid being rebuffed. The obvious disadvantage of self-isolation is that it lessens the possibility of emotional support and understanding.

Reacting to AIDS sufferers who isolate themselves, Jarman (Watts 1988) has stated:

Everyone copes with the virus in different ways; some become reclusive. But they are all wrong. Each of us forms our own individual perceptions in life. These are gained through personal insight and awareness and also through interpersonal experiences.

Support helps people to work through the variety of emotions they may experience (shock, anger, guilt, anxiety, depression, obsessiveness). Initially an HIV positive individual may have to work through feelings of shock, anger and guilt.

When I first found out I went into shock. There are few things more frightening than being confronted with one's own mortality. I experienced a total lack of feeling. There was nothing, just a hollow emptiness (*Cosmopolitan*, September 1988).

Signs of depression include early morning waking, fluctuations in everyday mood and loss of interest in activities previously considered rewarding. Anxiety manifests as constant concern about the body and a need for frequent medical checkups.

5.3.2 Anger

According to Murphy (1986), people with AIDS experience significantly higher levels of anger than people who are seronegative (test negative for the virus). Anger may be self-directed and other-directed (Kelly & Lawrence 1988); it may be directed at the people closest to the AIDS sufferer who, in turn, may feel angry because the person they care for is going to die, because the situation is hopeless and they are helpless. Anger may result from fears about how the illness will progress, social discrimination and stigmatisation, the lack of an effective means of eliminating the virus, and the lack of any assurance that a medical solution will be available in the near future. Those struggling to come to terms with their illness may also be angered by others' callous, indifferent or hostile reactions. Tactless jokes about AIDS and thoughtless casual comments by people who are unaware of the person's HIV status are painful.

5.3.3 Depression

For many, contracting AIDS means that their secrets are disclosed – secrets they wished to keep because they are ashamed of certain behaviour and may feel guilty about what they have done, especially if they believe that they may have exposed others to infection. Intensive media coverage has made patients aware of the high fatality rate and nastier manifestations of the disease and of the social stigma attached to such a diagnosis.

Obsessive thoughts are common in persons who have recently learnt that they have AIDS. Such thoughts may revolve around contamination, guilt and the unfairness of their situation. The focus of guilt may be the victim's past behaviour and life style, or

the possibility of having transmitted the virus to others. Sadness, hopelessness, withdrawal, isolation, lethargy and other symptoms of depression are often present. It is not unusual for individuals to respond to their diagnosis by giving up their jobs, disposing of their goods and property and then awaiting the AIDS death they fear.

5.3.4 Denial

Denial is a useful coping mechanism as it reduces emotional stress. The long-term danger, however, is that denial precludes behavioural changes to prevent further HIV transmission or further exposure to the virus (Parks & Weiss 1983).

5.3.5 Loss

AIDS victims face a series of losses. They fear losing their future, their jobs and their relationships. The fear of losing identity and self-esteem may be strong, since their independent, active adult life style may change to that of an incurably ill and dependent person. Self-esteem suffers as they imagine the loss of bodily functions and integrity and their changed appearance. The inability to continue in a career or to participate in social, sexual and loving relationships also diminishes self-esteem. If a person tests positive, the spouse or partner may refrain from sexual contact to avoid contracting the virus. This not only reinforces the infected person's isolation, but may also cause severe conflict. The loss of modes of pleasure and gratification reinforces low self-esteem.

5.3.6 Counselling difficulties

Counselling and education are expensive both in terms of people and time, as social and individual issues have to be worked through on a person-to-person basis. Effective counselling and emotional support can significantly reduce the anxiety, depression, fear and uncertainty which may follow the diagnosis of a life-threatening disease. Bringing AIDS out into the open in order to change society's attitudes is one of the reasons for Jarman's (Watts 1988) disclosure of his HIV positive status:

My primary reason for being open about the virus is I can't bear secrecy – like about my sexuality as a kid. The whole problem is to break the taboos: to be honest about it and mug up the courage. Even so, I did not announce it publicly the minute I heard the diagnosis. But living in an imperfect situation, you have to speak up. I haven't become a politico of the virus, but it's important to put yourself on the line. I'm always contradicting myself. One can be very optimistic one moment, and very pessimistic the next. I could give you an extraordinarily affirmative interview, telling you what a good thing it is that one acquired the virus at this point in history. It's brought a certain depth into our lives, and it's modern. The only thing is, the aches and pains are a nuisance. The whole thing is to do with a mental equilibrium. I don't think about the virus very much. I rarely talk about it. Yet I think it's very important.

5.4 FAMILIES AND AIDS

Families have to deal with many problems when a member is diagnosed as having AIDS. HIV positive people fear that their families may also be ostracised. They therefore isolate themselves because they anticipate negative reactions and in this way cut themselves off from possible emotional support and understanding. The family may well be ostracised, isolated and stigmatised by the community and support for them in this very vulnerable state may be nonexistent.

A pregnant woman who has been exposed to the virus has to make critical decisions. Should she terminate the pregnancy? Should she wait to see if she and her baby are among the lucky ones? Not every HIV infected mother transmits the virus to her baby.

Parents of children with AIDS suffer the pain of being separated from their children for long periods of hospitalisation, during which time they receive inadequate social support. Parenting is even more difficult for mothers with AIDS as they do not receive the necessary social support to care for themselves and their children.

Children suffering from AIDS are devastated by being separated from their parents. Because many paediatric AIDS cases involve children under six years of age, separation is a more critical issue than awareness of impending death.

5.5 AN ALTERNATIVE RESPONSE TO AIDS

Derek Jarman, 46, the painter and director of Britten's 'War Requiem', is one of the very few people in British public life to discuss what it is like being HIV positive. This is what he has to say about his own and his society's response to AIDS:

Everything is there within the virus: the way people relate to each other; the way society is laid bare in people's pronouncements about it. No one has been able to find a serious solution. I'm obsessive about the virus, and I don't like obsessions. And yet it's here, and it is a reality. The virus is wrong. It puts everything on a wrong footing. It all feels slightly out of joint. Yet I wouldn't have it any other way. If someone gave me an escape door into the paradise garden, I wouldn't take it. Because I feel that solidarity is, in the end, the most important aspect of one's life and this virus has given me a focus for that. I don't quite know who the other people are. But I know they're there (Watts 1988).

Society's need to identify a disease with evil and to blame its victims prevents people from seeking timeous treatment or from making a greater effort to obtain competent treatment. People are too afraid to be tested for the HIV virus because of the imagined and real consequences in an uncaring society.

Dr Michael Ross (1988) writes:

The metaphors or attitudes towards AIDS suggest we are not in all this together. But surely we are. There is no question but that ethically one ought not to harm innocent persons. But in this situation we are all innocent. Those who are carriers of the HIV virus need to care about and to protect those who are not. Those who have not been exposed also need to care for and protect those who have. It is not that some of 'us' need protection and some of 'them' need to sacrifice their

rights; that some belong to death while others embrace life, that some are criminals and others their victims; that some are enemies and other loyal and deserving citizens; that some may be cast out, while others are kept securely within.

What we need to learn is that AIDS is about mortality, not morality. The tendency to find a scapegoat for the things we fear causes us to disregard the morality of love, justice and truth too easily. Ignoring AIDS, treating it lightly, doing nothing to prevent its spread, being indifferent to the consequences for the infected and believing myths and unfounded rumours – all these reactions provoke panic and inconsiderateness. Indeed, uninformed and selfish reactions may be more immoral than the disease itself is said to be.

What then are the aims of programmes for people with AIDS (PWAs)? The Shanti project in the United States, for instance, insists that the unique psychosocial needs of PWAs should be recognised, and it tries to ensure quality of life for them by highlighting the importance of nonjudgmental support. In a brochure on the Shanti Project the World Health Organisation (WHO) has defined counselling to AIDS sufferers as “an ongoing dialogue and relationship between client and counsellor that has as its objectives the prevention of HIV transmission and the provision of psychosocial support for those affected directly and indirectly by HIV”. The National Institute of Mental Health in the United States has reported that the experiences of people who have lived with, loved or cared for AIDS patients are varied, but that they have all learned that AIDS takes its toll emotionally. Yet with compassion, hope, determination, stamina and help from others, many are coping with the responsibility of caring for persons with AIDS.

Counselling should therefore be a caring, therapeutic relationship which assists individuals to cope with the practical, social and emotional problems arising from HIV infection. By definition this means that counselling may be appropriate for HIV seropositive patients (symptomatic or asymptomatic); partners, relatives and friends of infected patients; persons affected by the existence of the HIV; and the “worried well”, people who have ARC symptoms and fear that they may develop AIDS. The “worried well” need special counselling to convince them that their symptoms and fears are the result of anxiety rather than HIV infection.

The implications of AIDS extend beyond mere medical care. The medical profession sees death and the entire process of dying as a failure on its part. The Latin word *sanare* means to heal, to cure, to make sound or healthy. If the task of medicine is always to cure (*ad sanandum*), then death is a denial of that task. If the task of medicine is to take care of, to cherish (*ad curandum*) even when *sanare* is no longer possible, then treatment has a positive goal. Patients report that they feel controlled by the virus and by the medical system when they find that they are infected, and the uncertainty of the prognosis adds to their feelings of hopelessness. The aim of counselling is to minimise the development of psychosocial problems and to help people cope with those that do arise. Emotional support is essential for the individual who is confronted by the very real threat of death and the stigma attached to AIDS.

We all have to die, I am going to die sooner than expected. But I still love, still have dreams and still have much to do and see. I intend doing and seeing as much

as I can in the time that's left. I don't want to do it alone. You can make all the difference (*Cosmopolitan*, September 1988).

How can (and do) we support HIV positive people and enable them to *live* with AIDS and HIV infection rather than merely waiting to die? The preferred approach is a package of supportive community and social services and counselling, using cognitive-behavioural intervention. Although crisis intervention is important, counsellors are mainly concerned with supporting HIV positive patients and enabling them to live with AIDS and HIV infection rather than merely waiting to die. To develop long-term strategies it is necessary to explore patients' aspirations, priorities and goals and to examine their strengths and weaknesses. In this way their own coping mechanisms can be invoked to adjust their life style appropriately. Counsellors allow them to express their thoughts and feelings, they provide information to the sufferers and offer support when they need someone to rely on, and they involve sufferers in activities which improve their state of mind and their sense of wellbeing.

In addition, active cognitive coping – which involves developing the understanding necessary to help fight physical or psychological deterioration and to give meaning to life despite a dismal prognosis – can help reduce anxiety and improve the quality of life. Paul is 27 and for him the diagnosis of AIDS has strengthened his determination to get everything he wants out of his life and death, and he does this courageously and humorously:

The only sign of AIDS I have is the Kaposi's (sic) Sarcoma. I told my mum I'm going to end up looking like a leopard. When things worry me, I make a joke and it did worry me to start with. But then I realized that it's not doing me any harm, nor causing any pain, except to look ugly. And the patches haven't got any worse since I started on chemotherapy ... You may as well make yourself as happy as possible and make the best of what you've got left. Life is a terminal disease too – it just lasts a bit longer. As far as I'm concerned I'm one of the lucky ones. I'm here and I intend to stay here for a damned sight longer than anyone thinks (Watts 1988).

Because HIV positive people are vulnerable to additional infections, healthy eating habits, exercise and rest are essential. William for instance says:

The way to deal with AIDS is to have a positive mental attitude – it helps to cut out alcohol and sugary things as well. They say a macrobiotic diet is the best, but I find it too demanding, though I do eat very little red meat and lots of vegetables and lots of grains (Watts 1988).

5.6 PERSONAL RESPONSIBILITY

Every individual has a personal responsibility to help prevent the spread of AIDS. Parents must talk to their children about AIDS, as many of them get information from unreliable sources. Depending on their cognitive abilities, children may spread distorted information which may cause severe distress. Facts conveyed about AIDS should be in keeping with the values of the family and community. Adolescents in particular need to

be taught how to protect themselves against AIDS and peer pressure which might lead to high-risk behaviour.

Domestic workers in South Africa need specific AIDS education. Language difficulties may result in serious communication breakdowns in AIDS education. For instance, words like “immunity” do not exist in some languages. Educational background may also cause learning problems in AIDS education. Some women do not encourage their partners to use condoms simply because their knowledge about human anatomy is inadequate. People have to be advised about places where condoms are freely available. Often, however, condoms are viewed with suspicion as they are regarded as a means of birth control in order to cut population growth.

Certain peoples may not understand the Western disease concept. To them illness is caused either by being bewitched by a sorcerer (*umtakathi*) or by the wrath of ancestral spirits who may cast spells causing illness. There are two possible ways of solving this problem: first, accommodating existing beliefs and working within them and, secondly, imparting factual knowledge about AIDS by explaining clearly and using visual aids.

Safer sex must be encouraged and condoms are the most readily available prophylactic. However, because condoms are traditionally associated with the prevention of gonorrhoea, syphilis and other sexually transmitted diseases, some people are reluctant to insist on their use because they are afraid of labelling their partners. In addition, most people believe that condoms reduce sexual excitement. Men are reluctant to use condoms and women may not put enough pressure on them because they are afraid of losing their sexual partners. But even if people can be persuaded to use condoms, they do not provide perfect protection.

5.7 CONCLUSION

Various slogans are emerging in the fight against AIDS: “Develop trust and understanding”, “Build partnerships and stop AIDS”, “Have the courage to care”, “Walls will not protect us from AIDS. But knowledge can”. The most we can offer PWAs is a willingness to show them love, to lend a compassionate ear – that is, to listen with our ears and our hearts. We need to listen to William once more:

Just the fact that someone out there cares how you feel – it makes a big difference. Now I have a group of people around me who I feel comfortable with, and I have a support group here too. But I’ve not been able to approach my family with this (Visser 1990: 7).

The AIDS crisis presents a challenge and an opportunity for all. As a reviewer in a London newspaper has argued: “If the disease, as the Moral Majority claims, was sent as Divine retribution, it was not sent to strike down drug addicts and gays. It was sent to test the values of a whole society” (Visser 1990: 7).

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Glossary

AIDS: Acquired Immunodeficiency Syndrome

ARC: AIDS Related Condition/Complex

ELISA: A blood test used to test for HIV infection

HIV: Human Immunodeficiency Virus

HIV positive: Indicates that the Human Immunodeficiency Virus is present.

PWAs: People with AIDS

Seropositivity: Indicates that the Human Immunodeficiency Virus is present.
