

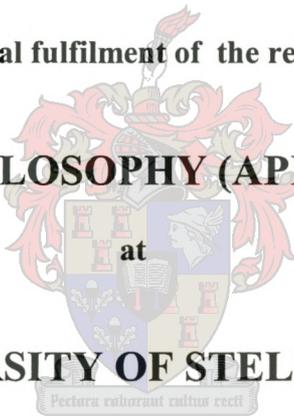
# **CONFIDENTIALITY AS VALUE IN THE MANAGEMENT OF HIV/AIDS IN SOUTH AFRICA**

**Assignment submitted in partial fulfilment of the requirements for the degree of**

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## **DECLARATION**

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree

Signature.

Date:.

## SUMMARY

AIDS is the most important threat to world health. Recent years have seen a dramatic spread of HIV and AIDS in South Africa. Health education directed at modifying risk behaviour appears to be the only way in which the disease can be contained. Controlling AIDS is not only by controlling the virus, but also involves tackling social, economic and political issues and putting AIDS into the broader context of sexuality and gender roles. This requires a broader understanding of this aspect of HIV-AIDS ranging from population dynamics, through to research on individual behaviour and its socio-economic impact; so that we can dispel the myths and rumours that surround AIDS and answer searching questions that will be asked by the community.

In South Africa, HIV-AIDS remains a stigmatized disease. There have been calls from courageous and influential people for those who are living with HIV-AIDS to be open about their status and to destigmatise the disease. Institutions too have been drawn into the controversy about whether to remain silent or speak out. Southern African Anglican bishops, as well as some politicians declared their intention to undergo testing for HIV status in order to sensitise the public to the seriousness of the epidemic.

Were AIDS not regarded as intolerable, the entire issue of confidentiality would fall away. Calls to destigmatise the disease through openness cannot stand alone. Government must put effective treatment programmes in place. In the absence of treatment, AIDS may represent only frustration and hopelessness to those who test positive; and fear, danger and resultant animosity to those who are HIV negative.

The text is in four chapters. Chapter 1 focuses on confidentiality as an important principle in the management of disease. In HIV-AIDS, confidentiality is a more sensitive issue as AIDS is particularly viewed as a social stigma, accompanied by discrimination and harassment. The chapter also addresses HIV infection, transmission, counseling and screening.

Chapter 2 deals with the principles of biomedical ethics namely, autonomy, to enable the patient to determine his/her course of treatment; informed consent, designed to protect the interests of patients from exploitation and harm, and encourage health professionals to act responsibly; beneficence and nonmaleficence, to protect the welfare of others; and justice, to ensure access to health care for all. It also highlights the aspects of and limitations to confidentiality.

Chapter 3 discusses broadly the ethical dilemmas pertaining to professional-patient relationships, women and HIV-AIDS, religion, prisoners and employer-employee relationships. When the AIDS epidemic started, very few people suffered from the disease, and the disease was treated with great caution and confidentiality. Today, AIDS is a pandemic and emphasis should shift from the ethic of autonomy and confidentiality, to a social ethic, which emphasizes the responsibility of minimizing the risk of spread of

infection. The chapter also examines the role of the Department of Health, the participation of health professional bodies and the legal aspects relating to confidentiality in HIV-AIDS.

Chapter 4 attempts to construct an argument to destigmatise HIV-AIDS by arguing the responsibility of the government to make sufficient resources available for the treatment and control of the pandemic. Health professionals are challenged to engage their expertise and skills in the service of the sick with dignity and respect. The community is encouraged to support the drive towards controlling the spread of HIV infection and enable people living with AIDS to disclose their status without fear of harassment.

## OPSOMMING

Vigs is die gevaarlikste bedreiging van wêreldgesondheid. Die afgelope paar jaar het 'n dramatiese verspreiding van HIV en VIGS in Suid-Afrika plaasgevind. Gesondheidsopvoeding wat gemik is op die verandering van risiko-gedrag is skynbaar die enigste metode wat die siekte kan beheer. Die kontrolering van VIGS is nie net die kontrolering van die virus nie, maar dit betref ook herbesinning oor sosiale, ekonomiese en politiese en geslagsrolle. Dit vereis 'n omvattender verstaan van hierdie aspek van HIV-VIGS, wat strek vanaf van bevolkingspatrone tot by die navorsing oor individuele gedrag en die sosio-ekonomiese impak van lg. So kan ons hopelik help om die mites rondom VIGS te besweer.

In Suid-Afrika bly HIV-VIGS 'n gestigmatiseerde siekte. Daar is 'n verantwoordelikheid op invloedryke mense wat met HIV-VIGS leef en wat as rolmodelle sou kon dien, om hul HIV-status te openbaar en sodoende te help om die siekte te destigmatiseer. Instansies is ook by hierdie twispunt betrek om vas te stel of die mense moet praat of swyg. Suider-Afrikaanse Anglikaanse Biskoppe, asook sommige politici het hulle intensies aangekondig om die HIV-toets te ondergaan om sodoende die publiek te help opvoed oor die gevaar van hierdie epidemie.

Oproepe om die siekte te destigmatiseer deur openbaarheid kan nie in isolasie funksioneer nie. Die staat moet effektiewe kuratiewe en voorkomingsprogramme hier rondom loods en kontinueer. In die afwesigheid van 'n geneesmiddel, sal VIGS slegs frustrasie, hopeloosheid, en vrees skep by diegene wat positief getoets is, sowel as vyandigheid onder diegene wat nie HIV positief is nie.

Die teks het vier hoofstukke. Hoofstuk 1 fokus op vertroulikheid as 'n belangrike beginsel in die bestuur van die siekte. In HIV-VIGS is vertroulikheid 'n meer sensitiewe beginsel aangesien VIGS in die besonder as 'n sosiale skandvlek, aangevreet deur diskriminasie, gesien word. Die hoofstuk bespreek ook HIV-infeksie, transmissie, raadgewing en toetsing.

Hoofstuk 2 gaan oor die beginsels van die biomediese etiek, naamlik, outonomie, waaronder ingeligte toestemming, ontwerp om die belange van die pasiënte te beskerm teen eksploitasie en gevaar: om gesondheids professionele aan te moedig om hulle op 'n verantwoordelike manier te gedra. Ander beginsels is goedwilligheid en nie-kwaadwilligheid om die welsyn van ander te beskerm, asook geregtigheid, om toegang tot gesondheidshulp vir almal te verseker. Dit beklemtoon ook die aspekte verwant aan beperkinge tot vertroulikheid.

Hoofstuk 3 bespreek breedweg die etiese dilemmas met betrekking tot die verhouding tussen pasiënte en professionele gesondheidswerkers, vrouens en HIV-VIGS, godsdienste, gevangenes en werkgewer-werker verhoudings. Toe die VIGS-epidemie begin het, het

min mense aan die siekte gely, en die siekte is met groot sorg en vertroulikheid behandel. Vandag is VIGS 'n pandemie en die klem moet geskuif word vanaf outonomie en vertroulikheid na 'n sosiale etos wat verantwoordlikheid en die vermindering van die risiko van die verspreiding van die infeksie beklemtoon. Die hoofstuk kyk ook na die rolle van gesondheidsdepartemente, deelname van gesondheids professionele organisasies en die juridiese aspekte met betrekking tot vertroulikheid van HIV-VIGS.

Hoofstuk 4 poog om 'n argument te ontwikkel wat daartoe sou kon bydra dat HIV-VIGS gedestigmatiseer sal word. Klem word gelê op die verantwoordelikheid van die staat om soveel moontlike bronne beskikbaar te stel vir die behandeling van en beheer oor hierdie pandemie. Gesondheids professionele word uitgedaag om hulle deskundigheid en bekwaamheid in die diens van die siekes met waardigheid en respek te gebruik. Die gemeenskap word aangemoedig om die poging tot die beheer van die verspreiding van die HIV-infeksie te ondersteun en om die mense wat met VIGS leef in staat te stel om hul status sonder die dreigement van stigmatisering bekend te maak.

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## **ABBREVIATIONS**

<b>AIDS</b>	- Acquired Immunodeficiency Syndrome
<b>ALP</b>	- Aids Law Project
<b>DOH</b>	- Department of Health
<b>HIV</b>	- Human Immunodeficiency Virus
<b>SAA</b>	- South African Airways
<b>SABC</b>	- South African Broadcasting Corporation
<b>SAMA</b>	- South African Medical Association
<b>SAMJ</b>	- South African Medical Journal
<b>TV</b>	- Television

## **CHAPTER 1: OUTLINE OF PROBLEM**

### **1.1 INTRODUCTION**

Confidentiality is an important principle in the health management of disease. Health professionals pledge that at all times they will maintain absolute confidentiality when dealing with patient information. This pledge leads to a relationship of trust between patient and health professional. The fact that health professionals have to keep patient information confidential is not new. It is an old age tradition as stated in Beauchamp & Childress (1994: 418), that requirements for confidentiality appearing in the Hippocratic Oath and Code of Ethics adopted in 1957 included the rule that, “a physician may not reveal the confidences entrusted to him in the course of medical attendance ... unless he is required by law or it becomes necessary in order to prevent the welfare of the individual or of the community.” Similarly, the nursing profession is supposed to practise under similar regulations according to the Nursing Act no 45 of 1944, that, “a registered nurse or midwife shall not divulge deliberately, or through lack of proper care, any information with regard to a patient, which ought not be divulged” as quoted in Vlok & Rykheer (1962:24).

With the AIDS pandemic, patient information confidentiality is a more sensitive issue as HIV is particularly viewed as a social stigma accompanied by discrimination and harassment. Confidentiality is becoming an ethical dilemma in the management of HIV-AIDS because it would appear that there is more concern about the protection of the rights of privacy and confidentiality of the HIV positive, than the right of protection of

the partner and the public. While health professionals are expected to protect the privacy and secrecy of information, such expectations cannot always be met. Schoub (1995:12) highlights the dilemma as he refers to aspects such as:

- The doctor may breach confidentiality of the patient to divulge HIV status to a spouse or sex partner, should the patient refuse to do so
- Court decisions have ruled in favour of health professionals to warn colleagues about the HIV status of a patient
- The doctor may need to sign a life insurance document where the wording may compel him/her to make a false statement or breach the confidentiality of the patient's HIV status.

Ethical considerations should maintain a balance between community rights and individual rights. Similarly, HIV positive persons should be aware of their obligation to minimize the risk of infecting others and seek medical advice when necessary. It is essential that health professionals set aside prejudices against HIV and give meaningful information to clients about HIV-AIDS to enable them to make informed choices. These choices may include a planned marriage, termination of pregnancy or a decision to inform the partner about HIV status.

Confidentiality is a 'guarded' principle in HIV-AIDS. Emphasis is more on how to maintain confidentiality than on ways and means to find a cure. These issues will be discussed in the text. I will focus on the complex interpersonal and dynamic processes of HIV-AIDS, highlight ethical dilemmas of the principles of confidentiality and make

recommendations. Data will be drawn from a literature review, reports and interaction with the public.

## **1.2 HIV INFECTION**

The human immunodeficiency virus (HIV) is a parasite that invades the T-lymphocytes in the body, which are responsible for the production of antibodies to protect the body from infection, and induce the lymphocytes to produce more HIV instead of antibodies, according to Cross & Whiteside (1993:4) According to Ffrench et al, infected cells stimulate the cellular and humoral immune responses necessary to combat viral infection, which results in the reduction of lymphocytes circulating in the blood and an increase in the level of HIV (1997:22) Within four weeks of infection, the lymphocytes attempt to fight the HIV by increasing the number of cells in the blood and that results in flu-like symptoms on the affected individual. Should the individual's immune system be able to regenerate and contain the virus within the lymphoid tissue, the replication process will slow down and reduce the progression of disease. Should the individual be suffering from other infection at the time of HIV invasion, then the chances of progression to full blown AIDS are greater.

People living with HIV infection usually function well at their physical, mental and social capacity for a number of years, especially where individuals have acknowledged the disease and maintain a healthy lifestyle. A 29 year old man living with HIV is reported to have said, "a really common coping style with HIV is denial which is pretty

understandable when you are healthy. During this time, it is particularly important for your doctor to encourage you to prepare for the time ahead without undermining your positive attitude ... you need to get some decision-making happening,” Stewart et al (1997:11).

### **1.2.1 Transmission**

Van Niekerk (2000:2) raises concern about the fact that South Africa has become a convenient vehicle for the HI-virus to find its destructive way. He argues that some factors make South Africa an exceptionally suitable environment for the current uncontrolled spread of the pandemic. Among these factors are migrant labour and poverty. Migrancy involves labour in the mines, where workmen live in construction camps and spend long periods away from home. Migrancy is viewed as a movement occupation and involves underground work in dangerous and harsh environments. The need for intimacy at the end of the day is a necessity, but being away from their families, the workers are prone to intimacy with available partners, some of whom may be sex workers who practise unsafe sex with other clients.

Chirwa (1998:61) confirms that migration workers, including long distance truck drivers, form high risk occupational groups that are more likely to transmit HIV. He refers to a report from the South African Chamber of Mines (1985-1986) whereby tests conducted among Malawi mine recruits confirmed HIV positive results. Furthermore, “the central and eastern African countries are said to be where HIV appeared earliest and are now the

most heavily infested parts of Africa; from here the disease is reported to have moved southwards to the rest of the sub-Saharan region.” Poverty is seen as a condition in which AIDS flourishes. This view is shared by the Minister of Welfare and Population, Dr Skweyiya, who in his address at the XIII International AIDS Conference in Durban said: “the truth is, this disease is associated with poverty and in South Africa poverty faces black people ... the effects of AIDS will turn us into a minority” Daily News (2000:1).

According to the latest Report on Global HIV-AIDS Epidemic (2000:8), already 18,8 million people globally have died of AIDS and of these, 3,8 million are children. 34,3 million are now living with AIDS and of this figure 6 million are South Africans.

Schoub (1994:93) explains that HIV is transmitted through sexual intercourse (vaginal or anal). It is exacerbated where other sexually transmitted diseases are present, and exchanging of blood occurs. (This, incidentally, raises the question whether the treatment of HIV ought not from the outset be accompanied by a more efficient treatment of other sexually transmitted diseases.) A high concentration of the virus is required for transmission to be successful and this is possible in sexual secretions and in blood from infected individuals. The other form of infection may be from HIV positive mothers who may pass the virus to their babies during delivery. Minkoff et al (1995:179-180) confirms that, “findings indicate that in most cases transmission occurs close to or at delivery ... however other pregnancy outcomes do not appear to be affected by serostatus among asymptomatic patients”. The placenta first needs to be infected, the virus then

spreads to the foetus; in prenatal infection, the foetus may be in contact with infected blood from the mother. Infection from mother to child may occur also after birth via breastfeeding (Schoub 1995:118). Chirwa in his article published in the Journal of the Royal African Society (1998:59) states that in some African societies and cultures, it is a commonly held view by both men and women that sexual satisfaction is derived from the natural and direct contact of genital organs. The use of condoms therefore is seen as unnatural and unacceptable. As such, low acceptance of condoms fuels transmission of HIV-AIDS. Boys and girls are taught that sex is penetrative not just for emotional satisfaction but for procreation, which is their role in society. However reference is not made to the responsibility that goes with procreation and the options that may be engaged to prevent transmission of infection. Boys and girls grow up to be men and women, with their own views and thus have a right to their own life decisions. Decisions about procreation should not be prescribed. Rather, young people should be given a broad perspective of life situations and be advised to make informed choices.

Blood transfusion may serve as a route for the transmission of HIV-AIDS by direct infusion of infected blood into the blood stream of another person. It is unethical for an individual to donate blood knowing that he/she is HIV positive. But at times the blood donor may not be aware of his/her status. Individuals who habitually inject drugs into their veins and share syringes and needles are at risk of contracting HIV from infected partners.

HIV infection is real and people should be in control of their lives and be prepared to make rational decisions for their wellbeing.

### 1.2.2 Counselling and Screening

“HIV testing and counselling have formed the cornerstone of HIV monitoring, treatment and prevention, despite the lack of cure, once positivity has been established.”

(Minkoff et al, 1995:108). Counselling has been seen as important not only to prepare individuals for the possibility of a positive result but also to help them decide whether they wish to be tested at all. It is important to realise that screening has benefits. For example, antenatal screening for the pregnant woman to protect the newborn baby. Screening is also carried out for the benefit of society as a whole as in the case of epidemiological screening, to obtain information about the disease; and screening of sex workers to protect clients. In all cases of screening, informed consent of the individual must be obtained and assurance for confidentiality of results given.

Gay men gave different views on HIV testing. According to Aggleton et al (1991:57) their concerns were based on disclosure of personal information and the effect on the character of the individual. Their fears were based on the notion that their results could be used to identify, stigmatise and alienate gay men who are HIV positive. The scope of abuse of information about HIV status remains a major concern in the gay community.

Ethical considerations relate to the issue of who should know about the screening results. If a woman is positive, should the partner know? If the husband is positive, should the wife know? If an employee is positive, should the employer know or the prison warden in the case of a positive HIV prisoner. These are ethical issues that need to be resolved.

## **CHAPTER 2: THEORETICAL CONTEXT: THE PRINCIPLES OF BIOMEDICAL ETHICS**

### **2.1 PRINCIPLES OF CONFIDENTIALITY IN HIV-AIDS**

Debates and disagreements among health professionals regarding confidentiality of issues in HIV-AIDS emphasise the need to discuss related ethical principles. AIDS has evoked widespread fear, panic and anger. These emotions may override considerations of efficiency and the importance of confidentiality and liberty in the management of disease. Principles such as autonomy, beneficence, nonmaleficence, informed consent and justice will be discussed briefly in this chapter to examine the strengths and limitations of confidentiality.

#### **2.1.1 Autonomy**

Broadly speaking autonomy refers to, “freedom to act in accordance with a self chosen plan ... without constraints and with a capacity for intentional action.” (Beauchamp & Childress, 1994:121).

This view is supported by Illingworth (1991:10) who states that AIDS ought to be approached from a liberal perspective to give people an opportunity to pursue and enjoy their individual life span. Individuals can exercise their autonomy to choose to accept and submit to authoritative demands of an institution or tradition (Beauchamp &

Childress, 1994:124). For example, the health centre may advise all visiting clients to attend pretest counselling sessions and take an AIDS test as a precaution. The decision to attend will depend on whether the individual concerned accepts the view. Whilst individuals have the capacity to choose with understanding, intention and without constraints, they are usually influenced by their own moral principles, which govern their social and cultural being. The ethical principle of confidentiality implies that a health professional may not divulge confidential information about a client unless the client grants such permission. The dilemma arises when the infected client who controls the right to personal information and access to it, refuses to inform the partner about his/her positive HIV status. To address the issue of control of access to information by not divulging the HIV status to a partner, as an autonomous individual, Mill (in Beauchamp & Childress 1994: 125) maintains that “citizens should be permitted to develop according to their personal conviction as long as they do not interfere with a like expression of freedom of others ... and that we are obliged to persuade others when they have false or ill-considered views”. This view is in keeping with the principle of autonomy which asserts that, “we must respect individual views and rights so long as their thoughts and actions do not seriously harm others” (1994:126).

Under certain circumstances an individual surrenders his/her autonomy, as is the case when visiting a physician for medical examination; here the physician is granted access to personal history and the body for diagnostic and therapeutic purposes. The results pass through several people before being reported to the owner. This situation may seem to infringe on one’s autonomy but it is unavoidable. Health professionals are bound by a

code of conduct to maintain confidentiality and therefore it is assumed that they may not divulge information to unauthorized persons. "The principle of respect for autonomy should be viewed as establishing a right to authority to control one's personal destiny but not as the only source of moral obligation and rights." (Beauchamp & Childress, 1994:126).

Informed consent plays an important role in our understanding of the principle of respect for the autonomy of patients. As mentioned earlier, the capacity of self-governance, such as understanding and reasoning, is essential for the individuals' independent choice. A pregnant mother, who gives consent for blood testing for a routine pregnancy test, does not necessarily give consent for an HIV test as well. The moral rule for the professional is to tell the individual the truth, that is, inform her that the HIV test is for epidemiological survey. The mother will then give consent willingly, understanding the implications. Otherwise testing the patient's blood for HIV without her consent violates the person's autonomy. Health authorities may be guilty of an offence as blood from pregnant mothers is often tested without their express knowledge, for statistical records.

The AIDS epidemic started off as virus infection common in homosexual males. Today, the demographics have changed, making it necessary to shift its ethical focus as well. Touhey (1995), suggests "a need to shift from an individual ethic which emphasizes autonomy and confidentiality, to a social ethic which emphasizes acceptance of reality of risk in health care, acceptance of one's own role in risks".

Respect for autonomy does not reduce the moral responsibility of the professional nor does it give the patient the power to flout authority. Respect for authority has only *prima facie* standing and can be overridden by competing and moral considerations (Beauchamp & Childress, 1994:126).

### **2.1.2 Informed Consent**

The consent requirement is derived from the ethical principle of respect for persons and their autonomy. Informed consent is designed to protect the interests of individuals from exploitation and harm, as well as to encourage health professionals to act responsibly when interacting with clients. To be able to provide informed consent, the person must be competent to make the decision. He/she must be informed and understand available options, possible benefits and harm that may result from the decision and must make the decision intentionally. Judgement as to whether a person is competent to give informed consent or refuse consent should be based on whether the person is autonomous. Preventative advice should be given by health professionals during consultation and in particular, to people who may need advice on HIV infection such as those with sexually transmitted disease and who are vulnerable to HIV such as sex workers, gays and clients seeking contraceptive advice.

Beauchamp & Childress state that, “informed consent is typically given over time and can be withdrawn over time” (1994:43). An HIV positive mother may give informed consent to terminate the pregnancy to prevent transmission of the HIV to the foetus.

When time is due for the procedure, the mother may refuse to undergo the operation by withdrawing the consent. The doctor will have no right to coerce the mother into changing her decision. The health professional may advise on available treatment to prevent transmission of the virus. Bennet & Fernie (1994:69) state that medical science has a long history of ignoring social contextual factors, but theorists coming out of social movements emphasize the primacy of the lived experience as a source of knowledge. The emphasis on informed consent confirms this view that despite the expert knowledge of the health professional, he/she cannot do anything on the patient's body without getting informed consent from the patient. Informed consent is an autonomous authorization, by the individual, of a medical intervention; the HIV positive person will authorize the doctor to divulge his/her positive status to the partner. Failure to give such consent restricts the doctor from divulging such information. However, ethical issues involving disclosure of information, which may lead to litigation, remain unsettled and open to interpretation.

Beauchamp & Childress summarise the definition of informed consent as such: "one gives an informed consent to an intervention if one is competent to act, receives a thorough disclosure, comprehends the disclosure, acts voluntarily and consents to the intervention" (1994:145).

An HIV positive person may agree to participate in clinical trials for testing vaccines if and when the person is informed of risks and benefits of participating in such trials. Informed consent restores the dignity and human rights that are taken for granted

especially in minority and disadvantaged groups; as stated by Kerns (1997), HIV vaccine research on an impoverished population may conflict with ethical guidelines such as the requirement for individual informed consent without undue inducement.

Of greater concern is the practice currently in KwaZulu Natal where young girls aged twelve to fifteen are reported to undergo a virginity test. In this situation, young girls are paraded in front of a group of elderly women chosen to inspect the breasts and abdomen for firmness and shape, and the vulva to see if the hymen is still intact. A certificate is awarded to those girls who pass the test. The purpose of inspection is to check sexual activity and abuse, as a preventive measure against HIV, (Daily News, July, 2000).

Whether this group of parents is acting in the best interest of the girls, remains to be seen. Whether the young girls give informed consent for the practice is another issue. It could be explained as a cultural procedure or some form of exploitation, but according to the Bill of Rights, “a child has a right to be protected from degradation.” I view this situation as a violation of autonomy of the young girls and using presumed consent on the basis of relationship and morality. Everyone’s body is private and confidential.

Shanon (1987:339) explains that, “the less one understands and identifies with the purpose of the procedure, the less valid is one’s consent and the less desirable is one’s participation.” The question remains, “do the girls have a choice?”

Requirements for informed consent according to the Nuremberg Code, as quoted in Shanon (1987:340) are that, to consent to participate in a procedure one must:

- Have the legal capacity to give consent

- Be so situated as to exercise free power of choice
- Have sufficient knowledge on which to decide
- Have sufficient comprehension to make an enlightened decision

Compromise on these conditions violates ethical principles of respect for persons. Children are not autonomous as adults, but must be protected from abuse. Based on the ethical principle of respect for persons, we have to respect the rights of the HIV person to self determination.

### **2.1.3 Beneficence and Nonmaleficence**

“The duty of beneficence argues that we have a positive obligation to regard the welfare of others to be of assistance to others as they attempt to fulfill their plans” (Shanon, 1987:8). Life is a give and take situation. We have an obligation to give back to society our experience and knowledge. Society is under siege with the AIDS epidemic and strategies have to be devised to prevent the spread of infection. Health professionals must work in close co-operation with government and community organizations to develop ways and means to prevent further spread of HIV-AIDS.

Strict confidentiality laws protect the identity of the person identified with HIV-AIDS. However, I believe that confidentiality does not promote the welfare of the HIV infected person and does not prevent the spread of the infection. The benefit is that the individual has the privacy to deal with his/her illness, but is deprived of the support of family and friends. Sufficient knowledge is, however, necessary to deal with the disease.

The principle of nonmaleficence asserts that harm should not be inflicted on others intentionally. The expression in the Hippocratic Oath as noted in Beauchamp & Childress, "I will use treatment to help the sick according to my ability and judgement, but I will never use it to injure or wrong them" (1994:189), expresses obligation of beneficence and nonmaleficence. The framework of the principle of nonmaleficence should maintain a balance between patients and health professionals in that, persons who are infected with HIV ought not to intentionally spread infection to others, whilst professionals ought not to intentionally disclose confidential information to do harm to the sick.

The obligation not to harm others in the case of HIV infection is to refrain from engaging in unprotected sex with an unsuspecting partner, when you know that your HIV status is positive. It is meaningful and just to break the silence and inform the partner about the HIV status so that, together, you can engage in prevention of the further spread of infection and be supportive. The obligation to help others is selective in that it depends on the ability to help. For example, if one has adequate knowledge about HIV infection then one is able to help to promote the health status by advising about preventive strategies and available resources; without knowledge there is minimum benefit to others. Guidelines have been developed to specify requirements of nonmaleficence in health care with regard to treatment and non-treatment decisions, for example, withholding and withdrawing life sustaining treatment. If we consider a patient severely ill from AIDS, known to be a progressively fatal disease, (as stated in Hubley, "once a person develops AIDS, the average survival time is between one and three years" 1995:25), would it be

morally right to withhold treatment or should the patient be started on treatment which will not reverse the condition anyway? Beauchamp & Childress refers to caregivers who feel uncomfortable about withholding treatment and state that starting treatment often creates expectations, whereas stopping it appears to breach expectations to the patient and family. False expectations and misleading promises should be avoided from the onset (1994:197).

#### **2.1.4 Justice**

The Constitution of South Africa states that, “everyone has a right to life.” It is thus within the social justice policy to ensure that the allocation of health resources is equitable and available for utilization by all citizens. Equally important is the human rights perspective around the issue of HIV-AIDS, to allow people infected by the disease fair opportunity to utilize health services, without discrimination and prejudice.

According to a theory of justice attributed to Aristotle, “equals must be treated equally: and unequals must be treated unequally” (Beauchamp & Childress, 1994:328). This translates to the fact that no person should be treated unequally, despite differences with other people, “unless some difference between them is relevant to the treatment at stake.”

HIV positive persons are generally discriminated against socially in the allocation of health services and receive differential treatment based on their HIV status. The principle of needs states that distribution based on needs is just and specifies relevant characteristics for equal treatment. Information about the HIV status of an individual should be kept confidential to protect the individual from harassment and stigmatization.

The most influential theory in the management of HIV-AIDS is the egalitarian theory, which emphasizes equal access to goods that everyone values in life. Daniels (in Beauchamp & Childress 1994: 340) supports this view when he argues that the health care system should be based on a system of fair equality of opportunity, and that health care distribution should be arranged to allow each person to receive fair opportunity. “Forms of health care that have a limiting effect in the functioning of individuals should receive priority”. According to the egalitarian theory of justice, HIV-AIDS should receive priority attention by way of identification, prevention and treatment; adequate facilities should be made available to treat AIDS patients as well as patients suffering from other diseases. The fair opportunity rule requires that persons be given a fair chance in life since the disadvantage may not be of their making, just as HIV infection may be transmitted to another person via blood transfusion or accidental blood mix via an open wound on the skin. Therefore, HIV patients should not be denied access to treatment just because it is expensive. Currently, the South African government is engaged in talks with the public about the fact that HIV causes AIDS. The government does not want to openly admit that fact because the effective drug for reducing the harmful effects of HIV is very expensive. Gazi (1999) disputes this view and reports from a WHO report that, “WHO had fully endorsed a short course of AZT for HIV positive mothers as being affordable and effective in protecting about 50% of babies born to positive mothers in developing countries”

The right to life entails the right to medication that can promote and prolong the livelihood of people; although this is a generally known fact, discrimination on the

grounds of social standing still exists. Many health insurance programmes still require a medical examination including a blood test, for HIV before signing up an individual. This policy may deprive deserving individuals of health benefits, because not all HIV positive individuals suffer from AIDS and subsequently die. Some live for a number of years, and during that time are engaged in productive employment. People infected with HIV-AIDS have a right to at least a basic minimum of health care and it would benefit health services as well if they contribute to some insurance that will cover their health care costs.

HIV-AIDS may be caused by sexual activity with an infected person. Many women and girls living in underdeveloped parts of the world, such as South Africa, are often sexually assaulted by men who may be infected with the virus. Unfortunately, very few public health services are available to give antiretroviral treatment as a precautionary measure, and many sex offenders roam the streets due to problems in the justice system. Moss & Siegler argue in support of a utilitarian position that seeks the greater good for the greater public, although providing fair opportunity to the public may result in increased prejudice towards HIV and AIDS related infections. Health professions often must decide within public policy guidelines, who will receive scarce medical resources in the light of HIV patients and patients with generic conditions. Beauchamp & Childress recommend two broad approaches:

- A utilitarian strategy that emphasizes social efficiency and maximal benefit to patients

- An egalitarian strategy that emphasizes equal worth of persons and fair opportunity

Ethical theories have limitations with regard to justice in the allocation of health care to all, and often result in a conflict between policies and rules. Rawls, as quoted in Bell & Mendus (1998:75) concludes that, “justice, as fairness, rests on the assumption of a natural right of all men and women to equality of concern and respect.” The equality principle covers all individuals, including those suffering from HIV-AIDS and states that people’s lives and fundamental interests should be given equal weight, regardless of status and position. After all, everyone has a right to life.

## **2.2 ASPECTS OF CONFIDENTIALITY**

Confidentiality is the key factor of a therapeutic relationship and has special meaning for the HIV infected individual who experiences discrimination, harassment and rejection by family and friends. Information about the patients’ HIV status, even general medical conditions, should be strictly confidential and shared only with the express consent of the individual. The professional should honour this promise. In Mason & Smith (1991:173) it is stated that, “the doctor is under a duty not to voluntarily disclose, without consent of the patient, information which the doctor has gained in his professional capacity” The rapid spread of AIDS has given rise to problems related to confidentiality as persons with HIV cannot talk freely about their sickness and get advice from friends, because of the possible consequences.

Given the controversy and widespread misunderstanding concerning the HIV pandemic, confidentiality is important and must be entrenched in rules governing testing for HIV and record keeping to avoid leaking of information; which may lead to discrimination. Ratzan states that effective and ethical communication is the key ingredient of a mutually satisfying health professional – patient relationship. The quality of communication includes, among other things, asking and answering pertinent questions, exploring and discussing interests or concerns of each other (1993:41). Through such communication a sense of trust develops, thus enabling the patient to disclose deep feelings that bind the professional to secrecy. Sometimes professionals use confidentiality as an excuse to avoid facing up to certain problems, such as, avoiding to talk about the prognosis of an AIDS related illness to relatives of the patient. Ross, (in Singer 1997) states that rights are indeed important. As such, the right to confidentiality especially in HIV-AIDS is important. However, “there will always come a point where an individual’s right could be infringed” (1997:227). For instance, it would not be right not to disclose the HIV status of an HIV positive husband, who refuses to inform his pregnant wife to save the life of the baby.

Confidentiality is incorporated in the principle of autonomy whereby the individual makes independent choices as to who and how his/her health matters are communicated. Illingworth (1990:11) writes, “each person should be free in so far as his freedom is compatible with the freedom of others ... by focusing on actions that harm others, it also directs attention to actions which are incompatible with the freedom of others” Health

professionals pledge to maintain confidentiality in their code of ethics, but this position should not be held at the expense of the lives of others. An HIV positive person should not use his/her confidentiality position to harm others. Professionals must maintain ethical principles of confidentiality without compromising their moral values. Not only does confidentiality give a patient the right to privacy but also protects the individual from harassment. Reluctance to take the HIV test has developed because of fear of the absence of confidentiality of results as quoted in Aggleton et al (1991:58). The majority of gay men expressed anxiety about HIV tests because of uncertainty about confidentiality of information and the risk of diminished access to life insurance, medical and dental services. This reveals a heightened sense of vulnerability to social discrimination. With reference to employers and employees, the necessity to maintain full confidentiality of information concerning employee HIV status cannot be over-emphasized, to avoid litigation as well as discrimination by other workers.

Duckitt (1988:7) argues that HIV-AIDS testing of employees on the job should be done with the full co-operation of trade unions, and on a voluntary basis. Employees should give informed consent and be guaranteed confidentiality and no adverse consequences in the event of positive results. Some co-workers may react with anxiety and refuse to work with a colleague who is known to be positive, due to fear of transmission of infection. Education about the mode of spread of HIV-AIDS is essential, to allay fears and anxiety. Again as a general principle, confidentiality is regarded as a fundamental right. Minkoff et al (1995:61) write, "HIV confidentiality and consent issues need to be addressed in advance of service provision ... specific procedures for documentation of test results must conform to state laws"

Issues of confidentiality and ethical concerns continue to pose challenges to health authorities and the state, because the people that are affected by the disease have to be protected from being marginalized by the general public. The need to break the silence was the key issue at a recent international AIDS conference, due to escalation of the disease.

### **2.3 LIMITS TO CONFIDENTIALITY**

Ethical issues pose a strong challenge to the principle of confidentiality that must be maintained in the relationship between the AIDS affected person and health care professional. The conflict arises between the professional obligation of the doctor to respect patient confidentiality and his/her moral responsibility to breach that confidentiality in order to prevent transmission of AIDS infection to colleagues or a spouse. Related to this issue is the right of the patient to be protected from an infected health professional, as well as the right of the infected patient to privacy and freedom from fear of discrimination. Schoub (1995:208) also challenges confidentiality when he argues that the planning and implementation of HIV-AIDS surveillance programmes are dominated by anonymity and confidentiality. Patients who test positive to HIV cannot be followed up for counselling, treatment and tracing of contacts. The assumption that anonymous testing is a way of respect for autonomy is a fallacy. It is doubtful whether the public good is served by continuation of anonymous testing of women receiving antenatal care because there is no follow-up when results are positive.

DeZulueta claims that, “it is no longer ethical for health professionals to refrain from informing pregnant women of the benefits of voluntary testing” (Journal of Medical Ethics, February 26, 2000:16-21). The ethical justification is that the good of protecting the individual identity outweighs the harm to the individual.

Professionals are bound by a code of conduct, attitudes, beliefs and values that embrace confidentiality, but not all professionals adhere to these values. It was reported from a Florida Hospital, in the United States of America, that a public health worker used a confidential list of people with HIV-AIDS to screen potential dates for himself and his friends at a bar, (AIDS Weekly, October 26, 1996:9). The health worker compromised sensitive patient information by using the confidential departmental database as a reference for himself and his friends. Confidentiality should be accompanied by individual norms and values based on professionalism. In South Africa such behaviour is regarded as disgraceful conduct, and disciplinary action would be taken against a professional who engages in such activity.

Limits to confidentiality may arise from a communication breakdown between the professionals and the public. For example, community members are sometimes recruited to work in health centres as community health workers and are given limited skills in health matters to be able to assist with non-professional duties. At the end of a busy consultation session, they may assist with filing of patient records. Invariably, the community health worker may catch a glimpse of a patient diagnosis and because he/she is not bound by a code of ethics, may talk about such information at home.

Despite increased professional and public awareness, some patients and professionals avoid discussions about HIV infection and prevention of spread. Epstein et al, associate this breakdown to, “lack of opening line, inappropriate context, awkward moments, vague language and physician-centred rather than patient-centred interview style” (AIDS Patient Review, 1999:9). Some professionals discuss patient conditions openly during a ward round or leisurely with friends. On the other hand, patients may discuss private doctor-patient talk with friends or in public transport, which may not be proper. Confidentiality is not a universal ethic for humankind. However, we all have a common interest in the management of HIV infection, and this is prevention of infection. We need to develop forms of control, through education, that will convince everyone to play a proactive role. Perhaps we need to change the approach from ‘AIDS confidentiality’ to AIDS as a disease in the main stream of medicine.

## **CHAPTER 3: ISSUES OF CONFIDENTIALITY**

### **3.1 ETHICAL DILEMMAS**

The growing number of people living with HIV-AIDS is a dominant feature of the evolving situation in South Africa, and gradually, people are speaking out about their condition despite the confidentiality clause that 'protects' HIV infection. Women, some of whom may be living with HIV and AIDS, are usually relied upon to meet the care needs of children and other family members who may also be HIV positive. The health professional is often faced with a dilemma whether to tell a partner or colleague about the positive HIV status of an individual, thus breaking the trust that binds them, or remain silent. It is currently permissible by law to inform an HIV positive patient's sexual partner(s) of his/her status if the patient consistently refuses to do it by him/herself.

When the AIDS epidemic started, very few people suffered from the disease and the disease was treated with great caution and confidentiality. Today, AIDS is a pandemic and the emphasis should shift from the ethic of autonomy and confidentiality to a social ethic which emphasizes the responsibility of minimizing the risk of spreading infection and disclosing HIV status to partners, parents or professional colleagues.

#### **3.1.1 Professional – patient relationship**

Confidentiality rules are an essential part of the code of ethics for health professionals and these have been revised over time to keep up with health care developments and legal

aspects. Siegler argues that, “confidentiality in medicine is a decrepit concept ... it is compromised systematically in the course of routine medical care”. Siegler also supports his argument by presenting the case of a patient concerned by the number of people in the hospital other than his physician who had access to his clinical records, and subsequently remarked, “I always believed that medical confidentiality was part of doctor’s code of ethics; perhaps you should tell me just what you people mean by confidentiality” (quoted in Beauchamp & Childress 1994: 419). According to the rules of confidentiality, individuals grant access to their personal history or their bodies to health professionals, surrendering some measure of privacy but retaining some measure of control, and no one has a right to divulge that information without the express consent of the individual concerned.

A plastic surgeon in a New Jersey medical centre where he worked tested positive for HIV. He expected and also requested that his medical records be kept confidential. Despite his expectation and request, the following day he received messages of sympathy from colleagues and patients. The obligation of the medical centre to the staff member is moral in character. The colleagues also have a moral and ethical obligation to protect confidential information about their colleague, but they also have a moral obligation to protect themselves from cross infection. Telling his patients about his HIV status thus posed a moral dilemma. In a moral dilemma, two values of seemingly equal worth have both to be considered, but cannot be adhered to at the same time. Choosing in favour of the one of necessity compromises adherence to the other. The patients have confidence in their surgeon but if he is HIV positive, will they have faith in him as a safe practitioner?

The team approach to health care is cause for concern for people with HIV infection, as patient information is available to all staff and this multiplies the risk of a breach of confidentiality. Whilst health professionals have an ethical and moral responsibility of confidentiality towards patient information, people with HIV on the other hand see the health professionals as a threat to their privacy. This scenario threatens the continued practice of the team approach in modern medicine, as against the traditional medical relationship involving the patient as confider and the doctor as confidant.

Stewart et al (1997:154), suggests four reasons to make doctors working with HIV patients consider confidentiality seriously:

- Confidentiality is a legal and professional requirement
- Respecting confidentiality protects the privacy, interest and social values of patients
- Breaches of confidence can cause misery and suffering through harassment and discrimination
- Patients will be reluctant to come forward for HIV testing and treatment if their confidentiality is compromised.

Public health requires the protection of confidentiality but health professionals working with HIV individuals sometimes face difficult cases that tempt them to disclose confidential information in the public interest, as some infected people continue to act irresponsibly.

HIV positive people present themselves differently to the public. Some are willing to break the silence and talk about their condition, others are pushed to the limelight by the media without choice, as was the case with a well known figure in political circles who recently allegedly died of AIDS – an incident that was widely publicized in the press. One can imagine the harmful effects this publicity had for the family. Health professionals and the law have a duty to educate the public about privacy of personal information and the repercussions of such publicity. How far should a health professional go in attempting to protect others from HIV risk from his patient? Health professionals are uncomfortable with knowing that an HIV positive person continues to have unsafe sex with a partner who is not aware of the condition.

On the other hand, if people with a high public profile who contract AIDS were to be more frank and reveal their HIV status, as judge Edwin Cameron has recently done, it could do wonders to de-stigmatize the disease, encourage people to be more frank about their own condition, and thus facilitate more effective ways to ascertain reliable knowledge about the spread of the disease. All the emphasis on confidentiality as value in the debate about HIV/AIDS sometimes does give rise the question whether the right to confidentiality, which in essence is a right of the individual, ought not sometimes to be weighed up against the right of a community to protect itself from the disease. That can only be done when sufficient surveillance strategies are put in place – strategies that would almost necessarily jeopardize the emphasis on confidentiality.

Pinching et al, states that the health professional may either be unable to act because of confidentiality or feel obliged to breach confidentiality to protect the third party, as long as the professional is able to justify his/her actions.

The AIDS pandemic has brought about a necessary change of attitude in health professionals, from a prescriptive, authoritarian, secretive approach to a consultative, interpersonal and confidential approach, as one health professional stated, “perhaps this greater openness has been one of the gifts forced on us by AIDS” (Pinching et al, 2000:6).

Communities are overwhelmed by the devastating effects of HIV-AIDS. As a result, they are not sure whether to believe that AIDS actually causes death or perhaps something else. The dilemma results in communities denying the existence of AIDS as a disease to the point of rejecting any member of the family who reports suffering from such disease. For example, when Sylvia Vezi (34) told her family she had AIDS, she was kicked out, and her relatives also rejected her. A survey done in the area of Ndwendwe in KwaZulu Natal, revealed that families would be reluctant to care for a relative suffering from AIDS, despite the ethos of the Zulu culture which strongly adheres to caring for sick relatives, (Daily New, July 13, 2000. Cf. also Jali 2000). As Kopelman (1999) argues, Kant sometimes agrees with Plato that there are cases where lies or intentional deceptions are justified. Referring to Vezi, who was kicked out by the family for reporting that she was HIV positive: if she had not disclosed her status to the family, no one would have known she had AIDS.

To avoid unfortunate situations like the one referred to above, health professionals should intensify the education drive about HIV-AIDS and counselling. Members of the family should probably be included in the counseling sessions to prepare them for the possibility of a positive test outcome.

### **3.1.2 Women and HIV-AIDS**

UNICEF reports that women, in particular young women, are more likely to contract HIV than young men, often because they have a lower status in society and in sexual relationships in particular. This situation is compounded by the interplay of biological and cultural factors, (2000:47); simply in terms of their physical anatomy, women can contract the virus far more easily than men. During the development process, girls and boys in African culture often engage in consensual experimental sex, but it is reported that girls are more likely to be coerced or abused by someone older, stronger or richer. Young girls may be overpowered physically, sometimes by pressure not to object to elders as it sometimes happens with 'sugar daddies' that offer schoolgirls expensive gifts and money for school fees in return for sex. This is confirmed by Dlwati (2000:41) in her study, who found that teenage sexuality, especially with girls, is strongly influenced by peer pressure, social trends and stability of relationships. This inevitably resulted in sexually transmitted disease, HIV-AIDS and teenage pregnancy. The principle of respect for elders and confidentiality perpetuate these acts of immorality. Young women and girls therefore find themselves particularly vulnerable and at risk in a traditional African setting (cf. Van der Vliet).

Violence against women is often overlooked yet it contributes significantly to the AIDS pandemic. It is reported that a member of the family (male) who is well known to the mother or daughter is usually the one responsible for abusing the young girl within the family. The abused member often does not report the incident for fear of embarrassing the family and causing a rift.

Prostitution is another phenomenon that occurs all over Africa – increasingly because women, unable to find any other means of livelihood, turn to it. Prostitution, in turn, exacerbates the problem of AIDS, and is believed to be a major contributing factor to the disease's rampant spread on the African continent. The sex worker believes she is doing a job to provide for her family and livelihood, whilst society views the sex worker as immoral, trading her body for cash and contributing to the spread of HIV-AIDS. Hart-Petzer argues that prostitution should not be seen as a moral issue but rather understood in the context of labour legislation and human rights. According to him, prostitution should be decriminalized by, “removing the control of prostitution from the criminal code and locate it within a framework of industrial regulation ... a better option for sex workers” (Daily News, July 13, 2000:20).

I believe that individuals have a right to their lives and every individual's right should be respected. Trading in sex work interferes with cultural and moral settings and ought to put the other family members in a difficult situation. The position of the sex workers defended in this text may not be compatible with ethical and cultural opinion, but we live

in a free society where differences are negotiated, and in the end the rights of individuals must be respected within limits that are acceptable to society (we would e.g. never tolerate child prostitution, child pornography, bestiality, etc.).

Gupta directs her focus on HIV positive women because they bear a double burden of being infected and being women. She explains that in most societies men are seen as responsible for productive activities outside the home, while women are expected to be responsible for reproductive and productive activities within the home, resulting in women being disempowered, subservient and vulnerable about issues affecting sexuality. I believe that the imbalance of power has resulted in the reduction of the woman's sexual autonomy and boosted the male's sexual freedom. This attitude may be responsible for the increase in HIV in both male and female, because men often seem to have unlimited sex encounters outside the home, probably unprotected, and then come home to infect the unsuspecting wife. McCarty (1999) states that, whilst she would like to report that in Zimbabwe health education on HIV-AIDS is working, men still go out with younger women as sex partners because the 20 to 45 year old women are already infected. Sexual abuse of children aged 11 to 15 years has resulted in some of them who have already progressed to AIDS, because the older men are allegedly 'protecting themselves' from HIV by having sex with younger girls. In the meantime, they are already infected. In South Africa the attitude of men is much the same, with claims that older men who are HIV positive prefer to have sex with virgins to cure themselves, (Sander, 2000:20). McCarty, however, reports progress in the management of HIV-AIDS in Zimbabwe from a situation where, "patients took their diagnosis to the grave" (1999:6), to a situation

where family counseling is being offered and when a diagnosis is made, contacts and family are traced for counselling and treatment as a team, with the dilemmas of maintaining privacy whilst AIDS progresses.

In South Africa, the continuing debate about HIV causing AIDS is sending out mixed messages to the public and causing a division within the community, the politicians and professionals who should be engaged in developing treatment for the disease. The Minister of Health is quoted in the Daily News, (September 19, 2000:2) as saying, "It's not only a virus, let us look at other issues that fuel the epidemic ... there are many people who don't get tested and they die. So I don't know whether to say a person can die of AIDS if not HIV positive" The political AIDS debate continues as the President, as quoted in the Daily Dispatch, (September 22, 2000:7) stated that, "It was inappropriate to say HIV was the cause of AIDS ... a virus could not cause a syndrome such as AIDS." To this statement, Gazi responded, "a virus causes a syndrome which later causes disease ... the syndrome then leads to AIDS," (Daily Dispatch, September 23, 2000:2). There are fears from civic organizations that the battle against AIDS was being waged on political platforms rather than solving problems confronting communities. A trade union of municipal workers expressed concern in the same publication that, "the link between HIV and AIDS had shifted the emphasis from prevention to finger pointing ... government should concentrate on preventing mother to child transmission and education of the public on how to live with AIDS.' Amid all the accusations and counter-accusations, it is reported that mother to child transmission of HIV is rising, with an estimated 70,000 infants affected annually, from an estimated 800,000 births per year in

South Africa, (McIntyre & Gray, 2000:30) as reported in the Science Editorial. The Head of the Medical Research Council also states that, “the decision not to use antiretroviral drugs for the prevention of mother to child transmission of HIV poses a serious moral and ethical dilemma in a nation where maternal-foetal transmission accounts annually for 10% of the total HIV disease burden.”

It is indeed a great pity that the president of this country got himself embroiled in this debate with this intensity and up to this level. It has cost South Africa dearly as far as international aid is concerned, and made the president the object of ridicule in many international fora. The president clearly does not have the scientific stature to get involved with the specifics of a debate in which the position that the virus is the primary cause of the disease has overwhelmingly been proved by the scientific community, and from which only a small group of dissident crackpots divert. The president’s efforts to grant credibility to this small band of lunatic egoists has not had the wished for effect; in fact, it only served to discredit them even more. South Africa deserves better for its millions of AIDS victims than to be made a pawn in a political game where the president’s lack of judgement is so sorely demonstrated.

Rural women have become particularly vulnerable. Their husbands work in the mines and urban areas where co-habitation is rife. When they return home they may be carrying the virus, unknown to them, and may spread it to their wives and mistresses. The wives have no control over their husbands’ use of condoms, and may not advise them to go for an HIV test. Women need to be empowered to take control of their lives and their

sexuality; they need to form small network groups to know about what is going on around them and abroad, to keep pace with social and economic development.

Whilst the key figures in South Africa accept that confidentiality in HIV-AIDS enables people to die without diagnosis and treatment, infection has developed into a pandemic, people continue to die and South Africa has become the epicentre of HIV infection in Africa.

### **3.1.3 Religion**

Religious communities have expressed different views on AIDS ministry as, “people with AIDS are an oppressed minority who deserve the concern of the church” (Kowalewski, 1994:25). The Catholic church has advocated a Christian response of compassion towards the sick and calls on gay people to accept the church’s teachings on homosexuality and repent. The church is faced with the dilemma of dual status presented by people living with AIDS; that some of them are gay or promiscuous and are sick. The Catholic Church is opposed to homosexuality, birth control and the use of condoms. HIV-AIDS affects gay people, as well as other people. Whilst the church supports and cares for sick people suffering from AIDS, the church would not like to be seen to accept homosexuality because, “to appear to accept homosexual relationships would represent an accommodation to social forces pressing for change, a compromise in what official church teaching maintains as divine law” (Kowalewski, 1994:1). The response of the church to the dilemma is to instill moral principles and at the same time, care for the sick people.

Protestant and Catholic churches hold different views about the AIDS crisis, but the clergy have to deal with lay persons who are clamouring for change in moral matters relating to birth control, abortion and homosexuality. A report from an international conference held by religious organizations to discuss AIDS states that, “unlike the Catholic Church, the World Council of Churches, an association of Protestant Churches, has called for a full range of approaches to deal with the AIDS pandemic, from sexual abstinence, to condom use and safe practices in relation to blood donation” (AIDS Weekly, November 10, 1997:21). Catholic bishops refused to participate at the conference for fear of being seen as promoting the use of condoms. A Catholic nun who participated at the same conference stated that some churches were slow to respond to AIDS because of ignorance and unease to discuss human sexuality. As a result through their silence, fear of the disease has spread all over the world. In South Africa, the Anglican Archbishop has called on all religious leaders to meet and develop a plan of action to fight the pandemic, stating that, “we believe that history will measure this country’s slow response to the pandemic in human, not statistical terms and that the inherent injustices will be judged as a serious crime against humanity ...” (Daily Dispatch, September 20, 2000:1).

I believe the church could play a more proactive role in the fight against HIV-AIDS and use its spiritual and moral power to influence changes in social behaviour and sexuality. Health professionals have taken the lead in some areas of the Eastern Cape by working with religious youth groups in AIDS education projects.

### **3.1.4 Prisoners**

Moral problems often present in prisons whereby medical values are made subordinate to functions of the institution and the state. Physicians attending to prisoners' health needs do not often disclose the diagnosis of the prisoner due to possible legal requirements, but these are known to prison officials. A prisoner who is HIV positive may not be aware of this and with the congestion reported in South African prisons, spread of infection may be difficult to control. A research report presented at a workshop in Port Elizabeth addressing, 'The Demographic Impact of HIV-AIDS' states that, " gang behaviour in South African prisons where inmates are victimized psychologically, socially and sexually is playing a significant role in the spread of HIV-AIDS" (Daily Dispatch, October 5, 2000:2). The report also dealt with the prison ethos as a contributing factor in the spread of HIV-AIDS. A news broadcast on, E-TV news, (September 9, 2000), reported that HIV is becoming the biggest killer in prisons.

AIDS is certainly taking its toll in the confined world, as well as the free world. Mandatory testing and disclosure will help control the spread of AIDS. If prisoners and other persons are known to be suffering from HIV and AIDS, the government would formulate policy guidelines to limit the transmission of infection, to reduce the fear and stigma associated with HIV infection, to enable the infected individuals to come forward for treatment, and guidelines for care of infected persons would be developed.

Communication strategy would be the key factor in the prevention of transmission of infection in and outside prison.

### **3.1.5 Employer – employee relationship**

According to Duckitt, “there is no legal obligation whatsoever for an employer to take action at all should he/she suspect or come to know that an employee has AIDS” (1988:8) This ruling is applicable even today as reported from the Constitutional court that, South African Airways (SAA) had denied an HIV positive applicant employment as cabin attendant on the basis of his medical status as unfair discrimination and unconstitutional. The judge stated that, “people living with HIV constitute a minority and society has responded to their plight with intense prejudice ... they have been stigmatized and marginalized, they have been denied employment because of their HIV positive status without regard to their ability to perform duties of the position from which they have been excluded,” (Daily Dispatch, September 29, 2000:9). Cross & Whiteside (1993) speculate that HIV-AIDS would have devastating consequences for the overall economic development in South Africa, especially in the first decade of the next century as the demographic impact of the disease begins to have an effect. One effect is disability and death that will result in shortage of skilled manpower and losses in the productive and competitive capacity of the economy; the other would be the shrinking of a domestic market for the consumption of South African goods. The Governor of the South African Reserve Bank alluded to this statement when he was addressing a social gathering. “The main enemy of economic growth, along with unemployment, was HIV-AIDS, with about

4,2 million people infected with HIV in South Africa,” (City Press, October, 2000:3). He confirmed that even health professionals were infected: “approximately 35,000 nurses out of a total of 174 000 are HIV positive” - that represents 20% of the total population of nurse in this country!. (See in this connection De Freitas 2000). Statistics are not available for doctors. The HIV status of nurses was confirmed by a researcher and reported in the (Daily Dispatch, September 7, 2000:4). This report states that 50% of student nurses at one nursing college were infected and that one student nurse was dying of AIDS-related complications each month. Questions are raised about confidentiality of information and the ethical considerations with regard to the moral dignity of the student nurses concerned. There is general consensus for openness about HIV status to enable infected persons to obtain treatment and for the state to recognize the plight of health workers, inadequate resources and remuneration, as well as support for health professionals. An official from the nurses union commented that nurses maintain close contact when caring for patients, even HIV patients. Fear and anxiety of contracting the disease came from fears about the careless handling of infected body secretions. The shortage of equipment, including gloves, exacerbates the problem. A challenge for the Department of Health is adequate preparation of health professionals to make them aware of attitudes and prejudices within themselves, which stand in the way of caring well for the patients. Nurses in Amsterdam who were accused of taking leave from nursing AIDS patients indicated that, “adequate preparation, evaluation and support were extremely important to them, as caring for these sick patients made them feel alienated and alone” (Public Health Publication, Amsterdam, 1995).

A survey of employee attitudes on HIV-AIDS reveals that employees are uncomfortable to work close to an HIV positive employee and expect the employer to restrict an infected employee or fire him/her, for fear of transmission of infection. In Michigan, more HIV positive people are returning to work because of anti-AIDS treatments that became available two years ago. This treatment has turned an automatic death sentence into a prolonged life for thousands of people living with AIDS. (AIDS Weekly, November 10, 1997).

There are perceptions that AIDS will have a negative impact on the country's ability to attract foreign investors, tourists and skilled labour to boost the economy. Contrary to expectation, Cross & Whiteside see 'benefits' of the pandemic as the long-term economic effects of reduced population growth and size, (1993:188). They postulate the likely increase of discrimination against AIDS sufferers in the workplace and loss of jobs resulting in unemployment, discrimination in access to life policies and housing, and the loss of lives. It is not possible to stop hundreds of people, already infected, from dying of AIDS, but it is not too late to prevent further millions from being infected with the virus by educating the public about HIV-AIDS. The attitude of the employer plays a vital role in worker relations and AIDS management. Employers ought to adopt an open and honest approach to employees who are HIV positive and to those who are negative and assist them to cope with the situation. An AIDS advisory committee should be formed made up of management and workers, to plan strategic policy and communication guidelines to prevent transmission of infection at the workplace.

## 3.2 GUIDELINES

### 3.2.1 Department of Health

“HIV infection is not, instead of, but is ‘in addition to’ other diseases ... thus if HIV infection is expected to precipitate a crisis in health care in the First World countries, it can only be imagined how much worse this will be in the Third World with its great numbers. South Africa is in the unenviable position of facing a Third World epidemic, with a population that may expect First World resources” (Cross & Whitehead, 1993:10). The Department of Health (DOH) is faced with the challenge of developing treatment protocols for HIV-AIDS, over and above the other prevalent conditions/situations in South Africa, such as tuberculosis, sexually transmitted disease and a high birth rate. Whilst trying to contain these conditions/situations, the DOH is now faced with new developments in health care. As was reported in the daily newspaper: “the government tried to quell fears over the economic implications for South Africa after the outbreak of ‘foot and mouth disease’ on a pig farm ...”, yet in another report it stated that, “health workers are fighting two separate outbreaks of cholera” (Daily Dispatch, September 18, 26, 2000:1,7). According to the 1991 Strategic and Policy guidelines, the Department of National Health and Population Development formulated strategic and policy guidelines for communication on the prevention of the transmission of AIDS. The guidelines were divided into long term, medium and short term goals, and as follows:

- Long term (30 years)

- profound change in behaviour patterns which will result in the limitation of sexually transmitted disease(STD) and HIV infection rate
- education and mobilization of the population, related departments and community leaders
- sustaining and improving channels of communication at international level to ensure co-ordination of efforts
- sustaining and improving communication at national level to ensure co-ordination of efforts
- mobilization of communities and politicians
- improving the standard of AIDS and STD prevention services
- preparation of society for the profound changes HIV will bring in its wake
- Medium term (12 –15 ) years
  - observable change in behavioural patterns
  - observable modification in the care for HIV and STD infected persons
  - observable changes in approaches to the pandemic
  - established channels of communication at international, national, regional, inter-/ intradepartmental, organizational, familial and interpersonal levels
- Short term (18 months)
  - the laying of the foundations for attitudinal change (Aids Unit, 1991).

The guidelines stressed communication with existing organizational and management structures. With the change of government, the previous Department of National Health and Population Development became the Department of Health (DOH). With the rapid

spread of AIDS over the years and change of departmental management, different views and approaches have been implemented. In 1999, the DOH funded a joint initiative known as the South African AIDS Vaccine Initiative, established to co-ordinate the quest for a locally relevant HIV-AIDS vaccine (Galloway, 2000:39). The aim of this initiative is research and development with a multicentred and multidisciplinary approach focused on vaccine development, vaccine trials and testing, advocacy, education and ethics.

The DOH works in collaboration with other organizations nationally and internationally, to look at the epidemiology, control and prevention of HIV-AIDS. The department, in order to monitor HIV trends, has conducted anonymous seroprevalence surveys of women attending antenatal public health centres.

With the escalation of AIDS the DOH is faced with the challenge of health professionals who are feeling the strain of dealing with very ill and dying patients on a regular basis, from AIDS related illnesses. Nurses in one province are reported to be, “overworked and overstressed, and vulnerable to HIV because they are with patients all the time” (Nzimande, as quoted in the Daily Dispatch, September 8, 2000:9). Workers’ unions are demanding that, “the DOH must shed light on its implementation of universal precautions as outlined in the national and international AIDS management protocol,” (Nehawu, Daily Dispatch, September 8, 2000:9).

While the department is trying to control the spread of HIV infection, it is faced with the problem of unclaimed bodies in state mortuaries, as reported in the City Press, (September 24, 2000:1): “bodies of paupers are piling up in Port Elizabeth’s state mortuaries.” One doctor believes it was possible that, “the paupers died from AIDS or

AIDS-related illnesses.” Sick people dying from undisclosed causes overburden hospitals in the province and health personnel are concerned about their own health. Another hospital is reported to discriminate against HIV positive patients by stamping their status in their files for staff to recognize sufferers. Although the superintendent denied this practice, a sticker system is utilized by the hospital to identify HIV positive patients for ‘statistics’ (Daily Dispatch, August 25, 2000:3).

The Department of Health has published a Patient’s Right Charter, in consultation with the Aids Law Project. The aim of the Charter is to strengthen the all-important partnership between patients and health care providers, to assist in changing health services into a caring and compassionate system (South African Medical Journal, December, Volume 89 no 12, 1999).

### **3.2.2 Health Professions Council of South Africa**

The escalating figures of HIV-AIDS are cause for concern. The chairperson of the South African Medical Association, Mlisana, said that his association supported the view that HIV causes AIDS. He added that the causal relationship between HIV and AIDS was firmly established, based on scientific data. However, Mlisana said, there was merit in the President’s message, warning people against running to medicines to try to solve health issues when he said, “the President is right if he is attempting to force us to consider more than just the virus and administration of medicines on the issue of HIV-AIDS” (SAMJ, December, volume 89 no 12, 1999). HIV-AIDS is a fatal disease.

However, by knowing the facts about the disease and adopting appropriate behaviour, one can stay free from AIDS. In 1999 a decision published by the Minister of Health to declare AIDS a notifiable disease was not supported by the Medical Association, and the Law and Ethics committee. Medical academics proposed further research on the reduction of perinatal transmission of HIV in South Africa. They suggested the use of antiretroviral medication to prevent transmission of infection, screening and counselling of individuals (particularly pregnant mothers), and the creation of greater awareness among the population. The doctors did not get much support from the Minister on their proposal because the Minister argued that the proposed drug, AZT (azidothymidine) was toxic and expensive. Government could not afford it for the general public dependent on the public health sector. Gazi, (1999) challenged the Minister to provide AZT to protect the unborn babies, because it was not as toxic and expensive as reported.

According to the South African Medical and Dental Council guidelines, a practitioner should inform a patient about the importance of disclosure of HIV status to the partner and health professional (Leech, 1996). If the patient refuses to conform, the doctor has an obligation to inform the colleague or partner to protect them from infection.

According to a report from the Aids Law Project, the Health Professions Council of South Africa, formerly known as the Medical and Dental Council, has legally binding guidelines on the management of HIV-AIDS. The guidelines recognize the right to privacy, confidentiality and informed consent in the doctor-patient relationship. Yet despite legal recognition of patient rights, the Health Professions Council still has to deal with unethical and unprofessional conduct by doctors (Aids Law Project, 2000:8).

### 3.2.3 Legal Aspects

According to the Bill of Rights, everyone has a right to health services, as well as a right to life. Because HIV-AIDS is a potentially fatal disease, the critical question arises as to whether the health professional has a duty to warn a partner or spouse of a known HIV positive person. In general, “health professionals are ethically required to treat all patient information as strictly confidential” (Duckitt, 1988:10). This is also a legal requirement. Confidentiality, as an ethical principle, forms an integral part of the ethical code of health professionals. According to the American Mental Health professionals, HIV positive clients are informed of the duty to warn as a limiting factor to confidentiality, to ensure the safety of others and are reassured that only necessary and relevant and verifiable information would be released. In South Africa, as was indicated earlier, disclosure to sexual partners, accompanied by counselling, is allowed if the patient refuses to do it by him/herself.

The ethics and legislation of AIDS are the result of the merging of the tradition of public health infectious disease control and the respect for societal values, the right of individuals to protection and the right to privacy. Because AIDS is an incurable disease that is progressively spreading, there is a need to protect the public, by enforcing certain laws where necessary. The problem arises when the laws breach the confidentiality of individuals, resulting in disruption of families. The effect of disruption of lives results in rejection of state laws and distrust of the health professionals.

The need to declare AIDS a notifiable disease has long been identified. The concern is the reaction of the public towards HIV positive individuals and concerns by professionals and people living with AIDS. A survey done on women attending antenatal clinics to determine consequences of disclosure revealed, “a variety of consequences for individuals, some beneficial, some harmful” (Matthews et al, 1999:1238). The morality decision to disclose a positive status where a couple is involved in a consensual sexual relationship, and where one partner refuses, is still controversial, but is allowed by law.

According to the Aids Law Project (ALP) report, despite recognition of patients’ right and ethical obligations by the doctor, there is widespread malpractice in the medical profession with regard to a breach of confidentiality with HIV infected persons. It is reported that, “it is common for doctors to test patients for HIV without their knowledge or informed consent and subsequently disclose their results to an employer, especially with domestic workers” (ALP, 2000:9).

The Aids Law Project is concerned by the unethical and unlawful conduct displayed by doctors and nurses. Complaints of unprofessional behaviour have been lodged with the Health Professions Council of South Africa, but there are delays and failures to act on complaints, according to the report. Whilst the principle of confidentiality is considered as protecting the right of privacy and identity of the individual, various cases sighted by the ALP raise concern about common practices of disregard for confidentiality, by

disclosure of patient/ individual positive status and subsequent discrimination, alienation and abuse as indicated in the cases reported to the project for attention:

- A doctor who failed to inform a pregnant woman that she had HIV; when the child was stillborn, the mother was told that her child, 'had died of AIDS'
- A patient whose doctor did not obtain his consent to conduct an HIV test or permission to disclose his results to his employer
- The ALP obtained an order from a magistrate requiring that the Department of Social Welfare return two minors to a mother whose children had been taken away to a place of safety by a social worker because she had HIV (ALP,2000:10).

Judging by the circumstances involved in the cases reported above, the people concerned are poor and clearly disempowered. Their dignity is not respected and professionals who pledge to maintain ethical standards and treat people with dignity and respect, regardless of status, ignore their privacy and confidentiality. HIV-AIDS should, in this respect, be treated like any other condition.

Employers need to be legalwise to secure the future viability of their businesses in view of the growing AIDS threat. They need to be well informed about HIV-AIDS, confidentiality and ethical issues with regard to employee health status, and labour practice. With reference to the ALP report, a number of employer/employee disputes were lodged with the Commission for Conciliation pertaining to breach of confidentiality of employee HIV status. The employers lost the cases and had to either reinstate or pay a settlement fee.

According to van Wyk (1993) regarding the obligation of the employer to the worker who is HIV positive, “when an employee becomes HIV positive, it may take years before he/she becomes incapable of doing his/her work. During this time, s/he need not inform his/her employer about his/her condition, except in circumstances where his/her HIV positivity constitutes a health threat in the work situation” (1993:10). It is imperative that employers design an AIDS policy and keep abreast of legal developments.

## CHAPTER 4 : CONCLUSION

Perhaps no disease has challenged the ethical and moral principles of society as has HIV-AIDS' (Makgoba, July 2, 2000:2). The area of most concern with regard to confidentiality is the question of disclosure of HIV status. People with HIV face the dilemma of having a disease that even health authorities are unable to cure. The sufferers themselves are very often reluctant to be identified for a variety of reasons. AIDS prevention is based on sensitive issues such as sexual orientation, marital fidelity, prostitution and other moral values. Leadership has to be exemplary in upholding good moral principles, and if these values do not exist, denial will thrive. This also occurs among people who test positive, they will deny that they have any health problem, since they feel so well! As such, the whole process of preventing an epidemic is delayed .

Nussbaum, as quoted by Inwood, states that the recognition of the importance of medicine, as a metaphor for moral education, indicates something significant. But as we have experienced, "many crafts and techniques get their results even if the practitioners do not know the truth" (1999:380). She explains that the truth is an essential component of the ethical tradition. This raises the question about the kind of truth a moral doctor needs, particularly with regard to doctor-patient relationship. We have seen in the text how some doctors relate to their patients, for example, the case of the doctor who does not tell the pregnant patient that she is HIV positive, but, when the baby dies, she is informed that, 'your baby died of AIDS'. Much as we have

to respect the privacy of the patient, the patient needs to know the truth, discussed sincerely in a language she/he understands. There is strong argument for autonomy for the benefit of the individual with HIV infection. By knowing what is wrong with him/her the individual is able to make decisions to cope with the disease. As stated by Brett Anderson in the text: before he was diagnosed with HIV, he was so sick that life was meaningless because he did not know what was wrong with him. When he got to know and accept that he had HIV, he engaged in treatment and formed a good relationship with his doctor, regained his strength and desire to live life to the full.

Education and information presented honestly and openly form the cornerstone of the management of HIV. Emphasis should be on understanding the disease and talking about it, more than the withholding of information that is not well understood by the sufferers and is thus misinterpreted.

Health professionals need to revisit their professional pledge and try to live up to acceptable ethical standards, not for their personal pleasure but from respect for their moral obligation. One might say they are under extra pressure because of the overwhelming effects of AIDS on the lives of people. Stewart et al, summarize the effect as such: 'AIDS crashed into public consciousness ... rarely is a disease charged with such strong social significance ... HIV was an unpleasant shock to western medicine and challenged the competence of medical science ... challenged doctors to provide leadership on public health issues for alarmed and divided communities and to assess the purpose of medicine in circumstances when a cure is

not possible, but long life with illness is” (1997:2). Therefore doctors and nurses have to face up to the challenge and win the war.

Health professionals feel the strain more, because of confidentiality, they are unable to talk to the patients about his/her disease, educate the patient about what is going on in the body and how to deal with the changes. The professional and the patient are in different positions, yet faced with the same problem. Confidentiality must be respected as far as not disclosing the patient’s condition to others. But relations between doctor and patient ought to be open enough to enable the doctor to discuss the problem with the patient and the family.

There is a tendency in the gay and lesbian communities to publicly reveal their HIV status. Judge Cameron, a self-admitted homosexual, who, during his address at an International Aids Conference, announced that he was gay and HIV positive, illustrated this . He reported that he had been very ill, but was kept alive by modern medicine and modern medical care. The judge stated that, on his judge’s salary he could afford to take a combination of drugs at a cost of R2550 a month. This combination of drugs left him feeling ‘vigorous, energetic and more full of purpose than at any stage of his life’ However, he acknowledged that, “these drugs barely touch the millions of people who need them most because they could not afford them” (Daily News, July11, 2000).

Individuals who are diagnosed with HIV infection, needs to know what to do, how and where to go for help. The government should make the drugs available and

affordable to the ordinary citizens by negotiating with the pharmaceutical companies, to offer AZT and Nevirapine cheaper to the public. The cost of medication at present (November 2000) is as follows:

- Nevirapine costs R21 pr tablet in South Africa (S.A.); and R4 as a generic.
- AZT costs R200 per course for mother to child transmission; and R20 as generic
- Fluconazole costs R80 per capsule in S.A.; and R1.70 as generic in Thailand.

There is new hope for South Africa with the announcement on SABC TV news, October 4, that an HIV vaccine has been produced and that the first trials on human beings are due to start in the year 2001. The introduction of the vaccine will hopefully promote positive reactions such as:

- Encourage the public to go for HIV screening to know HIV status
- Encourage debate on the role of confidentiality with regard to HIV positive and the public

The introduction of a vaccine in South Africa is a way forward in dealing with the disease and people are willing to respond to trials. It was quoted in the Journal of HIV Medicine, that a patient was asked why she would risk participation in a drug trial at Chris Hani Baragwanath Hospital. The reply was: "I am not only doing it for myself, but for my sisters who also face the terrible epidemic" This response indicates the plight of HIV positive women and their families, the desire for adequate

resources to meet their health needs, and the extent to which they will go to help themselves. HIV vaccine will need many years of development before it will be available on a large scale. At the moment, its safety and effectiveness are being tested and it is hoped that eventually, a useful and affordable mass produced vaccine will emerge. It should be remembered that such vaccine would not help the 4 million people who are HIV positive.

HIV-AIDS has created an opportunity for men and women to be aware of the gradual breakdown of family values, and socializing agents such as those represented by the family, the school and the church. This has resulted in permissiveness that has contributed to the AIDS pandemic. Against this background, AIDS has emerged, resulting in young people being the most affected by the disease because of the scarcity of role models. To help the youth and the public at large, we need to acknowledge the fact that HIV causes AIDS. We need to form strong family unities as backbone as well as form a close bond with health professionals in the fight against AIDS. This bond will give strength and support to the fight against the disease. It will enable openness between professionals and the public, allowing people with HIV to trust health professionals, to come forward for screening for HIV. Beneficence is about duty to actively contribute to the welfare of others by preventing harmful consequences and positive benefit to others, whereas, nonmaleficence is about doing no harm to others. We have identified areas of harm as a result of the abuse of confidentiality. Therefore, AIDS education of the public must be encouraged for the long term benefit of the public, in the fight against the disease.

The question arises: to what extent should the status of HIV positive individuals be withheld from the family? A concerned father, attending an HIV conference in Port Elizabeth informed the audience that his two teenage children, a son and daughter, died of unknown causes. Only after they were buried did he get to know that they had died of AIDS. He is concerned about the secrecy around this disease, as he feels that he could have done something to help and support his children by seeking medical expertise. He blames the doctor for not telling him the diagnosis and keeping it a secret. The question is, did the health professionals handle the situation ethically? Were they right not to disclose the medical condition to the family during hospitalization and even after death? Was it fair that the family got to know the diagnosis from the grape vine? Did they handle the dilemma in the best interest of the family? Could they be held responsible for the grief and suffering that the family is going through? Kopelman (1999) states that there are cases where lies or intentional deception are justified. Could this be such a case? There are too many questions asked, and families going through such painful loss continue to ask these questions. But in this situation, I would argue that perhaps the doctor acted in the best interest of the teenagers. They may have asked the doctor not to inform their parents about their diagnosis, because they did not want to hurt them. They could have been the pride and joy of their parents, and being diagnosed with a disease that carries a stigma, as HIV-AIDS, they felt they had betrayed their parents.

I believe the doctor did not intentionally deceive the parents in this case, and cannot be blamed for being secretive either. He had a moral obligation of confidentiality to

his patients and had to maintain professional secrecy. On the other hand, the doctor could have persuaded the teenagers to talk to their parents about their status. To learn that their children died of AIDS, from an official source would have helped them accept that AIDS killed their children, and motivate them to help other families going through a similar situation. Disclosure of the HIV status is an issue under discussion and hopefully a decision will be taken.

Considering the problems experienced with confidentiality in HIV-AIDS, I would support the proposal to make AIDS a notifiable disease. It would make it possible for the family to be aware of infected members, and contacts will be traced for treatment purposes, as is the case with other notifiable diseases. Hopefully, the AIDS pandemic will be under control.

#### **4.1 RECOMMENDATIONS**

The question remains: How can we run a personal confidentiality service for individuals while respecting the needs of the family group? It is important to remember that every game has rules, and rules must be understood by all players to participate effectively. HIV-AIDS affects everyone: the government, the health professional, the people infected with the disease and the public. It is vital that all role players understand what AIDS is all about and how it can be prevented and controlled. Openness and honesty are essential. I then proposes the following recommendations:

1. Government must make resources available for the management of the disease as a matter of priority. This is a complex matter, but government has to give immediate attention to ensure that treatment is given to the people in need, and treatment is made available for any other epidemic that may arise. The Uganda experience could be regarded as a role model, whereby HIV infection rate in some areas dropped from as high as 38%, to as low as 10%; because the Ugandan State President acknowledged that Uganda was facing a potential national disaster, and approached international countries for help. The AIDS epidemic was approached with a degree of openness and honesty ... and Uganda information centers offered testing facilities, from where action groups were formed to motivate the public at grassroots level (Daily News, July 11, 2000).
2. Health professionals must engage their expertise and skills and be morally obliged to serve with dignity and respect. They must give mutual support to patients to break the silence, and set realistic goals for AIDS control.
3. The HIV infected person should be open about his/her infection and illness to allow health professionals to help his/her cope with the disease, and join forces with AIDS support groups for continuing education . He/she must understand the importance of continued prevention of infection and health promotion.

4. Research in HIV-AIDS should be encouraged until a cure is found; “the research protocol should always contain a statement of the ethical consideration involved”(Declaration of Helsinki, 1975).
  
5. The AIDS pandemic has placed tremendous strain on health professionals and other health care workers who are over stretched. There is a need to mobilize community groups to serve as health care workers to intensify support. Health professionals have to work hand in hand with government and the public in implementing policy guidelines in the management of HIV-AIDS. They have to develop moral competence and support the individuals as they prepare to break the silence in the fight against HIV-AIDS.

AIDS has forced us to recognize that respecting individual rights remains critical for the health of the community.

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