

***ETHICAL PERSPECTIVES ON SURVEILLANCE
AND PREVENTIVE STRATEGIES FOR
HIV/AIDS IN SOUTH AFRICA***

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

MASTER OF PHILOSOPHY (APPLIED ETHICS)

at the

UNIVERSITY OF STELLENBOSCH

Mojalefa Johannes Koenane

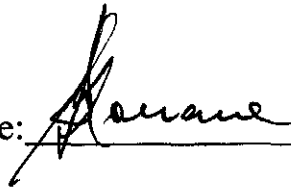
Supervisor: Professor Anton A van Niekerk

December 2000

“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: _____

A handwritten signature in black ink, appearing to read "A. S. S. S.", is written over a horizontal line.

Date: 08 – 11 - 2000”

Summary

It is a well-known fact that the sub-Saharan Africa is a continent most affected by HIV/AIDS. The HIV/AIDS pandemic has in other words become our disease. For many of us, this fact may be difficult to fully accept. There are elements of prejudice in our reactions. Ignorance and intolerance can be found around the world. Therefore, by presenting the facts about HIV/AIDS, this assignment challenges the misconceptions and focuses on the profound dilemmas confronting society.

I think the success in combating the HIV/AIDS pandemic could be found in President Thabo Mbeki's terminology "*Partnership against HIV/AIDS*". In his speech, the President appealed to both the private and public sectors and all South Africans to work together with greater determination than before to fight against HIV infection and AIDS. Arguably, this was the best speech President Thabo Mbeki ever made on HIV/AIDS on October 9, 1998. Back then, the government seems to have had a direction and led from the front in the battle against HIV/AIDS.

The title of this thesis reads: "*Ethical perspectives on surveillance and preventive strategies for HIV/AIDS in South Africa*". Presently, the South African Government through the Ministry of Health is seriously considering making AIDS a notifiable medical condition. This is a serious and a controversial move that has serious ethical and legal implications that will be discussed. Should partners of HIV-infected individuals be informed? If the answer is on the affirmative, who should inform them? I am also looking at the ethical obligation of health care workers to treat HIV/AIDS patients despite the fear of being accidentally infected. Tough questions need to be asked. Should health workers be informed of the HIV status of every patients they treat? On the other hand, some patients have some fears too that HIV-infected health professionals may infect them. Again, the fundamental ethical concerns related to confidentiality, privacy, the right to treatment will also be discussed. The country is divided on this issue. Ethical principles are directly involved in such a decision, for instance, the *principle of confidentiality, respect for autonomy and informed consent*. How can the government go about implementing this without disregarding these fundamental ethical requirements?

Another ethical issue that comes to mind regarding HIV/AIDS concerns AIDS vaccine trials, which are so far dominantly manufactured in '*developed countries*' while subjects of these trials are from '*third world*' or '*developing countries*'. The ethical concerns here are: How will informed consent be protected, especially where subjects of the trials are not educated and do not understand the terms used? What are the cost-effects or benefits of such trials? What are the risks involved? Together with this, other issues include ethical debates concerning market prices of drugs, which are too expensive for poorer countries and affordable for richer countries.

Finally, this work does not treat everything that needs to be dealt with insofar as HIV/AIDS is concerned. However, I hope that this thesis will contribute (in a small way) in making people appreciate the ethical dilemmas that are presented by HIV/AIDS.

OPSOMMING

Dit is algemeen bekend dat Afrika suid van die Sahara die gebied is met die hoogste voorkoms van MIV/VIGS. Die MIV/VIGS-pandemie het dus óns siekte geword. Dit is vir baie van ons moeilik om hierdie feit te aanvaar, en ons reaksies is dikwels bevooroordeeld. Onkunde en onverdraagsaamheid oor MIV/VIGS word trouens wêreldwyd aangetref. Hierdie verhandeling lê klem op die feite van MIV/VIGS, en konfronteer sodoende hierdie wanopvattinge terwyl daar gefokus word op die diepgaande dilemmas waarmee die samelewing gekonfronteer word.

President Thabo Mbeki se woorde “Vennootskap teen MIV/VIGS” verwoord myns insiens die enigste oplossing vir die MIV/VIGS-pandemie. Die President doen in sy toespraak ’n beroep op alle Suid-Afrikaners, in private en openbare sektore, om met groter determinasie saam te veg teen MIV-infeksie en VIGS. Hierdie toespraak, gelewer op 9 Oktober 1998, toe die regering klaarblyklik nog rigting gehad het en op die voorfront was in die stryd teen MIV/VIGS, was moontlik President Thabo Mbeki se beste ooit oor die onderwerp MIV/VIGS.

Die titel van hierdie verhandeling is “Etiese perspektiewe ten opsigte van waarnemende en voorkomende strategieë vir MIV/VIGS in Suid-Afrika”. Die Suid-Afrikaanse regering, by monde van die Ministerie van Gesondheid, oorweeg dit tans sterk om VIGS ’n aanmeldbare mediese kondisie te verklaar. Die ernstige etiese en regsimplikasies van so ’n daadwerklike en kontroversiële stap sal in die verhandeling bespreek word. Behoort die metgeselle van MIV-positiewe persone ingelig te word? Indien wel, wie moet hulle in kennis stel? Daar sal ook gekyk word na die etiese verpligting van gesondheidsorgwerkers om MIV/VIGS-pasiënte te behandel ten spyte van hulle vrees om per ongeluk besmet te word. Indringende vrae moet gevra word. Behoort gesondheidsorgwerkers ingelig te word oor die MIV-status van elke pasiënt wat hulle behandel? Aan die ander kant vrees sommige pasiënte dat hulle deur MIV-positiewe gesondheidsorgwerkers besmet kan word. Die fundamentele etiese aangeleenthede rakende vertroulikheid, privaatheid en die reg tot mediese behandeling sal ook bespreek

word. Suid-Afrika is verdeeld oor hierdie kwessies. Etiese waardes, soos die beginsel van vertroulikheid, respek vir outonomie en ingeligte goedkeuring is direk betrokke by besluite oor etiese kwessies. Die regering kan nie hierdie aangeleenthede implementeer sonder om die fundamentele etiese vereistes in ag te neem nie.

VIGS-entstofproefnemings is'n verdere etiese kwessie wat ter sprake kom. Hierdie proefnemings word grotendeels deur "ontwikkelde" lande uitgevoer, terwyl die proefpersone van "derdewêreldse" of "ontwikkelende" lande afkomstig is. Die etiese kwessies hierby betrokke is: hoe sal ingeligte goedkeuring beskerm word, veral wanneer proefpersone onopgevoed is en nie die tersaaklike terme verstaan nie? Wat is die koste-effektiwiteit of voordele van hierdie proefnemings? Watter risiko's is betrokke? Die etiese debat oor die markprys van medisyne, wat heel bekostigbaar vir ryk lande, maar duur vir armer lande is, word ook aangerak.

Hierdie verhandeling dek nie alle relevante kwessies wat betref MIV/VIGS nie. Tog hoop ek dat dit 'n bydrae sal lewer tot mense se bewuswording van die etiese dilemmas wat MIV/VIGS inhou.

DEDICATION AND ACKNOWLEDGEMENTS

With love and gratitude I dedicate this work to all that have shared their lives with me thereby making my life rich, fruitful and full of memorable experiences. This gratitude is especially directed to my family, especially my parents through whose love I came to be and am sustained. I wish to acknowledge my deep appreciation for the example and instruction I received from the University of Stellenbosch, Department of Philosophy. Prof. Anton van Niekerk (chairperson), Prof. Johan Hattingh, Prof. Paul Cilliers, Prof. Willie van der Merwe, Mr. Willem Verwoerd, Mrs. Lulu Botha (secretary) and Mr. Msekeli Ngquba for always caring. In a special way, I would like to thank Dr. Anton van Niekerk for his patient direction in the writing of this assignment.

I acknowledge my gratitude to Nomzamo Malinga for believing in me and generously supporting me in every way possible during my period of study, her unrelenting help paid dividend. Nomzamo, I know how much you wanted me to succeed, therefore, my success is your success, just as much as my failure would have been your disappointment. To the Koenane family in Tumahole-Parys especially Mom Sophia Koenane for her encouragement and unceasing prayers, and my sister-in-law Mampho Koenane for coming into my rescue in difficult times. How could I forget my little brother and his wife, Simon and Lucy Koenane for their help and support. To the Motsumi family, my sister Masosi and her husband Moss who were ever willing to open the door of their home for me to stay for as long as I wished with their family, thanks a million guys, you are great.

One other person I owe a word of thanks to is my brother Masilo Koenane for persuading me to go for higher study. I may have to quote him when he said to me, "Broer go for it". To the Kunene family in Eshowe, especially Mom Asceline and to all my little sisters, Happy-eve, Sihle, Mapho, Sanele, and Zona whose hospitality I enjoyed and caring family life I participated in, I offer my sincere gratitude. My special thanks to Mokomele family, Francis and his wife Morakane in Middleburg (Mpumalanga), as they say, "*A friend in need is a friend indeed*", guys words can never be enough to express how grateful I am to both of you. In the words of an artist Judy Boucher, I would also like to say, "*You are more than just friends to me*". In particular I wish to thank my brother Thabiso Koenane for his readiness to help with the preliminary and final printout of this work. I guess this is what brothers are for.

One family took particular interest in my progress ever since we met in 1985 at Esikhawini is the Mzimela family, now living in Durban. Mr. Boy Mzimela became a father, and Fisani his wife a mother to me. Minkiza and Gugu their daughters were true sisters, one could ever hope for. I will always treasure the time I shared with this *God given family*. Perhaps it was by God's design that I become part of their lives and they in turn, become part of mine. In gratitude for their contribution in my success, this work belongs to you just as much as it does to me. I will for ever be grateful to the Mncwabe family at Esikhawini for providing for my material needs, and for always making me feel at home in their family. To Mrs. Patty Mncwabe and family I dedicate this work. In a special way, I also wish to thank Mrs. Martha Mokoena of Vosloorus who provided me with some excellent first hand experience into her work as a nurse at Natalspruit Hospital. To Nhlanhla Majozi for his encouragement and friendship, I am sincerely grateful. I also wish to thank Mrs. Serialong Tsotsotso for all the help she offered.

I wish to thank Dr. Joe Shikhibane at the Kagisanong College of Education, Mangaung-Bloemfontein, for a critical reading and analysis of the text and Mark Colvin of the Medical Research Council Durban, for the numerous documents to which he drew my attention. My special thanks to Dr. John Larsen a specialist gynaecologist in Northern KwaZulu-Natal who was always ready to help. My very special thanks to Dr. Donna Knapp van Bogaert for providing me with study material on HIV/AIDS, which added content to my work. I wish to acknowledge my indebtedness to my fellow students whose criticism, encouragement and friendship made my time at the University an enriching experience for which I thank God. To Dr. Danile Geinumkhonto (a medical practitioner) with whose family I stayed during the writing of this thesis. Three Catholic priests, Frs. Benan Fahy OFM, Teddy Khumalo and Mosebetsi Mokoena of the Diocese of Bethlehem were always interested in my progress and thus an inspiration to me, to them too, I will always be grateful.

Last but not least, to everybody who contributed towards my success one way or another, I thank you all from the bottom of my heart. It was because of all of you I *walked tall* and looked into the future with *renewed hope*. To the multitude of people, I ministered to and whose lives I have touched, you all mean so much to me. Above all, I thank the *Almighty God* who, through each of you provided for my needs both spiritual and material. ***God Bless!***

Special Acknowledgement

The financial assistance of the National Research Foundation (NRF) towards this research is hereby acknowledged. Opinions expressed and conclusions arrived at, are those of the author and are not necessarily to be attributed to the National Research Foundation.

TABLE OF CONTENTS

Declaration	i
Summary	ii
Opsomming	iv
Dedication and Acknowledgements	vi
Introduction	1
1. HIV/AIDS in South Africa	7
1.1 The setting	7
1.2 HIV Infection Type in South Africa	10
1.3 Comparison of the global world data	11
1.4 HIV/AIDS and legal system in South Africa	12
2. Confidentiality	15
2.1 Informed Consent and Autonomy	21
2.2 Conclusion	25
3. Notification Diseases in South Africa	27
3.1 HIV/AIDS a Notifiable Disease? Ethical Considerations	28
3.2 Notification of Health Care Professionals	34
3.3 Communicable Diseases and Notification of Medical Conditions: 1993	36
3.4 Summary	36
4. HIV/AIDS and Social Inequality	38
4.1 HIV/AIDS a Crime Against Women	40
4.2 The Impact of HIV/AIDS on Children	42
4.3 HIV/AIDS in Schools	45
4.4 Conclusion	48

5.	Ethical Considerations in HIV/AIDS Vaccine Trials	49
5.1	The Politics and Ethical Problems Concerning the Supply of AZT	52
5.2	Conclusion	56
6.	Prevention Strategies for HIV/AIDS in South Africa	58
6.1	HIV/AIDS Infection in South African Prisons	65
6.2	Conclusion	65
7.	Conclusion	67
8.	Bibliography	69

Introduction

HIV stands for *human immunodeficiency virus*, and HIV is the virus that causes AIDS,¹ that is, *acquired immune deficiency syndrome*. HIV/AIDS is a difficult subject to talk about, because it is not just a '*social problem*', it is also very *personal*. By this, I mean that it touches the most personal parts of our lives, that is, the way we express love and sexual feelings. Any sensitive issue such as HIV/AIDS in my opinion needs to be approached sensitively or with diplomacy, but nevertheless seriously. For the purpose of this project, I will consider many different opinions about how to respond to the problem of HIV/AIDS and people living with AIDS. Nevertheless, in the end, every individual person will have to make up his or her own mind about how to deal with HIV/AIDS.

Most people think that there are clear-cut answers to HIV/AIDS. However, this is not the case. As the words which make up the acronym AIDS suggest, it is a syndrome or cluster of symptoms and conditions and these can vary widely. For instance, HIV/AIDS does not even have precisely the same definition in different parts of the world. In addition, there is some confusion about whether HIV really causes AIDS or something else does. Some scientists wrongly deny that HIV is the cause of AIDS.

On the other hand, it must be noted that even among those who support the hypothesis that HIV causes AIDS, there is a dispute as to whether HIV alone is sufficient to cause AIDS, or whether HIV is merely a necessary condition (Kuhse & P. Singer 1998:343). Along the way, there are many controversies involving scientists, health professionals and even AIDS patients and their families about many aspects of the management of HIV/AIDS. The ideal behind this assignment is to acknowledge the HIV/AIDS reality.

Secondly, in April 2000 there were concerns surrounding the issue that the current South African President Thabo Mbeki, associates himself with a '*dissident scientist*' Dr. David

¹ I am however, aware of the controversy surrounding the issue of whether HIV causes AIDS or any other disease does. Some scientists and other medical doctors hold a view that to say that HIV causes AIDS is an unproved hypothesis, these scientists are known as '*dissident scientists*.' Scientists who hold a *conventional position* that HIV causes AIDS are referred to as "*orthodox scientists*."

Rasnick. Dr. Rasnick is an American scientist who openly said that he strongly believes that HIV is not the cause of AIDS, and that he has very serious doubts about the existence of HIV.

Perhaps, the reason for current differing views on the relationship of HIV and AIDS lies behind the fact that the mechanisms by means of which HIV causes immune deficiency are still not completely understood. It generally takes eight to ten years from the point of infection to develop *full-blown AIDS*. Nevertheless, (for the purpose of this work), I am not going into the debate as to whether HIV does cause AIDS or not, that is for scientists to decide and come to an agreement about scientific facts. There is no disease that demonstrates better than HIV/AIDS the value of *co-operation*.

To take just one or two examples of such controversies, one may refer to the controversy surrounding the supply of Zidovudine (technically referred to as AZT) and nevirapine drugs, to pregnant women in order to reduce the chances of *mother-to-child transmission (MTCT)*. Another problem connected with administering AZT and nevirapine concerns the emergence of drug resistant forms of HIV in people receiving these drugs. The limited variety of HIV in the early stage is thought to make it more susceptible to AZT and related drugs.

By 1995, almost 20 million people throughout the world were believed to be infected with HIV. Of these, more than 60 per cent were in sub-Saharan Africa. North and South America accounted for less than 12 per cent of the infection. Since HIV/AIDS was identified, it has proved one of the greatest public health threats ever to face the human race. Therefore, since there is no vaccine or cure available, prevention remains our only strategy against this deadly disease. Around the year 1984, a reliable test for antibody to HIV was developed and became widely available in most parts of the world by 1985. According to Whiteside and Sunter (2000:47), the first confirmed case of AIDS in South Africa was diagnosed in 1982. Since then, AIDS has become one of the major causes of death in South Africa and many other countries worldwide.

Nel (1995:872) maintains that HIV is spread through direct contact with bodily fluids, such as blood semen. Although heterosexual contact accounted for only 10 per cent of the cases in the United States, in Africa it is the method of transmission in over 90 per cent of those infected. AIDS cannot be contracted from casual contact, such as kissing or sharing a drinking cup. The routes of HIV transmission are well known, but unfounded fear continues concerning the

potential for transmission by other means, such as casual contact, in a household, school, workplace etc. However, there is no scientific evidence to support any of these fears. HIV is usually transmitted in three different ways, and they are as follows:

- ❖ Most commonly it is passed from one person to person through sexual contact with an infected sexual partner,
- ❖ Through contaminated blood, for instance, contaminated blood transfusions,² or unsterilised needles and syringes. In a case where a surgeon or assistant is injured during an operation on an HIV-positive or AIDS patient, it is recommended that the area of injury must immediately be washed clean. Although the value of this is uncertain, the administration of Zidovudine (AZT) is highly recommended.
- ❖ From mother to child, through an infected mother to her baby while it is still unborn, during childbirth or during breast-feeding. Furthermore, Nel maintains that the mother-to-baby HIV risk infection through breast-feeding may be as high as one in four. Unfortunately, up until now prenatal tests cannot detect whether the unborn child is infected or will be infected, it is a matter of wait-and-see approach Nel (1995:872).

In the light of these modes of transmission, it is also clear who the particular risk groups and persons for HIV infection and AIDS are:

- ❖ Recipients of transfusions and organs via infected blood and blood products. In many countries people were exposed to infected donated blood prior to the implementation of HIV screening,
- ❖ Intravenous drug abusers using unsterilised needles
- ❖ Health workers who come into contact with the infected blood or fluids of infected patients

² Today it is compulsory to properly screen all blood used in blood transfusion for HIV virus before transfusion; this is done in order to protect recipients from infection. However, a big problem when testing for HIV antibodies is that there is a latent or 'window period' of variable duration, before the antibody can be detected.

- ❖ Sexually active people, whether homosexual, heterosexual or bisexual, can contract the infection by means of sexual intercourse with the infected person, and
- ❖ Finally, babies become infected by means of vertical transmission, from mother to child.

Another fact I observed is that among other households (especially poor black households), people share toothbrushes and this call for concern. However, it is important to note that a mere contact or casual contact with an HIV carrier would not necessarily lead to infection. Unfortunately, it is believed that once a cell is infected with HIV, it remains permanently with the infected person. HIV infects and attacks, and destroys a certain kind of white blood cells in the body, which are responsible for co-ordinating the complex functions of the body's immune system, the very system designed to protect the body against infections. HIV/AIDS was first recognised in gay men in the United States. However, throughout the world, up to 90 per cent of infections are through heterosexual sex.

Incidentally, once a person is infected with HIV, the virus multiplies rapidly in the first few weeks. Then usually within the next three months, the infected individual starts to produce antibodies HIV; this process is called seroconversion, with fever and enlarged lumphs glands (Sunter 1998:70). Following seroconversion, most infected people have no symptoms for months or years; this period is technically called *latency period*. According to experts, during the latency period, it is difficult to detect the virus in the blood. Finally, the latency period is long and variable, it ranges approximately from four months to a little longer than ten years (Overberg 1994:2).

The final stage of HIV infection is the *acquired immune deficiency syndrome*, or (AIDS) as is usually referred to. AIDS is characterised by opportunistic infections and malignancies that only occur in people with low immunity or resistance. Therefore, it must be noted that AIDS itself is not a disease but a syndrome which manifests in a situation where an individual is prone to many infections due to low immunity caused by HIV in the body of an infected person.

Tuberculosis, pneumonia and meningitis are opportunistic infections commonly found in AIDS patients. At least about 40-50 per cent of all people suffering from TB in the country is also HIV-positive (Whiteside & Sunter 2000:24-25). Neurological diseases (affecting the nerves), due to direct infection of brain cells by the virus may occur early or late in the course of HIV infection. Neurological diseases may include impaired speech and loss of memory etc. In addition, too clinical manifestations suffered by both sexes, HIV infected women may also suffer from severe vaginal Herpes and thrush and are more likely to develop cervical cancer.

There are a number of ethical concerns surrounding the HIV/AIDS pandemic and how we deal with the problem. To begin with, we may ask, should HIV-infected women become pregnant? Must contraception be an option? What about abortion where HIV/AIDS is involved? Another set of questions concerns HIV-infected individuals and their relationships. What is the responsibility of the HIV-infected persons concerning risky behaviour that could infect others? Must their sexual partners be informed? If so who should inform them? What about issues that involve health workers: privacy, confidentiality, and truth telling?

Another set of questions concern the role of the developed countries. What is the responsibility of developed countries towards developing countries insofar as the prevention of HIV/AIDS is concern? It is not clear what these countries must do. What and how much must they contribute? Under what condition must their intervention be made available to *developing countries*? What is the richer countries moral duty toward Africa as a whole? As a solution to this problem, I will suggest that if *developing countries* are to succeed, they need the intervention of *developed countries* to some extent. However, until the common grounds are achieved, the only weapon *third world countries* have is *effective prevention strategies*. In order for the world to fight HIV/AIDS pandemic together, developed countries and under developed countries must negotiate in good faith. If we can we must put our differences aside and fight for the common good.

The other set of moral questions directly involve the larger society. Does the common good demand the testing of rapists? Does the good of society call for separating HIV-infected inmates and non-infected ones? Would it benefit society if AIDS were declared a notifiable disease? How can society care for AIDS orphans? The HIV/AIDS problem presents its own unique challenge to cultural and economic structures of the society. What is the moral

responsibility of corporate employer to his or her employees who are presently infected with HIV/AIDS? I will also look at these critically.

In this work, I am attempting to highlight the impact of HIV/AIDS in every aspect of our human life and suggest preventive strategies that I believe would be effective in curbing the spread of HIV/AIDS. As the title of this study implies, I will focus in the ethical issues on surveillance and preventive strategies for HIV/AIDS in South Africa.

1. HIV/AIDS in South Africa

In this chapter, I will be looking at the impact of HIV/AIDS in South Africa's economy. As we may all be aware HIV/AIDS hits hard on the heterosexual youth in this country, given this one wonders what will become of the country if the future of children and young people is so uncertain. I will look at some statistics of how HIV/AIDS is impacting in the country. To do this the socio-economic, political and cultural structures of the country would be taken into consideration. Since HIV/AIDS impact on the entire South African population in the workplace and in school, the situation will be closely monitored at with a view of proposing a way forward in the prevention of the spread of HIV/AIDS. This chapter will also take account of the global HIV/AIDS statistics as compared to the South African disease.

The estimated HIV infections in Africa according to *World Health Organisation Factsheet, No. 242 of 2000*: p. 2 are as follows:

- ❖ 1994 9 million people
- ❖ 1996 14 million people
- ❖ 1998 22.5 million people

According to the WHO the estimated number of children in South Africa living with HIV/AIDS in 1999 was 95 000. Finally, the estimated number of HIV infections worldwide is 37 525 366.

1.1. The setting

Broadly speaking, no country in Africa has escaped the HIV/AIDS virus. However, some are more severely affected than others. The HIV/AIDS seem to be more concentrated in sub-Saharan Africa. Although by the end of 1998 South Africa was trailing behind some of its neighbours, this country is now catching on. That South Africa has HIV/AIDS pandemic is a fact. The highest rates of HIV infection in the world occur in sub-Saharan Africa, where some of the countries with the highest per capita incomes on the continent are most affected. I think nobody would dispute that HIV/AIDS presents one of the greatest threats to the stability of South Africa.

The most recent statistics on HIV/AIDS estimates that 33.4 million people worldwide are infected and 22.5 million people infected live in sub-Saharan Africa, *Time* (22 September 1999:18). Prof. Anton van Niekerk (Chairperson of the Department of Philosophy and Professor of Biomedical Ethics at the University of Stellenbosch) writes in his unpublished lecture of September 29, 1999:

What is much more alarming is the growing impression that South Africa, in particular, is fast becoming the epicentre of the pandemic in Africa.

Factors such as rural poverty and migration of individuals in search of work contribute to the separation of families and resulting to high-risk sexual behaviour. Probably the most common reason for people to leave their homes is to seek work. Nowhere is this truer than in South Africa. Thriving mining industries attract workers not just from rural areas of the country, but also from neighbouring countries where job opportunities are scarce wages are lower. It is very difficult to estimate how many people move into South Africa in search of work. With the mining come wages, and with the wages come all sorts of goods and services, including drugs and sex. In addition, with drugs and sex comes HIV.

The flourishing mining industry in South African is an important stimulus behind the rapid spread of HIV/AIDS. In addition, working and living conditions in South African mines are conducive to HIV/AIDS infection. Given these circumstances, HIV/AIDS spreads to the black miners at such a rate that great concern about this was already expressed around 1985 (Whiteside & Sunter 2000).

HIV/AIDS Awareness programmes in South Africa are abundant, throughout nine provinces and they are funded by the government, private sectors and the non-governmental organisations. Recently, the Health Systems Trust Report of 1999 indicated that 80 per cent of the South African population is aware of HIV/AIDS, yet the epidemic continues to coil out of control. One may ask, why the spin, if awareness of the consequences or effects are there? How does one write about the face of HIV/AIDS with all the ethical problems it raises? For instance, the ethical questions about birth and infancy. Should HIV infected women become pregnant? Is contraception possible when AIDS is involved? What about abortion?

Another set of ethical questions concerns the HIV infected individuals and their relationship. What are their moral responsibility concerning risky behaviour that could infect others? Should previous contacts be informed? What about their dealings with health workers: issues of *privacy, confidentiality, truth telling* and the *use of experimental drugs*?

The South African pandemic of HIV/AIDS shows no sign of abating, in fact, it appears to be increasing month by month. In South Africa, the HIV/AIDS epidemic unfolded with alarming speed since HIV prevalence rates were first measured in 1990. HIV prevalence rates among pregnant women have increased from 0.8 per cent in 1991 to more than 22 per cent in some provinces, (*AIDS: The Challenge for South Africa*). Whiteside and Sunter further note that in 1994 when the African National Congress took power HIV figures were as low as 7.6 per cent and five years later these figures were 22.4 per cent (*ibid.*).

Urban areas and regions with large mining communities or those based in industries are strongly affected, but HIV rates are also very high in rural areas from which many migrant workers originate. Moreover, it was also predicted that two thirds of those who would be infected are currently between the age of 15-24 (Whiteside & Sunter 2000:96). This suggests that if teenagers can avoid becoming infected, the epidemic in South Africa could be slowed down considerably. The *UNICEF's Report* of September 15, 1999 by Bellamy states that:

AIDS, not war, has turned Africa into a killing field and will wipe out enough adults to create 13 million orphans in the next eighteen-month [...]. By any measure, the HIV/AIDS pandemic is the most terrible undeclared war in the world.

Deane Moore, an actuary of South Africa Metropolitan Life Insurance Company, predicts that in the country there will be 580 000 new AIDS cases a year. Moreover, that the life expectancy rates in South Africa will be 38 years by the year 2010. All these figures indicate that HIV/AIDS is spreading faster in sub-Saharan Africa than anywhere else is in the world.

Commercial sex is a reality in many South African gold mines. Therefore, the high rates of curable sexually transmitted diseases in South African mining communities create an ideal foundation for HIV transmission. For example, the *World Health Organisation* (WHO) AIDS epidemic update of December (1998:11) reports that the gold mine in Carltonville has 60 per

cent of mine workers from Lesotho, Malawi, Swaziland and Mozambique. The report goes on to state that about four to five hundred (400-500) sex workers serve the Carltonville mines. Almost every family in the country has a relative who died; one has only to read newspapers to have an idea of the deaths of mostly young people.

Obviously, the HIV dangers are not just to the mineworkers and their sex partners around the mining sites. As expected, migrant workers return home occasionally, therefore, they carry the infection back to their wives and their communities. In Hlabisa, a rural district in KwaZulu-Natal,³ it is estimated that 60 per cent of households have one or more male migrants. In Hlabisa, HIV rates are rising dramatically, with the prevalence among pregnant women shooting high. Furthermore, Whiteside and Sunter (2000:50) maintain that the present trends based on the national anonymous testing of antenatal pregnancies indicate HIV-positive results of about 22.4 per cent since 1999.

According to Whiteside and Sunter (2000:49), the antenatal surveys have been conducted since 1990. The purpose of these surveys is to provide the base line information on which calculations of HIV prevalence cases and deaths are based. Given all this, serious questions arise. Is the South African government doing enough to address this complicated issue? What is the moral obligation of a government to its citizens when confronted with such a turning point? For how long will antenatal surveys be continued? My opinion about the ongoing antenatal tests for pregnant women is that it is becoming unethical and irresponsible to test these women without having services in place to deal with the consequences of the test. How does poverty contribute to the spread of HIV/AIDS?

1.2 HIV infection and AIDS type in South Africa

For about 7-8 years since the first AIDS case in South Africa, AIDS followed a typical Type-1 pattern. In other words, those mostly affected were homosexual males. In its initial stages, HIV/AIDS in South Africa was associated with gay men. Since HIV/AIDS was in its earlier stages associated with homosexuality especially among men, it was easy for heterosexual groups to define those to be blamed entirely, namely the gay community for spreading the virus. However, indications are that this pattern has changed systematically. Therefore, Type-

2 pattern is spreading at a much more rapid rate than Type-1 pattern. Associated with this, is the fear that it is becoming more difficult and impossible to combat the disease in high risk groups. In the earlier stages of the discovery of HIV/AIDS, heterosexual people believed they were untouchable, but the disease proved otherwise.

Information concerning HIV infection and AIDS in South Africa is for peculiar reasons not complete and questionable. Therefore, accessible material or information ought to be considered with the greatest caution. Information in this regard is collected primarily from three sources. Firstly, from statistics about *actual* AIDS cases. Secondly, from the *passive monitoring* of HIV antibody data, and finally, from *planned surveys in specific populations* in order to substantiate the incidence of HIV infection (Schoub *et al* 1988:153). Evidently, the South African environment is subsequently explored on the basis of each information sources.

1.3 Comparison of the global HIV/AIDS data with South Africa's

One cannot avoid comparing the country's statistics with those of the global world, since we are also part of the sub-Saharan Africa where AIDS is hitting the most. In sub-Saharan Africa poverty, social and political chaos, natural disaster and violence seem to have produced a fertile environment for the rapid spread of the Type-2 of HIV/AIDS pandemic. Around mid year 1991, South Africa reported 0.21 per cent of the world figure released by the World Health Organisation. This means that one out of every 480 AIDS cases in the world was a South African (*Weekly Epidemiological Record* 1991 66(23): 165-166). Now it is estimated that South Africa has 10 per cent of HIV-infected individuals (*SAJ of Science* 96, (6): 298). Harrison, Smith and Myer maintain that currently an estimated 3.2 million South Africans are infected with HIV (*South African Journal of Science* 96, (6): 285). However, Gouws and Williams maintain that on the basis of antenatal surveys the estimated number of HIV-infected South Africans is 3.6 million (*ibid.* p. 275). On the global scale, the AIDS epidemic continues a frightful expansion. Although Africa represents less than 10 per cent of the world's population, however, the continent carries more than 60 per cent of HIV infections among adults.

³ KwaZulu-Natal is a province most hit by HIV/AIDS in South Africa, and this province is presently experiencing a negative population growth rate because of the disease.

1.4 HIV/AIDS and the legal system in South Africa

South Africa and many other societies find difficulty taking actions that may impinge on individual rights and choice. Not very long after the identification of HIV and the first publicity surrounding the rapid spread of AIDS, legislatures throughout the world responded by passing laws in order to curb the spread of the disease. Most of this legislation was passed to curtail the freedom of action of people infected with HIV/AIDS and those at risk of infection. Nonetheless, other legislation was intended to protect the interest and rights of the very same people infected with HIV/AIDS. South Africa was no exception, and the first cases involving HIV/AIDS brought direct legislative interventions. First, amendments in the Health Act (*Act 63 of 1977*), Regulations relating to Communicable Diseases⁴ and the Notification of Medical Conditions, included AIDS as a communicable disease (Van den Berg & Viljoen 1994:55). This Regulation is formulated as follows: Section 14, no. 1 reads:

Any person a Medical Officer of Health suspects on reasonable grounds to be a carrier of a communicable disease (one of which is AIDS), and who as such constituted a danger to the public health shall, if so instructed by a Medical Officer of Health, subject himself to a medical examination at a time and place determined by the Medical Officer of Health in order to establish whether such a person in fact a carrier as suspected.

Furthermore, section 14, no. 3 reads: A Medical Officer of Health may, when he is satisfied on medical scientific grounds that the danger exists of a carrier of a '*communicable disease*' transmitting such disease to other people, order in writing that such a carrier:

- (a) Go or be removed to a hospital, other place of isolation or area referred to in order so as to remain there under medical supervision for a period determined in such an order.
- (b) Report for medical examination and treatment at the time and place determined in the order.

⁴ According to section 33 of Act No. 63 of 1977, "*communicable diseases*" refers to any disease that can be communicated directly or indirectly through any person who is a carrier of such a disease.

- (c) Comply with such other requirements as are deemed necessary by the Medical Officer of Health in order to safeguard public health.

What this means in concrete terms is that the Minister of National Health Services, and the House of Assembly has declared AIDS a "*communicable disease*". The local health authorities are given the powers where they are reasonably satisfied that the spread of AIDS constitutes '*a risk to health,*' to act accordingly. This effectively rendered HIV/AIDS '*notifiable*' to a certain extent as well as to bring into play the possibility of compulsory hospitalisation or isolation of individuals suspected of being HIV infected or people with AIDS.

Another law that was changed to include HIV/AIDS is the Regulation 2439 in terms of the *Admission of Persons to the Republic Act* (No. 59 of 1972). This law concerns diseases that will render foreigners in South Africa as "*prohibited persons.*" This practically implies that people who test positive to antibody viral can be deported to their country of birth (ibid.). On the other hand, Professor Van Wyk⁵ (in Van Niekerk 1991:61) notes that a person who infects another with HIV/AIDS could possibly be charged with criminal or civil action. According to him such criminal charges could be:

- Murder: If an individual intentionally causes the death of another person(s) by infecting them with HIV,
- Culpable homicide, which implies infection that occurs as a result of negligence, and
- Attempted murder or attempted culpable homicide.
- Many more add to this list '*rape*', some maintain that sexual offenders must be tested regardless of their consent, and where they test HIV-positive be charged for infecting their '*rape victim(s)*'. This also includes an act of sexual intercourse, in which an HIV-positive man has sexual intercourse with a woman and fails to disclose to her, his HIV status.

It is not very clear whether there should be any criminal charges where an HIV-positive woman fails to inform her sexual partner of her antibody status. I suppose the reason for this

is because sexual offenders are mostly men. Another problem worth mentioning here is that in criminal cases, it is the duty of the State to prove beyond reasonable doubt that the accused has indeed infected the other person with HIV/AIDS. Furthermore, Van Wyk maintains that charges of culpable homicide could be used as a means of coercing hospitals, blood transfusion services and medical staff to take sufficient prophylactic standards toward the spread of HIV/AIDS through administering blood intravenously or unsterilised injection needles (in Van Niekerk 1991:61). Civil cases may include the following:

- ❖ Claims for damages: if an individual intentionally and negligently harms another person. This may also include damages for pain, suffering, monetary loss and emotional damages.
- ❖ Defamation: which implies that it is perceived as defamation to publish a statement that a given person is HIV positive or has AIDS unless that is done for the interest of the public.

Currently there is an element of confusion encompassing the issue of confidentiality regarding HIV/AIDS. Given the legal and ethical guidelines of *doctor-patient* confidentiality, is it legal and ethical to warn an endangered third party, that is, a sexual partner(s) of another's antibody status? It appears as though failure to keep confidentiality could lead to defamation, invasion of *privacy* and *breach of confidentiality*. Insofar as the notification of HIV/AIDS is concerned, the South African Medical and Dental Council passed a resolution requiring a medical practitioner to warn health care workers and the spouse's known sexual partner(s) of people infected with the HIV/AIDS. However, legislation is needed to clarify this matter. This brings me to the next chapter in which ethical issues of *privacy*, *confidentiality* and *notification* will be discussed.

⁵ Professor van Wyk is a former professor of Commercial Law at the University of

2. Confidentiality

The focus of this chapter will be on confidentiality. Questions regarding medical ethics were once thought to be for the medical profession alone to answer. As I indicated earlier, issues involving the responsibilities of HIV infected persons and their relationship will be dealt with. The HIV/AIDS epidemic presents ethical concerns with regard to confidentiality, privacy, informed consent and truth telling; these will be discussed in this section. For instance, questions about whether it is ethically justifiable to breach the strict confidentiality that held, and still holds, in the *doctor-patient* relationship. Should the patient's family be told if he or she were suffering from an incurable disease such as HIV/AIDS, or transmittable condition? What if the patient did not propose to inform them him? These problems still arise in the acute form especially where HIV/AIDS is involved.

It is true that if a medical practitioner in South Africa behaves in some professionally disgraceful manner, he or she can be struck off the register by other practitioners who form the South African Medical and Dental Council. However, a reality is that in the 20th century, ethical issues have greatly widened in scope. *The Hippocratic Oath* is an ancient oath traditionally taken by doctors at their graduation ceremony. The code is attributed to Hippocrates, an ancient Greek physician, (460-377 BC) who is regarded by many as the '*father of medicine*'. However, modern research suggests that the oath probably originated in Pythagorean sect of the 4th century BC. As a code of behaviour and medical practice, the Hippocratic oath in its original form prohibits doctors from performing abortions, euthanasia and it requires a physician to promise to keep any personal information divulged to him or her confidential.

Some of the principles laid down in the *Hippocratic Oath* are still regarded as appropriate even today. For example, the importance of confidentiality and the maintenance of justice for the patient. Other aspects are no longer relevant. The Hippocratic ethics seems to me to have concentrated more on the welfare of the individual patient and not so much on the welfare of society or other people who are directly affected by the decision made between the doctor and his or her patient. In other words, the medical profession can no longer rely entirely on its own conscience, because the issues its members have to face are no longer concerned simply with the relation between individual doctors and their patients. A long range of people is directly affected. This is true especially when HIV/AIDS is involved.

Stellenbosch, and currently the vice-chancellor at the same University.

Broadly speaking the term *confidentiality* refers to a general standard of professional conduct that obliges a professional never to disclose information about a client or patient with a third party without the consent of the patient (Spiegel & Koocher 1995:57). Beauchamp and Childress (1994:420) on the other hand, only define the circumstances under which confidentiality is applicable. This is what they write:

Confidentiality is present when one person discloses information to another, whether through words or an examination, and the person to whom the information is disclosed pledges not to divulge that information to a third party without the confider's permission.

Therefore, *confidentiality* requires an explicit promise by a professional to maintain strict or absolute confidentiality, with the only exception where the patient or client voluntarily wants the information divulged. Strictly speaking, it is not only an explicit promise to maintain confidentiality that is expected from the medical staff. Since their code of professional ethics pledges confidentiality, it is within the patients' rights to therefore, expect confidentiality even when the health worker did not explicitly promise it.

Confidentiality in biomedical ethics emphasises the need to accept and apply the principle of non-discrimination in relation to a variety of medical problems, HIV/AIDS included. Ashley and O'Rourke (1981:105) arguing from a Roman Catholic Church's moral perspective hold a view that health care professionals who are questioned about the confidential issues, may without lying reply in any way that protects confidentiality. They further maintain that the question of whether the health care personnel is sometimes obliged to reply truthfully and give accurate information about the patient, depends on the right of the inquirer to the needed information. Although this is correct and to some extent ethical, this hypothesis is complicated by HIV issue. For example, it is arguably necessary for a medical professional to share information with his or her colleague as to the nature of a patient's illness, as long as such an information will be kept confidential, and as long as this is in the best interests of the patient.

Ackerman and Strong (1989:76) acknowledge that genuine moral dilemmas frequently take place when a physician has to balance the interests of the patient and those of the family. Again HIV/AIDS is a good example we can think of here. Nevertheless, recognition of some

justifiable exceptional circumstances in which confidentiality cannot be maintained is also outlined. For example, the South African Law requires that child abuse cases be reported to Child Protection Services. At the same time, it is not only laws that justify a breach of confidentiality; other circumstances by their nature could override confidentiality.

For example, the widespread controversy that surrounds the question of whether health care professionals should inform, that is, *notify* a spouse and lovers of an HIV/AIDS patient(s) of their partners' status. This is obviously about a patient who refuses to inform his or her sexual partner about his or her HIV status. In such cases, a breach of confidentiality is justifiable but only as a *last resort*, that is, when all other available alternatives, such as persuading the patient to notify his or her sexual partner(s) have failed (Beauchamp & Childress 1994:426-427).

The following is the list of proposals of the circumstances under which breaching confidentiality can be justified:

- ❖ In cases of child-abuse
- ❖ In situations where another person's life is threatened or endangered, and
- ❖ Where a patient is a danger to him or herself or to others, (this refers mostly to psychiatric patients).

This implies that the health care personnel not only have the right but also the duty to communicate information necessary to prevent serious harm to the patient and particularly to intended victims, (i.e. even when such information was given in confidence). In other words, the doctor is under some circumstances expected to fulfil what is technically called the *duty-to-warn* obligation. If then a *duty to warn obligation* applies especially where there is serious intention to cause harm to another person, I would argue that logically the same principle must apply to warn other people who may be harmed by the behaviour of an irresponsible HIV infected person. There reasoning behind this is very simple; earlier on, I outlined the conditions under which the breaching of confidentiality is justifiable. Moreover, according to one of these conditions violating confidentiality is required when the patient is considered dangerous to another person(s). Therefore, if the intended persons (victims) or partners in case of HIV/AIDS could be identified, the medical professional has a *duty to warn* them, as well as to take other reasonable steps to protect them.

The South African Interim Medical and Dental Council (SAIMDC) adds that the breach of confidentiality is justifiable when a medical practitioner is required to disclose a notifiable disease in terms of section 45 of the Health Care Act. The South African Interim Medical and Dental Council's guidelines also state that:

The decision whether to divulge the information to other parties involved must be in consultation with the patient. If the patient's consent cannot be obtained, the health care worker should use his or her discretion as to whether or not to divulge the information to other parties involved. Such a decision must be made with the greatest care, after explanation to the patient and with acceptance of full responsibility at all times.

This implies that a member of the medical personnel or health worker is expected to follow the guidelines provided for them and inform the patient in advance about the limits placed on confidentiality in a doctor-patient relationship. According to Beauchamp and Childress (1994:428) the prior notification referred to must not be equated to a justification for *divulging confidential information* to a third party, without the patient's consent. Therefore, the agreement between the medical practitioner and the patient should determine this as accurate as possible.

Although confidentiality is so crucial for medical practice, Beauchamp and Childress refer to Mark Siegler's argument where he maintains that in the medical practice confidentiality is a "*decrepit concept*" (Beauchamp & Childress 1994:419). Siegler observed a patient complaining that a number of health professionals to whom the patient had not permitted access to his medical records had studied his chart. It was under such conditions that Siegler concluded that *medical confidentiality* has become a "*decrepit concept*". Siegler maintains that the traditional belief regarding *medical confidentiality* does no longer exist. According to Siegler, in a hospital setting, there are often other people who gain access to a patient's medical records without a patient's consent.

Raanan Gillon (1985:106) who maintains that doctors seem not to regard medical confidentiality as an absolute supports Siegler's view. Although Gillon supports Siegler that medical confidentiality has lost its way, he thinks it is rather harsh for Siegler to conclude that medical confidentiality is '*decrepit*'. Gillon perceives calling medical confidentiality a

decrepit concept as a strong statement because those people the patient in Siegler's case complained about, had a right and moral responsibility to study his chart.

For the purpose of this study, let us assume that the patient in Siegler's case was infected with HIV. Then, the patient reveals his HIV status to a medical practitioner in confidence. He expects his doctor to keep this information confidential. However, other doctors and health workers also cared for this particular patient in the absence of his doctor. Surely, in order for them to effectively treat the patient, they need to study his medical records. However, the patient believes that they had no right to study his records without his permission.

HIV/AIDS has affected the medical profession profoundly. In South Africa, medical professionals are likely to care for inpatients infected with HIV/AIDS. Therefore, needle-prick injuries do occur from time to time. Given this, do doctors and other health care workers have the right to know the HIV status of every patient they treat? Do patients have the right to know their doctor's HIV status?

The *social stigma* attached to HIV/AIDS cannot be easily reversed. The devastating consequences of such a stigma can be prevented, among other things, by observing confidentiality when confronted with HIV-positive patients and people with AIDS. However, there are those who strongly believe that confidentiality is not conducive to the curbing of HIV and maintain that there be no *rigorous confidentiality* insofar as HIV/AIDS is concerned. Others see confidentiality as the only instrument for helping to bring about effective control of HIV/AIDS. The obligation of *confidentiality* is apparently enshrined in the law as an absolute medical privilege that no one (under normal circumstances) is allowed to override. The legal rules on *confidentiality* states that all patients have the legal right to confidentiality about their illness, (*HIV/AIDS and the law: A resource manual*, p. 50).

This emphasises that patients have a legal right to expect health workers and medical practitioners, to obey the ethical guidelines set by the South African Interim Medical and Dental Council (SAIMDC) which states:

No practitioner may divulge verbally or in writing any information which ought not to be divulged regarding the ailments of a patient except with the express consent of his guardian; or in the case of a deceased patient, with the consent of

his [or her] next of kin or the executor of his [or her] estate, (Rule 16 of the SAIMDC's Rule of Practice).

In support of this statement, the South African Interim Nursing Council maintains that nurses are required to respect a patient's *right of confidentiality*. This obviously vests the health care professionals with a distinguished ethical responsibility. In practical terms, this implies that the medical staff ought not to violate the trust placed in them by the patient.

The concerns of *confidentiality* permeate every aspect of HIV/AIDS issues. For example, who can tell what to whom? What information can medical professionals include in medical reports? What can crime victims, (for example, rape victims) be told and by whom? The list of questions is endless. Can the doctor maintain confidentiality when a husband reveals that he is HIV-positive, but asks that his wife never be informed? How can the information be held in confidence without risking harm to the wife, to whom the family doctor is equally responsible? In such a case, a medical practitioner is ethically obliged to discuss the relevant limitations of confidentiality.

In some situations, there are conflicts between the legal requirement and moral issues. Let us for a moment, consider a situation in which a person discovers that his or her colleague, whom he or she knows is HIV-positive, has an affair with someone related to the one who discovered the relationship. Ethically and legally speaking the person who is HIV-positive has a right to privacy, however, the sexual partner on the other hand, has the right to know, since this directly puts him or her at risk. We have said that the first thing one ought to do in this situation is to approach the person infected and convince him or her to tell or inform his or her partner. Nevertheless, should he or she refuse, then we are faced with a difficult ethical dilemma.

To highlight the difficulties surrounding the obtaining of informed consent Beauchamp and Childress (1994:426) cite a case study of a patient who tested HIV-positive, refused to tell his wife and insisted that the doctor maintain absolute confidentiality. A few weeks before the patient died, he permitted the doctor to inform his wife of the nature of his illness. The wife also tested HIV-positive and accused the doctor of violating his moral responsibilities to warn her. Was the doctor under any obligation to warn the wife without the consent of the patient? This is an illustrative case of severe harm presented to an identifiable person. Will it be

justified for the doctor to breach confidentiality? In the light of what has been said earlier in this work, the doctor ought to use his own discretion. However, whatever he chooses, there would be consequences.

During my visit to Bophelong Hospital in Mafikeng, I asked a question as to whether it is not at the discretion of the medical practitioner or health worker to disclose the HIV status of an infected person if this poses a threat to the partner? Attending professional health care providers were divided on the issue. A majority of those who attended the discussion hold a position that disclosing one's HIV status is absolutely the patient's responsibility. A member of the AIDS Training and information Counselling Centre stated that ATICC simply leaves it to the patient to disclose their HIV status to sexual partners. I think that in a situation like this, a medical practitioner may adopt an immediate position, in which certain information may be kept confidential. Unfortunately, it is not possible to know in advance which information may be kept strictly confidential and which should be divulged.

A Constitutional Court Judge Yvonne Mokgoro in her opening speech at the World AIDS Conference 2000 in Durban related how a man she know well committed suicide after his doctor revealed to his boss that he had AIDS, and thus lost his job. In other words, one's policy concerning *confidentiality* may have to be revised in accordance with the changing circumstances.

2.1 Informed consent and autonomy

Closely related to *confidentiality* is the notion of *informed consent*. I therefore propose to briefly discuss what informed consent entails. One of the essential components for a successful treatment are the right of all people to health, the patient's right to be informed, and the doctor's duty to explain. The relation of *doctor-patient* is changing. Gradually, patients are moving from an essentially subservient position to one in which they are involved in discussions about their therapy and are treated as partners. Arguments supporting such a partnership are compelling. Firstly, the patient has the right to decide about what is to be done to his or her own body. Secondly, from a pragmatic point of view, it is widely recognised that patients who are included in the therapeutic decision-making are more likely to take their treatment, comply with advice, feel better about a given advice and actually respond

positively to it. Thirdly, when things go bad, as it inevitably sometimes happens, the burden of responsibility for the outcome does not lie with the medical practitioner or health worker.

To begin with, in order for this principle to be applied fairly, the patient is expected to be '*competent*' to make a decision. This must be followed by a *non-coerced* or *free decision*. Finally, the patient must be informed about all available options, their advantages (i.e. benefits) and their disadvantages (i.e. risks). In other words, health workers must be able to produce the necessary information when offering treatment alternatives, and to share it with their patients so that they can decide whether they wish to receive the proposed product.

The ethical requirement here is simple: the doctor or health care professional is required to raise the relevant questions of information and explain the proposed course of action, including the main risks involved and how they can be dealt with. Therefore, the underlying emphasis of the notion of *informed consent* is that the other person's dignity must be respected. Beauchamp and Childress (1994:396) hold a position that even in cases where '*consent*' is not the issue, the obligation of veracity demands that another person or other persons be respected. This is also known as the principle of autonomy. Beauchamp and Childress (1994:121) define *personal autonomy* thus:

Personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice such as inadequate understanding.

It is important to note that the restrictions noted by Beauchamp and Childress are more severe than they seem at first. They leave much behaviour, even *unethical behaviour*, free of anyone's interference. In decision-making, *autonomy* is considered the most essential factor. Another equally important point to note is that an autonomous person can still fail to make autonomous choices. Autonomy presupposes that human beings have the capacity for maturity, growth and change. In practice, autonomy as an ethical principle can be overridden especially when a third person's life is endangered, because of the autonomous decision of another.

In view of the foregoing discussion on autonomy Ashley and O'Rourke (1981:71) argue that in order to obtain the true goals of human life through responsible actions, in every non-coerced decision involving an ethical question, people are morally obligated to:

- Inform themselves as fully as practically possible about facts and ethical norms.
- Form a moral judgement on the basis of this information.
- Act according to conscience, and
- Accept responsibility for their actions.

On the other hand, Beauchamp and Childress (1994:145-146) propose the following formulation for the requirements of the principle of autonomy:

1. Threshold Element (Preconditions)
 - a). Competence to understand and decide
 - b). Voluntariness in deciding
2. Informed Elements
 - c). Disclosure of material information
 - d). Recommendation of the plan
3. Consent Elements
 - e). Decision in favour of plan
 - f). Authorisation of the chosen plan

Perhaps Beauchamp and Childress' summary needs a little clarification. In the first classification, the word '*competence*' means the ability to understand what is at stake and decide on the best course of action. On the other hand, this goes with *voluntariness*, which refers to *freedom* to make a decision without any pressure or *coercion*. Next, in their classification is *Informed Elements*, which is substantiated by disclosure and understanding of the implications of such a disclosure and the recommended action. A related issue is the duty, if any, of a medical practitioner to disclose information concerning the treatment and the risks and benefits, (if any), that the treatment carries. A patient may not be tricked or deceived into consenting to testing or treatment. Ethically this implies that failure to disclose the material risks of a procedure will require justification.

Finally, a decision in favour of a recommended action rather than rejection, and authorisation means permission to go ahead with a proposed plan or action. Therefore, *autonomy* and *informed consent* require that in order to protect the basic needs of every person for health care and primary responsibility of each person for his or her own health care, no treatment may be administered without free and informed consent of the patient.

The increasingly important field of legal study covers some areas of the medical research and practice such as consent to treatment, medical negligence, abortion, euthanasia, and now HIV/AIDS. In theory, the law recognises the general principle that people have the right to bodily integrity, that is, to a choice about what happens to their body. Only in exceptional cases may treatment be given without the consent of the patient. In respect of this, every act of intervention is potentially a civil wrong against the patient.

However, where a patient is not in a position to be able to give consent, medical treatment will be regarded as lawful where it is essential for the survival of the patient. Examples of such cases are where the patient is a child, unconscious, or in a mental state that renders consent invalid. Legally, the medical practitioner can act in the absence of consent if the treatment is in the patient's best interests. Other ethicists recognise the professional privilege to withhold information that might be psychologically damaging to a patient. Nevertheless, where one draws a line, is not easy to determine. Provisions to determine the lengths to which health professionals need to go to ensure satisfaction must be clearly outlined. Therefore, there must be a system to ensure that the patient's rights to information can be honoured. A number of approaches are most likely to ensure this, for instance, a combination of professional codes, medical practitioner's terms of employment, published statements of patients' right, and a culture in which doctor-patient dialogue is encouraged. However, all this requires legal and ethical underpinning so that keeping patients properly informed becomes a normal part of health practice. Ultimately, it is for the patient to decide how much information is exchanged.

Promoting and respecting the autonomy of others is a basic principle in biomedical ethics and is codified in most professional codes of ethics. Some people are refused proper health care and equal membership of medical aid schemes, or their children are victimised at school. Many people are tested for HIV in our hospitals without giving '*informed consent*', or are told about their HIV status without receiving proper counselling. On the other hand, the *breaching*

of confidentiality and *privacy* happen almost every day. Consenting to medical treatment means that a person must give expressed permission before they are examined tested or treated.

Therefore, medical professionals are expected to accord appropriate respect to the fundamental rights of all people and respect the rights of individuals to self-determination and autonomy. However, individual autonomy may have to be sacrificed in some dysfunctional family. With HIV/AIDS testing, an individual must know exactly what the test is, why it is being done and what the results will mean for him or her before agreeing to blood samples being taken. As I explained earlier, HIV/AIDS is another area where the principle of *self-determination* or *autonomy* may come into conflict with other values or concerns. There are problems insofar as *informed consent* is concerned.

The HIV/AIDS pandemic raises difficult questions in relation to the right of the individual against the right(s) of others. As I indicated earlier, legislation focuses on the rights of the minority groups, that is the HIV-positive people. I think that someone would have to protect the rights of those who are HIV-negative so that their voice is also heard. Tough questions need to be asked? Who should be tested for HIV infection? When is it proper to suggest the test and how should it be suggested? How can confidentiality and informed consent be respected? What role does the state have in dealing with individuals' freedom of sexual life? How can the medical professionals or health workers protect infected individuals and society at the same time?

2.2 Conclusion

In this chapter, I dealt with *confidentiality*, *autonomy* and *informed consent* and their application in the HIV/AIDS debate. Again, although these principles are a guide in dealing with ethical issues, they do not necessarily provide clear answers. It is therefore important to know that these principles serve only as *prima facie guidelines*. Thus, it is important to balance things as much as possible and decide every case on its merit.

I argued that maintaining *confidentiality* about the patient's HIV status should be respected at all times. In general when considering whether to divulge the patient's HIV status to a medical colleague or other health professional the patient's interest should be the primary

concern. Occasionally the need to protect another person overrides maintaining strict confidentiality, such as in the case of a patient who refuses to inform a sexual partner of his or her HIV status.

I also argued that very often ethics and law differs considerably in the understanding and application of these concepts. Therefore, because of this, it is difficult to draw a line on exactly when and where medical confidentiality can be justifiably breached. For many, informed consent also makes it difficult for health workers to act within given guidelines because these do not spell it out in clear terms what one ought to do in a given situation where informed consent cannot be obtained. Some hold a view that a health worker has a *duty to warn*. However, the law and ethics emphasise that certain conditions must be considered before one can breach confidentiality. This implies that a breach of confidentiality must always be a last resort. This brings us to another related topic of notification of HIV/AIDS, which will be discussed, in the next chapter.

3. Notifiable diseases in South Africa

Despite the several inadequacies of a system of compulsory '*notification of diseases*', notifications or declarations nonetheless are a comprehensive conventional indicator of disease in a population, and indeed a significant source of information in the building of facets of a population's disease profile. Some of the most conspicuous limitations of such a system is, *inter alia*, underreporting, duplication in reporting, a lack of uniform diagnostic criteria, all of which result in wrong diagnosis or resistance against reporting because of the stigma attached to certain notifiable diseases.

In developing countries including South Africa, some of these limitations bear close relation to the ineffective administration of notifications, and consequently the data of these societies is not reliable. In spite of these inadequacies, compulsory notification of diseases in the South African context still yields useful information concerning the population disease profile. One can also accept that much of the country's health plan is based on these notifications and the trends so displayed. Another indicator, which deserves to be mentioned in this regard, is the *case fatality rate*, involved in notifiable diseases. This refers to the total percentage of all people notified as having a specific disease plus those who died from the disease. The *case fatality rate* is very important because, among other things, it gives an accurate indication of the following:

- ❖ The fatality of a particular notifiable disease
- ❖ The relative extent to which cases and deaths of the notifiable disease concerned are indeed reported, and
- ❖ The measure of skill and success with which the patients with this notifiable condition are treated and cared for, that is the extent to which their lives are being saved.

According to Van den Berg and Viljoen (1994:18) in South Africa, the list of compulsory '*notifiable medical conditions*' is revised time and again. From the 22 January 1991, the following conditions were included in the list:

- ❖ cholera,

- ❖ lead poisoning,
- ❖ leprosy,
- ❖ plague,
- ❖ malaria,
- ❖ rabies,
- ❖ measles,
- ❖ tuberculosis, (all forms)
- ❖ viral hepatitis A, B etc

Due to occasional omissions and additions, the creative writing of this list regularly changes in accordance with the demands of the day. Of course, many of these notifiable conditions are rare in South Africa; in fact, some have been substantially eradicated. However, they still need to be notified to guarantee continued vigilance and strict control. Mandatory notification remains the only way through which outbursts of a disease or an epidemic can be monitored or prevented with a certain measure of success.

Tuberculosis in all its forms was by far the most important notifiable disease among coloureds, blacks and Indians, but only secondary in importance among whites (ibid.). Deaths caused by other notifiable conditions were much fewer than those caused by tuberculosis. Tuberculosis of the lung had the highest case fatality rate because it seems to be the most common form of tuberculosis and the most common notifiable condition (Van den Berg & Viljoen 1994:225). Bacterial pneumonia and tuberculosis are also closely associated with HIV/AIDS. Whiteside and Sunter (2000:24) maintain that people infected with HIV are very likely to develop active TB. In HIV infected individuals, there is a gradual loss of immune cells and immune function so that the patient becomes vulnerable to pneumonia, specifically fungal infection, and other common ailments.

3.1 HIV/AIDS a notifiable disease? Ethical considerations

As discussed in the preceding section, making some diseases and infections legally notifiable has been a useful tool for many conditions. A common element about all these other diseases is that there is some proven medical intervention to prevent infection to other persons. However, there is a *big deal of argument* about whether AIDS should be made a notifiable disease in South Africa. In section 1.4, I referred to *Health Act 63 of 1977* in which the

Minister of Health is granted powers to make rulings concerning a range of various issues including the management of communicable diseases and the notification of notifiable health conditions.

Section 1 of the same Act defines notifiable diseases rather vaguely in that it does not say much but only states that a medical condition declared to be a notifiable condition by the Minister in terms of section 45. In practice, this means that a notifiable condition is *any condition declared* notifiable by the Minister of Health. This also implies that through the powers vested in her, if the Minister of Health wishes to use these powers to declare any medical condition notifiable then she should have regulations drafted, which identify a particular condition she wishes to declare notifiable. Benefits to the public include surveillance, which covers accurate disease trends, identification of groups at risk, prevention measures and evaluation of interventions.

In September 1997, when Dr. Nkosazana Dlamini-Zuma was a National Minister of Health, the South African government expressed its wish to make AIDS and AIDS deaths notifiable. Furthermore, at the Provincial MEC meeting of the 23-25 September 1997 a decision was taken to make AIDS deaths and the disease itself notifiable *without identification* and to require partner notification. Since then, the Department of Health developed a *concept document* which outlined the process that leads to HIV infection and AIDS notification with the legal framework and reporting system, which is designed to allow its implementation.

Dr. Dlamini-Zuma gave three arguments for making AIDS a notifiable medical condition. Firstly, she argued that such *notification* is necessary in order to provide information to track down the epidemic as well as to prioritise interventions. The importance of such data was never challenged or denied. However, opponents of making AIDS a notifiable medical condition argue that this does not weigh up to the inaccuracies of and cost involved in notification procedures. They also maintained that notification would tell us more about groups at risk and trends of infection 5-10 years ago, but hardly anything of note about what is currently happening.

Secondly, the then South African Minister of Health maintained that notification is also needed specifically to ensure *partner notification*. Dr. Zuma believes that the strict confidentiality statutes concerning HIV/AIDS seem to prevent health care professionals from

acting when confronted with infected patients who indicated that they would neither inform their partners nor alter their sexual practices. In response to the minister's second argument, her critiques argued that such notification is not necessary, because already, the professional ethical guidelines instruct the medical practitioners to counsel HIV-positive patients, and that if their consent cannot be ascertained, to notify *identifiable sexual partners* anyway. There is a fear that this important counselling would disappear if a compulsory notification would be implemented.

Thirdly, Dr. Dlamini-Zuma further argued that such a notification is needed to ensure *greater public visibility* of the pandemic and excessive concerns because confidentiality have helped to fuel the pandemic by making it hidden. The South African government through Dr. Dlamini-Zuma argued that where the greatest strides in Africa were made against HIV/AIDS, it is in countries where confidentiality is not highly protected, as is the case in South Africa. It seems to me that Dr. Zuma also based her argument on the approach followed by the Ugandan government in making HIV/AIDS public. In Uganda as we may all be aware, a compulsory publicity of HIV/AIDS worked. The South African Government maintains that in countries where individual HIV status is publicly revealed and known, these enjoy high levels of public acceptance. The underlying argument in Dr. Zuma's statement is that a decision to make HIV/AIDS a notifiable disease has been considered in other public health domains, where the perceived benefit for the common good has been believed to override the potential limitations to the rights of individuals.

Replying to the above argument, Leslie London⁶ argues persuasively that although the desirability of greater public visibility and acceptance of the disease is indisputable, *notification* does not seem the right way to achieve this goal. According to London, a more convincing and effective way of influencing public perceptions and dealing with prejudice would be to call on people with *high public profiles, cabinet ministers, sportsmen and women, musicians, artists etc* to take an HIV/AIDS test and *voluntarily reveal* their own HIV status. The Pan African Congress Member of Parliament Patricia De Lillie recently supported this idea. I also want to support this view and add that those other diseases listed with AIDS as communicable diseases can be acquired much more easily than AIDS.

⁶ This refers to an unpublished e-mail made available to me by Prof. Anton Van Niekerk.

Both London and De Lillie believe that people in public positions have a duty by virtue of being public figures to declare their HIV status. Although, this would be a commendable thing to do, we should seriously take into consideration the consequences of such a courageous act on the family members of any individual who voluntarily reveal their HIV status.

Since AIDS is a communicable disease, a school principal who has sufficient reason to suspect that an employee, pupil or someone who visits the school has HIV/AIDS or has been in contact with someone suffering from HIV/AIDS must report this to the medical authorities. To notify every school principal every time a child came into contact, that is, *safe contact* with a person infected with HIV/AIDS, would be in my opinion ridiculous and impractical, particularly as HIV becomes more prevalent in South Africa.

Presently, there is controversy about whether AIDS should be made a notifiable disease in South Africa. In principle this means is that it will be compulsory for any medical practitioner or health worker who diagnoses AIDS in a patient to report this finding without the patient's consent to the authorities and to confirm the finding in writing. The name, sex, population group, identity number or date of birth, address and school or the working place of a person with AIDS would be disclosed, including the information concerning the probable place and sources of infection.

Another argument against making AIDS a notifiable condition is that this would certainly lead to undesirable consequences for people living with AIDS and those infected with HIV. This means people infected with HIV and those living with AIDS would be subjected to the following:

- Their condition would be exposed to official listing,
- Public scrutiny
- Stigmatisation and
- Consequent discrimination.

A fact is that if HIV infection AIDS were made a notifiable medical condition, people with HIV/AIDS would go underground. I think that it would be a hasty and wrong decision to make HIV/AIDS a notifiable disease. I think most South Africans' level of tolerance for an

HIV/AIDS patient is non-existent. One may recall the tragic death by stoning of Gugu Dlamini in KwaZulu-Natal as a sad illustration of the risks entailed in compulsory notification of HIV/AIDS. The results of a move such as this would be that the attempts to combat the spread of HIV/AIDS would be counteracted. Arguably, making HIV/AIDS a notifiable disease would backfire on the very people the government is trying to help. Compulsory notification would prevent women from reporting rapes, and actually risk making it harder to locate and begin to treat the disease.

Unfortunately in South Africa, the idea of someone dying of AIDS is a product of our internalised prejudices about HIV infection and AIDS. In countries like the United States, it is an honourable thing for one to reveal his or her HIV status. I think that for a celebrity and any person, it is not merely an honourable thing to *come out* and reveal one's HIV/AIDS status; it also requires a considerable amount of *courage*.

As noted, there is an argument that openness about the disease will help in reducing anxiety and destigmatise the disease. However, I am convinced that the media with its witch hunting strategy could in reality achieve the opposite. Therefore, I also wish to argue that *the coming out* of prominent figures in declaring their status would benefit the fight against HIV/AIDS. I also think that the media's attitude and lack of responsibility also help in driving the disease underground and reinforcing perceptions that HIV/AIDS is indeed a disgrace. For instance, the manner in which the recent deaths of the IFP Themba Khoza and the ANC Pax Mankahlana were handled leaves much to be desired. Unfortunately political opposition(s) look into scoring political points as soon as the opponent dies of AIDS related illness.

In the year 1999, the South African Government has again signalled its intention to go ahead and make AIDS a notifiable disease. This decision was taken at a meeting of health ministers, all of whom agreed on the need for the measure in South Africa and its neighbouring countries. One of the reasons for the measure according to the South African Health Department does not differ from what Dr. Zuma argued for while she was Minister of Health, namely, that there is no accurate national information on the numbers of people living with AIDS. In addition, the government claims that the information is needed for planning resource allocation, and determining how many people may need to be hospitalised. The Department of Health also argues that making AIDS a notifiable disease is supported by public opinion, with

the 1998 demographic and health survey indicating 60 per cent of South Africans agreeing that AIDS should be reported to health authorities.

During the course of this study, I had the privilege of discussing the notification of HIV/AIDS with Mark Colvin of the Medical Research Council in Durban; his opinion about this is relevant for the purpose of this study. Colvin argues that the country will require massive investment of already scarce financial resources to train health workers and to provide the administrative supportive mechanisms necessary to attain high notification levels such as those obtained in *developed countries*. He further argues that a high level of notification for other notifiable medical conditions has not been achieved yet. Thus, it serves no purpose to add another condition to the list of already underreported diseases.

Colvin supported his argument by referring to the sentinel data over notification data on TB reporting in KwaZulu-Natal. He maintains that according to notification data, TB levels in KwaZulu-Natal have decreased by 39 per cent from 1991 to 1995. Nonetheless, a sentinel surveillance study in Hlabisa has shown a 278 per cent increase in TB over the past four years (*SAMJ* 1997, 87: 447-450). In addition, he notes that it is suggested that sentinel data are more reliable estimates of TB than notification data.

The thought of making AIDS a notifiable medical condition was greeted with dismay also by other South African non-governmental organisations working with HIV/AIDS patients. The counter argument given is that reasonable reliable statistics and information are obtainable already from standard HIV testing in antenatal clinics. As we may be aware, data from these clinics suggest a climbing or increase in HIV, with 1 600 new infections occurring daily in South Africa. Organisations working with AIDS patients argue that if AIDS is made compulsory notifiable, that would endanger the lives of people living with AIDS. On the other hand, HIV/AIDS organisations also question the reliability of diagnoses of AIDS in rural areas where there are very few (if any) laboratory facilities.

Michelle O'Sullivan of the Women's Legal Centre argues that the generally low social status of women and the poor acceptance of HIV/AIDS in South Africa could cause women further harm if members of their family were informed of their HIV status. She reported that according to United Nations Programme on AIDS estimation, young sub-Saharan African women between the age of 15-24 years, were twice likely to become infected with HIV/AIDS

than their male counterparts (Whiteside & Sunter 2000:96). Women resist partner notification because they fear domestic violence, emotional abuse and often abandonment. Notification to immediate family members and caregivers is more likely to create an unsafe insecure, threatening and ultimately disabling environment for individuals to access care services.

The main argument against making HIV/AIDS a notifiable disease could be summarised as maintaining that HIV/AIDS must not be addressed as a single issue or by vertical programme. A multi-sectoral approach is a prerequisite for the containment of the spread of the infection. Non-discrimination against people infected with HIV and those living with AIDS must be promoted. Therefore, this means that laws and regulations discriminating explicitly or implicitly should be reviewed and repealed.

Furthermore, *confidentiality* should be maintained because of the impact of notification on children. Arguments against notification are also strengthened by the view that these would cause unnecessary panic and that there is a danger of harassment. Apart from what London argued for, I think before making HIV/AIDS a notifiable disease, a 'see', 'judge' and 'act' method should be utilised.

Since the Department of Health is concerned about protecting health workers from being infected unknowingly and the underreporting of AIDS, South Africa, therefore, must adopt the system utilised by World Health Organisation and UNAIDS.

3.2 Notification of health care professionals

In this section, I propose to treat some ethical dilemmas that health care professionals are confronted with in their daily experience. Three fundamental ethical questions must be answered. Does the patient have the right to decide who should be informed of their HIV status? Do health care professionals have the right to refuse to treat individuals with HIV/AIDS? Should other health care workers involved in the treatment of an AIDS patient be informed of such a person's nature of illness without the patient's consent?

The health care profession is faced with tough decisions in the treatment of people living with AIDS. The care of people infected with HIV and living with AIDS has caused serious ethical concern and fear for health care personnel. Earlier on, I pointed out that the best way to go

about *informing others* about an individual's HIV status is for that particular individual him or herself to do so. If this fails then we are faced with a tough ethical decision.

During the course of my research, I visited a hospital in the North-West Province. Fortunately, my audience happened to be largely doctors and a few nurses. Although they acknowledged their obligation to care and treat AIDS patients, they were also concerned about the risk they face from treating an HIV-infected patient. I was then informed that since there is no cure or vaccine for HIV/AIDS, many health care professionals are doubtful of their *duty to treat* people infected with HIV and those living with AIDS. Some express their fear by actively refusing to provide certain types of care or by providing only the care, that would not put them at risk. Webber, Richards and Grey (*SAJ of Science* 96, (6): 295-296) support this view in their article. According to these authors, more than 40 per cent occupational injuries occurred among clinical students in 1998. They further maintain that:

In 1999, fifteen incidents of students being exposed to HIV and eighteen potential exposure events involving students were managed (ibid. p.296).

Although this is a realistic fear given incidents of accidental needle-prick injuries, the professional commitment must apply always not only when it is safe for doctors and other health workers. I immediately thought of the act of *beneficence* on the part of doctors and other health care professionals. Arguably, the *duty to treat* the sick must prevail even when the patient has a transmittable and sometimes deadly disease. While it is fair to recognise of the difficulty health workers are faced with, it is also important to emphasise the health workers' *moral duty to treat* and the patient's right to be treated.

It may be argued that the danger of informing health workers about the patient's HIV status would amount to that particular patient being discriminated against. The refusal to treat a patient because he or she is HIV-positive is definitely unethical. As a principle, health workers ought to treat every patient with great care that incidents such as needle-prick injuries are avoided. While most of us in South Africa recognise the risks health professionals might face from treating an infected patient, it can be argued that the risk is not only one sided. Do patients have the right to know the HIV status of those who treat them? In the event, that health professionals test positive for HIV, some people would argue that such a professional

should be forbidden to practise. There are isolated reports of the transmission of AIDS from health professionals to patients, for example, the transmission of HIV infection during an invasive dental procedure (*JAMA* 1991, 265: 563-568). The truth of the matter is that there is a worry over HIV transmission in both directions (i.e. from patient to health professional and vice versa).

3.3 Communicable diseases and notification of medical conditions: 1993

Many HIV/AIDS workers and Human Rights Organisations were concerned about HIV/AIDS being listed as a communicable disease. However, at a later stage changes regarding HIV infection and AIDS were noted as follows:

- i. AIDS is eliminated from the Annexure for Communicable Diseases: What followed was that AIDS was removed from the list of diseases that are regarded as *highly infectious* and requiring coercive measures to be taken in order to prevent new infections. However, HIV/AIDS remains a communicable disease in terms of the broad definition of the Act (Van den Berg & Viljoen 1994:57).
- ii. Handling Cadavers: Section 15 of the draft regulations outlines procedures for dealing with cadavers of people who have died of certain diseases, victims of AIDS or those who were known carriers of HIV at the time of death.

Since these regulations were never finalised, the South African Law Commission recommended that the Department of Health revise the draft regulations of 1993 and finalise them. Up until now, the Department of Health has not come up with any new recommendations.

3.4 Summary

Although in the past making some medical conditions notifiable in South Africa has yielded fruits, the same cannot be said about HIV/AIDS. The Government's arguments to make HIV/AIDS a notifiable medical condition, spearheaded by the previous Minister of Health, Dr. Nkosazana Dlamini-Zuma were outlined and so were counter arguments. The most

important reason in the move toward making HIV/AIDS a notifiable disease is the belief on the part of public health officials that effective programmes of partner notification require reporting the names of individuals with HIV infection as well as those living with AIDS.

I argued from an ethical perspective why I think this would not be the answer towards curbing the spread of HIV infection. Among the reasons why this would not be a recommendable solution to the problem facing South Africa, is the recorded death of Gugu Dlamini in KwaZulu-Natal for revealing that she was HIV-positive and was living with AIDS.

In South Africa, HIV/AIDS is stigmatised and people infected with HIV are discriminated against and their family members victimised. Therefore, making HIV/AIDS notifiable would be like fuelling the fire and exposing people living with AIDS to more cruelty. I suggested that South Africa must first undergo an intensive program in which the method of *see, judge and act* is utilised before making HIV/AIDS a notifiable disease. Therefore, making HIV/AIDS a notifiable medical condition is not the best solution we can come up with to fight the spread of HIV/AIDS. Relying on Leslie London's views, I argued that celebrities are *morally* demanded to test for HIV and *voluntarily reveal* their HIV test results. I also argued that South Africa ought to *destigmatise* HIV/AIDS and directly deal with its impact, because the stigma and fear of discrimination drives those who are HIV-positive underground.

In deciding whether to request an HIV test on a patient, there are two aspects to consider. The first is whether knowledge of the patient's HIV status will alter the patient's management in any way. If the answer is *yes*, then it is probably necessary to order the test. The second consideration is whether it is in the interests of the patient and his or her sexual partner(s) to know that they are HIV-positive, so that they can protect close sexual contacts and modify their behaviour so as to *minimise the risk of transmission* to other people. Finally, the government's position on HIV/AIDS needs to be spelt out clearly.

4. HIV/AIDS and social inequality

Unfortunately as a fact of life, HIV infection and AIDS is very often closely connected with power. Social class affects health in ways that we do not fully understand. In class in January/February of 2000, in our M. Phil lecture Prof. Van Niekerk drew our attention to the fact that “Inequalities are inevitable part of our everyday life”. What seems to be important, however, is which methods of intervention with inequalities are right and which are not?

The HIV/AIDS epidemic has shown a consistent pattern by means of which discrimination, marginalisation, disgrace and the general lack of respect for human rights and dignity of individuals and groups increase their vulnerability to HIV/AIDS. This implies that worldwide it is the least powerful people who are mostly affected and at high risk insofar as HIV/AIDS is concerned. Identification of the causal factors assumes critical importance because most of the people living with HIV/AIDS worldwide belong to *low-income groups*.

Lurie (*SAJ of Science* 96, (6): p. 343-347) argues (and rightly so) that HIV/AIDS is “*not only a social disease, but also a political one*”. He sustains his argument by stating that AIDS is mainly spread within the black communities. Lurie’s work seem to me to be an eye opener for all of us in South Africa to look back and truly reflect on the policy of apartheid and its contribution towards AIDS epidemic. He challenges us to look at the influence or impact of *forced removal* and *migrant labour* particularly in relation to commitment to family life and the Christian values governing the same among black South Africans. In addition, Lurie⁷ writes:

The spread of disease in societies is shaped, at least in part by the political, social and economic environment in which people live. In sub-Saharan Africa, where ‘circular’ migration is fundamental to the way in which society is ordered, migration has been an important determinant of the spread of infectious diseases, and has contributed to the extraordinary rapid spread of HIV (*SAJ of Science* 96, (6): p.343).

⁷ M. Lurie is a member of the Division of HIV Prevention and Vaccine Research, Medical Research Council, and the Centre for Population Studies and Reproduction Health in Mtubatuba near Hlabisa.

The South African Government under the previous dispensation may have not directly intended to spread HIV/AIDS among the black communities but unfortunately as many others have argued, the consequences of the apartheid policy has contributed to the spreading of HIV/AIDS. Whiteside and Sunter (2000:65) make us aware of the almost unbelievable submission that came forth at the Truth and Reconciliation Commission in 1999, where security officers, Willie Nortje and Andries van Heerden revealed that askaris were used to spread the HIV infection.

There are more female HIV/AIDS sufferers than male sufferers. Health research has also shown that populations with lower socio-economic status are those at higher risk of morbidity and mortality resulting from health-related problems for a wide variety of both infectious and chronic diseases, and also with limited access to health care. Poverty has been associated with increased risk for a variety of both infectious and chronic diseases, and with limited access to health care. The same finding equally applies to AIDS, as the disease has, in recent years, come to affect disproportionately poorer communities (*World Health Organisation Fact-sheet No. 242 – June 2000*).

Mark Colvin of the Medical Research Council outlines the role of poverty in the spreading of HIV/AIDS. He argues that sexual structure and practice cannot be perceived *entirely* as the free choice of an individual or be separated from the dominant socio-economic environment (*SAJS*, Vol. 96, (6): 336). However, it is not clear whether HIV/AIDS is indeed a disease for the poor or otherwise. What we are certain of is that HIV/AIDS leaves most of those it affects very poor. Although the connection between HIV/AIDS and poverty is obvious, I think we should not lose sight of people's attitude and behaviour towards sex and drugs, the two routes through which the rapid spread of HIV/AIDS is also evident. The following groups of people are the most affected by the AIDS disease:

- ❖ People in Africa, (i.e. the poorest continent) are more infected with HIV than people in richer countries. For example, the United States and Europe in particular.
- ❖ The Black population in South Africa is most likely to be infected than their white compatriots.
- ❖ Women and children are more infected than men are, that is, women are traditionally and culturally more disadvantaged than men are. Besides,

women have lesser power or sometimes they have no power at all to negotiate *safer sex* with their sexual partners, and

- ❖ People living in rural areas are most likely to be infected than those in urban and semi-rural areas. Rural communities are largely economically disadvantaged. In other words, the geographic distribution of HIV/AIDS indicates bias in urban and rural areas (*World Health Organisation Fact Sheet No. 242 of June 2000*).

Officially, statistics provide valuable information about the extent of the HIV/AIDS problem. They also give us a rough indication of how HIV/AIDS is distributed between different social groups. Therefore, the chances of contracting HIV/AIDS are not equally distributed. Some groups are much more prone to ending up with AIDS than others. Throughout the world, socio-economic status is also an important predictor of mortality, (ibid.). An inverse relationship between income and mortality in HIV infected persons is not surprising. Reasons given for the contrast between income and mortality are that individuals with low income have no access to health care and that low-income result from poor health and not the other way round. Furthermore, women and children will be increasingly hit as the AIDS epidemic unfolds. Changes are expected to bring with them serious social and economic implications.

4.1 HIV/AIDS a crime against women

Much has been said about the inequalities that exist between different social groups. HIV infection and AIDS is another clear indicator of this fact. According to Nancy Fraser, gender inequality is not only based on economic differentiation but also enhanced by *cultural-valuational differentiation* too (From Redistribution to Recognition? Dilemmas of Justice in a Post-Socialist' Age, in *New Left Review*, p. 78). As a remedy to redress gender inequality, Fraser suggests that there is a need for *transformative remedies*. In her argument, Fraser maintains that without change or social transformation, there would never be genuine redress of gender, race and class imbalances.

Even in stable communities women have little control over their sex lives. This is worse in situations where sex is a commodity, because in such situations women are often exposed to abuse and exploitation. Many instances of domestic abuse and incidents of rape in South Africa go unpunished. As mentioned earlier, the ability of many, particularly poor,

uneducated rural women to negotiate safer sex practices is non-existent (*World Health Organisation Fact Sheet No. 242 June 2000*). The ability of *prostitutes* and *very poor women* to negotiate in sexual agreements is very low or non-existent too. The evidence of this is the number of allegations about sex workers who are raped. Therefore, because they are known prostitutes, some of these women's rights are violated, their life is characterised by violence or the threat thereof, mostly because they are disadvantaged by social, political, economical and cultural stereotypes.

Most women, (especially black women) are single mothers. These women live in overcrowded conditions, in poverty, with poor health and most importantly with many dependants. Many of these young women depend on sex service to make their *ends meet*. This is self-evident when one drives or takes a walk at night; young women standing at the street corners and incidents at the roadside settlements are very noticeable.

The spread of HIV/AIDS among black women in rural areas is largely because of simultaneous partnerships. Usually polygamy is associated with men who have more than one wife, but infidelity among women is something very common within African communities. A number of women acknowledge that they have more than one sexual partner. Yet, for African woman, the decision whether to protect herself lies in her partner's feeling on the matter. She may resolve to take precautionary measures to protect herself from possible infection, but if her sexual partner will not hear of it, she has no option but to surrender. Such is the suffering of women in Africa (South Africa included) today. From what I can tell, almost every married or sexually active African woman expresses fear of infection, but they are seemingly helpless to do anything about it. One of the social implications of AIDS in South Africa is that the epidemic threatens improvements in female education, which has been a key factor in rural development. To curb the spread of HIV infection and AIDS, women must surely be empowered.

The HIV/AIDS problems also affect life in its initial stages since most HIV-positive mothers infect their children before they are born, at birth or shortly after birth. Carole Campbell (in Overberg 1994:83) supports this view, noting that AIDS in women is of special interest because women with AIDS or HIV infection are the major source of infection of infants with AIDS. The main ethical issue here is the right of an HIV-infected woman to become pregnant. Childbearing for some women (especially among Africans) is a strong cultural expectation.

Some fundamental ethical questions related to HIV-infected women must be asked. How free is an HIV-infected pregnant woman to carry her pregnancy to full terms where there is a 30-50 per cent chance of giving birth to HIV-infected child? There is no law in South Africa preventing women, men or couples who are HIV-positive from conceiving and bearing children if that is their wish. This implies that HIV-positive people can and do conceive. However, it is hoped that if they do, they will do it in the knowledge of the risk they are running, particularly the risks to their potential offspring and that they will do all they can to *minimise those risks*. There are those who argue that a pregnant HIV-positive woman must be advised to abort. The reasoning behind this argument is because the chances of giving birth to an infected infant are high. On the other hand, if the child escapes HIV infection, the mother will probably die and leave the baby orphaned. I think South Africa must have a law about this problem.

4.2 The impact of HIV/AIDS on children

A number of years ago, Dr. Alan Paton wrote a book entitled *Suffer Little Children*. Little did he know that the essence of the book would be so true today. Although his book was based on the suffering endured by children because of the political situation in South Africa then, I think that the book still has a great significance given the impact of HIV/AIDS on children. I think that Paton's work is still relevant because at the writing of this assignment, the impact of HIV/AIDS on children infected with HIV and those living with AIDS, orphaned by AIDS and whom AIDS will orphan is noticed by many. Therefore, the relationship between children and HIV/AIDS are twofold, *cause and consequences*.

Historically, large scale orphaning has been an occasional, short-term problem equivalent with war, political instabilities, natural disasters or disease. HIV/AIDS is changing this into a long-term persistent uncertainty. Cameron (1993) maintains that children in need of care and protection are often tested for HIV before being placed in an adoptive or foster care facility. He goes on to state that in most cases these tests are carried out without the necessary informed consent, and are sometimes used to discriminate against children. Regarding the testing of children before they are placed in a foster home, there are those that argue in favour and against such a practice. Arguments in favour of HIV testing are as follows:

- ❖ Adoption is permanent and a final placement. Therefore, according to welfare organisations, it is the policy to inform prospective parents as fully as possible about the child in order to enable them to make a final decision concerning adoption;
- ❖ It may be argued that HIV testing is in the best interest of the child, in that knowing the HIV status of a child allows the caretaker to plan and manage the child's health care and welfare appropriately;
- ❖ Prospective caregivers have the right to decide whether they feel able to care for a child with a life-threatening condition;
- ❖ Failure to test for HIV discourages those who are keen on adopting children or new-born babies.

Arguments against HIV testing of children to be placed under the care of someone else include the following:

- ❖ HIV tests are frequently carried out without the requisite consent, since the parent or guardian of the child is not available to consent to the HIV test;
- ❖ The HIV-positive status of a child can only be established with certainty by means of an HIV antibody test, at an average of 15-18 months (Overberg 1994:86),
- ❖ Disclosure of any child's HIV status without consent is a breach of the child's right to confidentiality;
- ❖ Most importantly, the results of an HIV test may be used to discriminate against a child, since because of such a test a child may not be adopted or accepted into any family.

My position on this is that every HIV testing must take place within the ethical guidelines of *informed consent*. In the case of a child, testing must take place, *if and only if* that is in the best interest of a child. Furthermore, where a child is orphaned, the legal custodian of such a child would be expected to give consent. Generally speaking, in South Africa almost all HIV infections in children under 13 years of age result from *mother-to-child-transmission* that is, an HIV-infected mother to her baby, before, during or soon after birth. The government's refusal to provide an effective treatment (i.e. AZT and nevirapine) to prevent mother-to-child-transmission means that a much higher percentage of newborn babies will be infected.

Besides, a number of children orphaned because of AIDS will increase rapidly until such a time that it would be difficult to determine the exact number. Therefore, insofar as this is concerned, I would argue that statistics are often misleading.

Sadly, *myths* and *misconceptions* surround the problem of AIDS. These can be summarised thus:

- (a) Cleansing of one through engaging into sexual intercourse with a virgin, with a belief that the virus is removed from the infected person and passed onto the target. One clear target group for this is children, hence the increasing statistics on *child abuse*.
- (b) Closely associated with point (a) is the prevention of self infection by engaging in sexual relationships only with uninfected individuals, foremost among these are children and old grannies (hence, the increasing rapes of elderly people), and
- (c) Retribution leading to the indiscriminate spread of the virus because of fear, anger and a desire for revenge.

Children have done nothing, except being born in situations over which they have no control. It is a myth to say that if a man has sex with a virgin, especially a child, it will cure HIV. From what we can tell, there is no cure for HIV infection and AIDS. The truth is that sexual intercourse with a child will cause that particular child incredible pain and misery, and may infect them with HIV and thus end their life. Because of the death of parents, most children in households with HIV-infected adults take responsibility and assume adult responsibilities. We usually find that an older brother or sister leave school to work and fend for his or her younger siblings. Within the orphaned children, more degrees of vulnerability exist with children being heads of the households and others having become *street kids*, become more exposed to dangers.

Until appropriate compromises are created to provide for the needs of these children and their families before their parents' deaths, the trauma, misery and remorse so common among these children are complicated by the doubt of their future or their relocation within the extended family. The dangers of orphaned children have been well documented and can be briefly divided into:

- (a) Those experienced by pre-school children, and
- (b) Those of the school aged children.

Unfortunately, the host families very often take advantage of the older orphans and exploit them. They are forced to stop attending school and work within or outside the family to supplement the family income. In addition, the inferior levels of education and high levels of physical and sexual exploitation expose these children at an increased risk of becoming HIV-infected, therefore, realising a circle started by their parents' infection. Sunter (1998:68) supports this by stating that:

The number of full-blown AIDS cases among young girls between 15-24 years old is appalling. This means that they became HIV-positive when they were 8 to 15.

Sunter further states that other African States have currently lost ten years of life expectancy because of HIV/AIDS.

4.3 HIV/AIDS in schools

Schools in South Africa are already experiencing the impact of the epidemic, as teachers, learners and members of their families become ill and die of the disease. Before the disease is brought under control, the effects of AIDS will become severe and more widespread. Almost every teacher will eventually be teaching pupils and students who have AIDS. On the other hand, most staff rooms would also be filled with infected teachers, and other school employees would not be exempted too.

HIV/AIDS and illness in general disrupt both learning and teaching. For instance, uninfected teachers or those in whom the virus has not yet revealed itself, have to take on an extra load when sick teachers are absent from school. Pupils and students who are sick would under normal circumstances absent themselves regularly and remain behind with their studies. Worse, if family members become ill and die of AIDS, teachers and pupils (students also) are forced by the circumstances to take care of or carry the burden of their families. Many schools are already crippled by the impact of HIV/AIDS on staff members, learners and their family.

The problem is overwhelming, but Cilliers argues positively that schools too can play a major role in the combating of the disease (Cilliers in Van Niekerk 1991:75). Whiteside and Sunter (2000:145) argue along the same line of thought. They maintain that the education system is where prevention must begin. They write:

[Therefore], it is a matter of highest priority to have an educational plan in place which specifically copes with the consequences of the epidemic.

For one reason or another, South Africa has reacted differently from other countries worldwide, in its attempt to curb the spreading of the disease. For example, in many countries, HIV/AIDS prevention strategies have been long incorporated into the secondary school and tertiary education, but South Africa is lacking behind regarding the implementation of this. Cilliers (in Van Niekerk 1991:80-81) makes the important point that the fight against AIDS must be in the *classroom*, given the number of official statistics of infected pupils in primary and secondary schools.

Cilliers earlier proposed that in addition to informal preventive programmes (i.e. a hidden curriculum), a formal preventive programme be introduced into the existing curriculum as a compulsory subject known as "*life skills education*".⁸ When Cilliers wrote it was made clear that schools are not doing enough to curb or prevent the spread of HIV/AIDS. I believe that the situation has not changed yet (ibid.). In addition, Whiteside and Sunter (2000:138) recommend that the Department of Education implement what they call "*life skills education*" as part of its contribution towards the preventive strategy. They further maintain that parents need to take some responsibility for this education.

Some thorny and sensitive issues arise when we address the problem of HIV infection and AIDS in schools. Unfortunately, there are among teachers the practice of falling in love or demanding sexual intercourse from pupils (the same is true for both male and female teachers). This to me shows a serious violation of a pupil's right to education. It shows disrespect of the self (on the part of the teacher) and of the other. Having sex with learners appears to me as unethical as a medical practitioner who would take advantage of his or her

⁸ It is almost ten years since Charl Cilliers made this recommendation, that is, in 1991 but up until now very little has been done in South African schools by the government to implement this recommendation.

patient does. It betrays the trust of the parents who send their children to school. Indeed, it betrays the trust of the community. It is also against the law and, therefore, it is a disciplinary offence. Teachers have the moral duty and a special responsibility to protect children under their care. Child abuse by a teacher is something despicable, because it betrays the trust invested in teachers by the parents.

The *South African Constitution on article 29 of the Bill of Rights* maintains that every person has the right to basic education. In addition, the South African Schools Act says that every public school must admit learners and serve their educational requirements without unfairly discriminating in any way. Therefore, a child cannot be excluded from any school, private or public, because of his or HIV status. The logic behind this law is that HIV/AIDS cannot be transmitted through casual contact. According to this law, the risk of infection of other children cannot be used as a reason to discriminate against HIV-positive children in schools. As they say, easier said than done. Facts are that many children living with HIV/AIDS do face many forms of discrimination. HIV-positive children are *victimised* and *marginalised* by both teachers and other children. Probably there are other unreported incidents of this nature.

Therefore, given the rapid daily deterioration of HIV/AIDS statistics, I wish to suggest that HIV/AIDS programmes need to be introduced in schools, perhaps in a form of *sex education* even in primary schools. I suggest that such programmes be part of the primary schools for the simple reason that children are easy victims of sexual abuse. I believe that if children in primary schools are made aware of certain things, they will be *extraordinarily cautious* and in that way, incidents of child abuse may decrease.

On the 10 August 1999, the Department of Education issued a document entitled *The HIV/AIDS guidelines for Educators*. The National Minister of Education Professor Kader Asmal outlined the impact of HIV/AIDS in South African Schools. He further warned strongly against male teachers to end the practice of demanding sex from schoolgirls or female teachers. Unfortunately, this is a fact we cannot deny no matter how much we want. Furthermore, Asmal maintains that 12 per cent of educators are HIV-positive. Therefore, he warned that unless preventive strategies are made, effectiveness in schools will decline towards 30-40 per cent because of teachers, officials and children who are ill, and cannot be able to concentrate.

4.4 Conclusion

As members of society, we must develop ways to prevent the spread of HIV infection and AIDS. However, prevention strategies should embrace the great variety of values, cultures and pressures that shape and limit people's choices. For example, what possibilities do most women in Africa have of changing oppressive cultural stereotypes insofar as sexuality is concerned? I think education and behaviour modification ought to be gender-based. I therefore, believe that transformative remedies would make a difference. This implies that a profound change in social, cultural and economic asymmetrical relations between men and women must take place.

Finally, making men more responsible is another effective prevention strategy. Very little has been said about men's participation in efforts to protect women. However, I think raising awareness of men's own risk would change certain behaviours. Therefore, every intervention must be aimed at both men and women if women are to be protected.

5. Ethical considerations in HIV/AIDS vaccine trials

In this chapter, I will be looking at the ethical considerations central to the international debate about HIV/AIDS vaccine trials. The ethical principles of autonomy, beneficence and justice are inscribed in the research practices such as informed consent and the defence of confidentiality (*South African Journal Science* 96, (6): 291). Besides, human rights questions have been raised insofar as these trials are concerned. How would the risks and potential benefits involved in such trials be explained to participants? Is it ethical that the poorest populations should become the testing grounds against a disease that affects people everywhere in the world?

As a point of departure, I wish to refer to the recent call for international co-operation in developing a vaccine, especially from developing countries where AIDS hit the most. Jose Esparaza of the **United Nation Programme on AIDS (UNAIDS) Vaccine Team** at a meeting held in Pretoria on July 29, 1999 made the following statement:

The knowledge and technology for an AIDS vaccine that can be effective in developing countries is an international public good. International collective action is vital to speed up development of an AIDS vaccine that will meet the needs of countries in greatest need.

The research concerning an HIV vaccine is initiated, designed and funded by sponsor agencies in countries with *relatively high social and economic development*. However, *trials or tests* are conducted in countries that are *relatively under developed*. Perhaps one of the main reasons why these tests are tried on subjects in four developing countries is because HIV/AIDS has found its roots in these countries more than it hits developed countries. The second reason for vaccine trials to be conducted in developing countries according to Udo Schuklenk *et al* (in Kuhse & Singer 1998:360) is that these countries have reliable and efficient infrastructures convenient to perform these sort of investigations.

This to many, gave rise to important political and ethical challenges. Therefore, for most politicians and ethicists, safeguarding the rights and welfare of individuals participating as research subjects, that is, those used as *guinea-pigs* in developing countries is nowadays a top priority. In September of 1997, the Joint United Nations Programme on HIV/AIDS embarked on a process of international consultation; its purpose was to define the important *ethical*

issues and to formulate guidelines that would facilitate the *ethical design* and conduct of HIV vaccine tests in international contexts.

Professor Solly Benatar⁹ gave a lecture for M. Phil, students at the University of Stellenbosch, in which he treated elements of how a research involving human subjects ought to be conducted. Benatar maintains that before any research on human subjects takes place, researchers must clear some ethical considerations. According to him, participants' dignity ought to be respected always; acceptable informed consent procedures ought to be followed. The researcher must be sensitive to the local cultural values and get a permission to conduct his or her research. Benatar argues that if the community is involved then the research may be successful. He believes that justice demands that the community must be well informed about the purpose of such a research and how the research will benefit the rest of the community. In other words, the fears of the local community should be addressed. Furthermore, he maintains that it is also important to establish whether it will benefit science to carry on with such research.

Lindegger and Richter deal extensively with fundamental ethical issues that arise in HIV vaccine trials. They emphasise that informed consent is the main element of clinical trials and thus, a fundamental requirement for participants in a given study (*SAJ of Science* 96, (6): 313). Deducting from the Nuremberg Code formulated in 1947, Lindegger and Richter summarise the code as follows:

- ❖ Disclosure of all relevant information about the research,
- ❖ Comprehension by the prospective participant of the information to make an informed decision
- ❖ Explicit and formal consent by the participant

Lindegger and Richter make an important point that informed consent must be obtained in every stage of the trial. Another ethical requirement concerning the use of human subjects in HIV vaccine trials, is that willing candidates must be informed of the risks involved in such trials (ibid.). Informed consent is also characterised by another important issue namely *the understanding of information by a participant*. The problem here is how does a researcher

make sure that participants comprehend all the relevant information, particularly uneducated participants?

Beauchamp and Childress (1994:147) maintain that the above question could be answered by determining the community's customary practices. This standard assumes that the professional's proper role is to act in the best interest of the patient. They furthermore, argue that *the reasonable person standard* must be utilised as another way of making sure that an individual understands the risks and advantages of the trial (Beauchamp and Childress 1994:148). Although there are guidelines insofar as conducting trials on human subjects is concerned, this does not necessarily eradicate abuses and manipulative behaviour of professionals.

Developing an effective HIV vaccine presents the global world with formidable challenges. Many *candidate HIV vaccines* have proceeded to the point of testing for safety in human subjects (Phase I and II clinical trials). However, multiple factors have slowed down progression to the final step of randomised, controlled, large scale phase III efficacy trials. The challenges have been scientific, logistical, political and economic.

HIV/AIDS was virtually unknown in 1980; however, today it is the most important infectious disease in the world. As I pointed out earlier, AIDS is currently the major cause of death in Africa. The burden of the disease is great in the poorest countries. More than 95 per cent of all HIV infections occur in '*developing countries*' and sub-Saharan Africa is home to two out of every three people living with HIV/AIDS. Despite intense national and international efforts to control the HIV pandemic, still more than 1 600 HIV infections occur daily in South Africa.

Another complex issue related to HIV is that the development of an *effective vaccine* requires that clinical trials be conducted among numerous different populations, including some with relatively low level of social and economical development. There are a number of reasons for this. Firstly, the large majority of HIV infections occur in *developing countries*. Phase III efficacy trials need to be conducted in populations with high incidence of HIV infections in order to produce valid and timely results. Furthermore, high incidence populations in

⁹ Professor Solly Benatar is a lecturer at the medical school in the University of Cape Town. He is also a regular visiting Professor at the University of Stellenbosch.

industrialised countries are already participating in present trials. However, the incidence in most *developing countries* is much high and affects larger populations.

The need for affordable drugs dominates the HIV/AIDS debate in developing countries. The pharmaceutical industry challenges the South African law, claiming that the controversial proviso in medicines control legislation that sanctions comparative foreign-made if drugs already licensed in South Africa breaches the country's obligation under the World Trade Organisation agreement.

On one hand, the United States demands that the South African government amend a 1997 law that gives South Africa undefined authority to secure inexpensive generic HIV/AIDS drugs for the country. South Africa on the other hand, needs to import HIV/AIDS medications from countries where they are sold with low cost under patent agreements, or to licence production from within South Africa.

According to the report by the *South African Press Association* (August 5, 1999) differences between the United States government and South Africa over the law allowing imports of cheaper medication should be resolved soon. This followed an on camera conference of Trade and Industry Minister, Alec Erwin and the United States Trade Representative. At this meeting, various issues connected to the preservation of *intellectual property rights* were discussed.

5.1 The politics and ethical problems concerning AZT and nevirapine

HIV/AIDS patients are eager for access to medication. However, there has been an ongoing debate as to the cost-benefit of AZT. The debate about whether the use of antiretroviral drugs will save money for health service or enormously increase the drug bill for no great benefit in terms of survival or cost of hospitalisation is a complicated debate and it is impossible to cover all sides of it in this work.

According to article 27 of the *New South African Constitution* (in the Bill of Rights), everybody has the right to have access to health care services. Therefore, fundamental ethical questions need to be asked. Who should pay for such treatment since most HIV-infected individuals are poor and cannot afford expensive treatment? Should society take a strict

utilitarian approach of the best care for the most people? Should HIV and AIDS drugs be made available at public expense to everyone without discrimination? Do drug manufacturers have an obligation to reduce prices in the face of the needs of HIV-infected and AIDS patients?

Another issue that seems to have added fuel to the HIV/AIDS flames is the controversy surrounding the government's failure or refusal to approve the use of AZT and nevirapine for the treatment of pregnant women. According to Lisa Jacobs, (*Press Officer for United Nations Programme on AIDS*) trials were performed with the government sanction, and results are under normal circumstances integrated into governmental policy. In South Africa as far as we know these trials were performed and they yielded positive results. Therefore, to bridge the gap between the trial end, and the research implementation national policy, free drugs are made available.

However, the South African government announced in October of 1998 that it would not supply AZT to pregnant women. This announcement caused uncertainty and consequently, the United Nations Programme on AIDS held back on supplying these drugs, and ever since the government's stance as well as the department of health remained unchanged. Most South African citizens believed that it is the government's duty and responsibility to supply drugs for HIV infection and AIDS. On the other hand, the South African government counterclaims that there are no sufficient funds to purchase these expensive *drugs*. According to the government, there were negotiations between the government and the manufacturer, Glaxo-Wellcome. As these negotiations continue, the reality is that there is no cure for AIDS and people are dying. Therefore for government, intensifying education and increasing public awareness will make the most effective prevention of the disease. Consequently, much of the debate about HIV/AIDS is centred on the unavailability of HIV/AIDS drugs especially for HIV-positive pregnant women. According Whiteside and Sunter (2000:12), the chance of mother-to-child-transmission (MTCT) is about 30 per cent.

The South African government's position concerning mother-to-child-transmission (MTCT) can be summarised as follows:

- **Cost:** This implies that the price that Glaxo-Wellcome charges for AZT and Nevirapine in South Africa prohibits the equitable treatment of all

South Africans for this purpose. It is therefore unacceptable for government to endorse the treatment of only those that live either in the more affluent provinces or in urban areas while ignoring the treatment of our rural poor.

- **Health Systems:** Besides the economic considerations, it is critical that the appropriate health systems are in place to ensure that a policy shift will do good rather than harm. Provision of dried milk formula if breast milk is to be substituted is one example given.
- **Ethics:** The government maintains that clinical trials performed in South Africa should be relevant to the needs of South Africans. The question of whether clinical trials should be performed on our people if the drug is not affordable for the majority of South Africans is presently under discussion within government structures. The lack of sufficient informed consent in clinical trials and non-provision of treatment medication once the trial is completed are other ethical considerations.

Recently, *the Mail & Guardian* (July 21 to 27 2000 p. 5) featured an article by Howard Barrell where he draws our attention to a research study, made by University of Cape Town postgraduate student Jolene Skordis. According to Barrell, Jolene Skordis' research arrives at a conclusion that "*South Africa cannot afford not to treat HIV-positive pregnant women with AZT and nevirapine anti-retroviral drugs*". Whiteside and Sunter (2000:148) also support Skordis. According to the article, Skordis' criticism is that since the government is literally doing nothing to curb the spread of HIV transmission from mother to child, this is costing the country much more than when the said drugs were made available to pregnant HIV-positive women. The article also refers to the support Skordis received from Professor Nicole Natras who supervised Skordis' research.

One must also look critically at whether the *United Nations Programme on AIDS's* (UNAIDS) acted in good faith or not. It is difficult to know or even give a direct answer to this question. However, I think UNAIDS did not act in good faith because the organisation supported the trials without looking into the extended financial affordability of the investigated drug regimen through the government's health care budget. Moreover, the internationally accepted ethical guidelines demand that drugs are made available at an affordable price to communities where the drug trials occurred. In practice this means that

those who sponsored the research have to make available the drug for the people, regardless of the price the manufacturer predetermined. The cost of AZT for all infected South Africans is currently R3, 6 million with 1 600 new cases reported daily; the government defends itself by saying that the price of AZT is unaffordable. Whiteside and Sunter (2000:148) argues that Glaxo-Wellcome offered a treatment course to the department of health at a discount price of 70 per cent, thus making it the cheapest price in the world.

The government's position can be summarised thus: If we cannot treat everyone infected with HIV, we will treat none. The government here wants to be seen as protecting the poor. However, is this not a clear expression that the government is obsessed with embracing the macro-economic growth, employment and redistribution (Gear) policy? Perhaps if this is not obvious, it is at least suspicious. In other words, the government claims that it refuses to discriminate between the rich and the poor. No matter the situation, the government (like everybody else) to put it in Peter Singer's words (1997:v) cannot avoid involvement in ethics, for what it does and does not do as a possible subject of ethical evaluation.

According to McIntyre & Gray (*SAJS* 96, (6): 278) babies born to HIV-positive mothers have a significantly increased chance for life if they receive a drug called *nevirapine*. This is a new drug constituted of non-nucleoside reverse transcriptive inhibitors. This new drug has two advantages over AZT. The first is that the drug is administered twice: Once to the mother during labour then to the baby within a period of three days of birth, while AZT requires that a course goes to at least four weeks. As far as we know, with nevirapine the risk of HIV transmission from the mother to the baby is reduced by 47-50 per cent. The second is that it has a different chemical basis, close to the common drug *Valium*. Although this drug is much cheaper than AZT, the South African government is still not willing to import it and has shifted its focus to parallel importing and vaccine development.

The *Pan-Africanist Congress* and the *Azanian Peoples' Organisation (AZAPO)* have repeatedly criticised the government's policy on HIV/AIDS. These two organisations accuse the government of depriving the poor of access to the only available weapon for preventing HIV/AIDS among those who are already infected with HIV. They maintain that for the government to say South Africa cannot afford AZT drug is nothing but whining. Lately, the South African government adopted another excuse for refusing to supply AZT to those infected with HIV, namely, that '*drugs must be tested in case they are toxic*'. To counteract

this argument, pharmaceutical companies maintain that in reality everything or any action human persons perform has its *side effect*. Although this is true, we need to balance the cost and effects or benefit.

The Pan Africanist Congress and Azanian Peoples' Organisation furthermore argue that the government must stop dithering about HIV/AIDS and start fighting it effectively before it destroys the entire nation. We may ask: Has HIV/AIDS not destroyed the nation already?

The South African government has been criticised for its lack of commitment to HIV/AIDS, while the private sector has continuously demonstrated its willingness to help. As already indicated, HIV/AIDS has become one of the most common and serious complications of pregnancy in South Africa. Recently evidence from Uganda has indicated that one dose of Nevarapine to mother and one dose to infant halves the rate of transmission and provides the most feasible and affordable intervention for developing countries. The obstinate refusal of the Ministry of Health and politicians to provide AZT to pregnant women is viewed by others as tantamount to a violation of human rights according to principles of the Universal Declaration of Human Rights (Universal Declaration of Human Rights, *JAMA* 1998:469-470).

5.2 Conclusion

In this chapter ethical issues relating to HIV vaccine trials were discussed. I argued that informed consent is the foundation on which the success of these trials ought to be built. In a sense, informed consent aims at protecting the autonomy of human subjects in such trials. I also pointed out that justice must be done to prospect participants in that they must be informed about every relevant information regarding the trial. This information disclosure ought to be truthful and it must take into account the cultural norms or values of participants.

The other issue of great importance is that the research must make sure that participants understand the details of the proposed research and the implications thereof. The study must meet the medical or scientific requirements. In other words, the study must be motivated by scientific objectives. Finally, subjects of these trials must not be coerced in any manner whatsoever. In other words their dignity must be respected. To put it in Kant's philosophy, human subjects must not be treated only as a means to an end.

Dr. Manto Tshabalala-Msimang's administration has inherited from the previous Health Minister the controversy surrounding the government's reluctance to approve access of AZT to HIV-infected pregnant women. The hope of everybody in South Africa was that this issue would have been resolved by now. The government argues that providing AZT is very expensive for poorer nations (Whiteside & Sunter 2000:148). The South African government claims that even at a reduced price it still cannot afford AZT for its HIV-infected pregnant women.

Nevirapine came in as an alternative effective drug and it is affordable. However, the government argues that nevirapine is still under consideration by the Drug Control Council of South Africa. Therefore, the department of Health maintains that a decision on whether the government would buy the drug would be made after the relevant test information from local drug trials was available. This makes the government commitment and policy on HIV/AIDS questionable (Whiteside & Sunter 2000:148).

Most scientists believe that both AZT and nevirapine would limit mother-to-child-transmission and these drugs would be cost-effective; and thus bring with them *a ray of hope*. Edmund Pellegrino (in Overberg 1994:79) rightly maintains that if treatment is to become readily available to all that need it, it will have to be better integrated into the health system. Therefore, the burden of caring for HIV-infected persons and people living with AIDS would have to be on the shoulders of the society. In other words, the society must be prepared to support those who are unable to pay for their treatment and hospitalisation.

In the end, the debate about supplying AZT and nevirapine to pregnant HIV-positive women will not be resolved until something has been done. This is obviously the only way of reducing the escalating mother-to-child-transmission of HIV/AIDS. Everyone is hoping for a vaccine, or several vaccines, that are affordable to everyone and effective at all time. Whether the world can devise a fair way to distribute it is another matter. Basic health care is a fundamental right guaranteed in the constitution. However, the extent to which the state is responsible for securing socio-economic rights that might be costly to implement has not been determined.

6. Prevention strategies for HIV/AIDS in South Africa

I think most of us are familiar with the saying that "*Prevention is better than cure*", and this slogan seems to me to be the one adopted by the South African Government as a means to curb the spread of AIDS. The government in its effort to curb the spread of HIV/AIDS and make the population aware has changed this slogan to be "*Prevention is cure*". Is it? I would not go as far as saying *prevention is cure* while everybody knows well that even the prevention strategies the South African government has encouraged or implemented have so far failed dismally. The search for effective intervention approaches to reduce the spread of HIV and AIDS is an ongoing one.

While extensive resources have been expended in trying to find a cure, little significant progress has been made. Globally, although the international AIDS research has accumulated considerable experience with interventions and has made realistic assessments of their effectiveness, it continues to debate the relative importance of different approaches, including the channels of communication or which risk-reduction messages should be promoted (*World Health Organisation & Global Programme on AIDS: Effective Approaches to AIDS Prevention, May 1992*). The need for a multifaceted intervention has already been well established, but also has the need for broader thinking about prevention options.

It is clear that a reliable protective or effective vaccine would not be available for many years to come. Therefore, I am personally convinced that it is necessary to give people accurate scientific information about the HIV/AIDS pandemic. Community-based organisations and the National Health Department have propelled efforts aimed at public awareness. Public figures and celebrities have taken part as well.

Important to note is that the most effective treatment, antiretroviral medication is complicated to administer, requires a close medical monitoring, and can cause significant adverse effects and is extremely costly. The logistical and economic barriers render treatment inaccessible for the majority in South Africa, thus creating a sense of urgency to develop a safe, effective and globally accessible HIV preventive vaccine to complement other strategies. Although 80 per cent of the South African population is aware of the HIV/AIDS problem, however, such knowledge and information have little influence (if any) on the way people behave. This

indicates that knowledge by itself does not necessarily induce people to change their behaviour. I accept that knowledge and information are indispensable. However, these two elements do not manage by themselves to bring about a change of behaviour and that is a fact. For example, most medical practitioners know that smoking is bad for their health, but they go on smoking anyway. In the same way, people know that AIDS kill but they do not even attempt to protect themselves against HIV infection. To put it bluntly, they have the knowledge but lack the *will* and the *heart* to act upon the knowledge they have obtained and to avoid HIV/AIDS in all circumstances.

South Africans want more information about HIV/AIDS. They want the government to provide it to them, and they want the schools to provide it to children (*SAJS*. 96, (6): 357). The most emphasised prevention strategy in the country now is the use of condoms. For example, speeches of both the South African President (while still a deputy president) and the current deputy President Mr. Jacob Zuma ended by promoting the use of condoms. Generally speaking, South Africans acknowledge that, other than abstinence and chastity, condoms are presented as the best method of prevention.

However, the public is divided over the question of the distribution of condoms in schools. I think the need for South Africa to rethink its prevention approaches is necessary in order to develop a wider range of options in an effort to complement existing strategies. In the absence of a vaccine, the Christian Church leadership maintains that the only means to prevent the spread of infection is to avoid personal behaviour that carry a risk of transmission. To emphasise this point Van Niekerk (1991:15) writes in italics:

In the absence of a cure, it has become clear that a (sometimes-radical) change in life style is the most important way that provides protection from the disease and its fatal consequences.

The condom issue is in fact the focus of AIDS education and prevention throughout the world. Among those who publicly protested against *safe sex talks* and the '*distributions of condoms*' were the South African Catholic Bishops' Conference through its President archbishop Wilfred Napier, African Christian Democratic Party leader and MP Reverend Kenneth Meshoe and many other individual Church leaders. Their counter argument is that to *completely prevent HIV/AIDS transmission*, drastic changes in sexual behaviour and drug

dependence would have to take place in the country and worldwide. Furthermore, prevention efforts that promote sexual awareness through open discussion and *condom distribution* in public roads and schools were opposed because of the fear that these efforts may encourage sexual promiscuity and unfaithfulness.

The Christian Church instead promotes prevention of HIV transmission through chastity, *faithfulness* and *abstinence*. On the other hand, politicians accuse some Christian denominations of wanting to impose their '*religious ethics*' on the entire population. The government and religious groups have reached a deadlock and they do not see eye to eye concerning the use of condom. Similarly, prevention programs that identify HIV infected individuals and notify their sexual partners, as well as programs that promote a compulsory HIV testing at the time of pregnancy, have been criticised as the invasion of personal privacy. Ethically the issue of personal privacy ought to be weighed or balanced against the responsibilities of society to ensure public health and control the spread of HIV/AIDS.

I believe that a distinction ought to be made between prevention approaches that aim at *persuading* individuals to change their behaviour and those that *enable* change to occur. The latter focus on non-individual, or the social determinants that facilitate or impede behavioural change. In addition, enabling approaches intend to remove barriers or constraints to protect action or, conversely, to erect barriers or constraints to risk-taking. In some cases, enabling approaches that remove barriers for some people, such as women (especially among black communities) who actually have no say regarding sexual matters, may erect barriers for other, such as men who may find their traditional dominance constrained. On the other hand, an enabling approach that removes a barrier to change might be a policy that allows a purchase and possession of sterile injection equipment by drug users.

Evidently, altering the environment in which risk behaviour takes place through comprehensive sexually transmitted disease treatment can result in decreasing HIV incidence even in the absence of significant behaviour change, (Grosskurth, Mosha, Todd *et al*, 1995:530-536). This is evidence of the preventive effect of a structural intervention, despite a physical one, which relies on enhanced service delivery. While continuing to recognise the role of individual decision-making, all structural interventions acknowledge that meaningful reduction of HIV transmission can still occur even though the range of an individual's action may be too limited in certain contexts to allow for sufficient behaviour change.

Many safe sex campaigns have been conducted to encourage the public and the groups most at risk from HIV infection to avoid *unprotected sex*. According to Thornton and Gatalan (1993; 4:311-316), condoms are not only viewed by those who use them as protective devices but also communicate messages which act as obstacles to their use. Obviously changing sexual behaviour is a very difficult task, which requires much more than just an effort. Asking people to use condoms is easier than encouraging them to be faithful to one partner and abstaining. Abstaining from sexual practices means that people ought to give up immediate pleasurable activities in order to avoid a possible negative consequence at a relatively distant future point.

Change is never easy, either at an individual or a community level. Therefore, a holistic view is required, which combines health education with programmes to create supportive environments for behaviour change. HIV/AIDS prevention based on condoms is faced with a number of potentially insuperable logistic programs (Lamptey & Goodridge 1991). To some extent, the same could be said for all other attempts. For instance, how does one ensure that prevention programmes reach every individual in every rural village when vehicles are few, petrol is getting more expensive by week, vehicles are few, roads leading to most rural people are very bad sometimes impossible to drive at using private cars.

In an article in the *Sunday Times* (June 4 2000) Laurice Taitz writes that the Minister of Health ducks AIDS question. According to her, the South African Minister of Health Dr. Tshabalala-Msimang was asked a question: "Why is the government struggling to make an impact on the HIV crisis?" It must be acknowledged that the question asked by the minister is a very important one. However, I want to agree with Taitz that this tactic is a technical manoeuvre on the part of the government to shift responsibility rather than tell the South African society problems contributing towards a failure on its part to make an impact on the HIV/AIDS catastrophe. Dr. Tshabalala-Msimang evaded the question and shifted the focus from the government to *individual responsibility*. According to the Taitz' article, the minister went on to say:

I am not saying this to minimise government responsibility but there is no way government can make an impact on AIDS unless every individual takes responsibility for their sexual behaviour, (ibid.).

This in my view, is a simplistic approach to the government's policy on preventing HIV/AIDS. Again, this is a dangerous statement to be uttered by head of the department of health of any given country. While it is true that individuals should be responsible for their sexual behaviour, this implies that it is only through *sex* that HIV/AIDS is transmitted, which is not always the case. This is not even half of the story. There are groups as I indicated earlier that are infected through other channels. Even in the medical practice we often hear of doctors and nurses who become infected through needle-prick injuries.

The focus of this section concerns the concept of the reciprocal obligations; obligations of the state toward those who are infected and the obligations of infected individuals toward non-infected members of the society. In order to protect others from the disease, the state should advocate infected individuals' responsibility, with measures for their protection rather than discriminatory or coercive measures. It is therefore, important that educational efforts aiming at AIDS prevention be culturally sensitive.

Currently, AIDS research has increasingly focused attention on the vulnerability of women in sexual relationships, especially when taking into consideration the constraints on women to propose or negotiate risk reduction practices with their sexual partners. One explanation advanced, are the prevailing social norms on gender roles, which encourage men but not women to make decisions concerning sexual matters. Yet, this vulnerability may also be a result of economic factors, such as women's limited access to resources and their subsequent financial dependence on their partners.

Economic factors such as the need for others to leave their families, and seek employment in new settings, and therefore, live apart from regular and stable partners for a considerable long periods, heighten the probability of casual sex and thus the risk of HIV transmission among men and women alike. Evian (*SAMJ*, 83, September 1993:635) writes:

Sex is exchanged for jobs, food, transport, school fees, tuition and favours. In addition, sex in poverty situations is sold very cheaply; there are many buyers, many sellers and the market flourishes.

In no case is the evidence for economic determinants of risk behaviour clearer than it is for sex work or industry. Worldwide, evidence suggests that the overwhelming motive behind the

exchange of sexual services for the provider is economic opportunity. While this is often a desperate survival strategy for some, it can sometimes be a profitable alternative to existing employment opportunities for others.

Worse, the present unemployment situation in the country is a reason for many young women to flow into sex industry. Therefore, education programmes must also persuade family members that sex work is not an acceptable employment for teenage girls in the age of AIDS. Obviously, the absence of employment opportunities to generate incomes of comparable magnitude or educational opportunities that might lead to such employment, is the reason why some may feel they have no choice but to remain in sex industry. What is at stake here, is that those involved in exchanging sex for money often have limited power to negotiate safer sex practices with clients.

Perhaps the important question to ask is what are the possibilities of modifying economic determinants to reduce the risk of HIV. Approaches to increase the economic role power of women as a means of increasing their ability to exercise control over their lives, including over their reproductive and sexual behaviour, have been tried in several places. However, even in those societies where women clearly have a significant economic role, they often continue to have limited negotiation power in sexual decision-making. The culturally propagated conceptions of gender role defining men as the decision-maker often override other considerations and will continue to be a hindrance to significant HIV risk reduction for women.

Within some black cultures in South Africa, there are those cultures in which it is tradition for young men to go into circumcision schools. Unfortunately, the *actual cutting* or mutilation as critiques calls it, is done by a traditional healer, so far there are proven cases of unsterilised blades used by these healers. Every year there are deaths reported as a result of unsterilised blades and negligence in performing operations.

Early in 1999, Professor Loretta Koppelman a visiting professor at the University of Stellenbosch gave a lecture on the subject "*Medicine and multiculturalism*", the core of her lecture was "If we can learn from other cultures, can we criticise them too?" Important points were made in that particular lecture, from it we learnt that shared values and methods enable us to learn from each other and to criticise each other in a way that has moral authority. In

practice this implies that shared values and methods in science must have in them certain elements and those can be classified as follows:

- ❖ That information be critically evaluated based upon evidence and merit.
- ❖ Disinterestedness or impartiality in the collection and weighing of evidence, and
- ❖ Truthfulness in reporting evidence

It is in the light of this that I understand Van Niekerk's criticisms of the traditional circumcision and the apartheid policy and what he calls its influence on the spreading of HIV/AIDS. He holds that in Kenya the government was considering banning circumcision, a reason being the usage of the unsterilised knives, (Van Niekerk 1991:11). All these contribute to the escalation and transmission of HIV/AIDS. Modification of circumcision practices can be a promising avenue for HIV prevention. Together with national policy change, these structural interventions are a powerful addition to, not a replacement for, the more standard HIV/AIDS prevention approaches recommended. I want to suggest that it is in the environment such as this, where there is high risk of transmission. Therefore, the national government should make compulsory policy; that in every circumcision school the operation is:

- a) Performed by a registered medical practitioner
- b) Sterilised instruments are provided for every individual candidate and properly disposed of, and
- c) The price of sterilised instruments is included in the fees paid to every circumcision school.

I think this will help to minimise the risk of HIV infection. Unfortunately, there is so much competition among different circumcision schools. Some do get many young men going to them during the circumcision period, while others get a lot fewer. Therefore, the fewer a particular camp gets the lesser the income and the more the candidates in the other camp, the better the income. However, in order for all these to succeed, careful preparation and consensus building are necessary to assure the implementation and continuation of these approaches.

6.1 HIV/AIDS infection in South Africa prisons

As a point of departure, I would like to look at the consequences of HIV infection in South African prisons. *The Mail & Guardian* (August 28 to 3 2000) has an article by Marianne Merton and Aaron Madadasane, they reported that an anonymous man who was an *inmate* in Pollsmoor prison for six years sues the Minister of Correctional Services for being infected with HIV while incarcerated. According to the report, this particular person claims that the Department of Corrections Services knows that prisoners are raped and quite a number of them are HIV-positive in South African prisons. The concerns of most of us, who are aware of the situation in South African prisons, know that the department has so far failed to implement preventive strategies and policy (ibid. p.15). This causes a legal and ethical concern, especially when the government is blamed by so many for its ineffective HIV /AIDS policy.

In South African prisons, HIV/AIDS also spreads rapidly through gangs whose culture is characterised by tattoos and sexual intercourse with other inmates as part of the prison setting. The purpose of these tattoos make inmates belong, they are identified with some powerful gangsters. Therefore, the needles used to implant these tattoos are shared among a number of inmates. This implies that the chances of HIV transmission are very high.

In conclusion, I agree with those who argue that preventive strategies and HIV/AIDS awareness programmes must be enforced in our prisons. The government and the Department of Correctional Services have a moral responsibility to protect inmates who are powerless and not infected against the powerful and infected inmates. However, there is a problem as to how this should be address, because if mandatory testing of all convicted prisoners and the separation strategies were used, this would go against ethical requirements insofar as *informed consent, respect for autonomy, privacy, confidentiality* and *discrimination*. Nevertheless, there is an urgent necessity to act, other wise; the state would experience many more lawsuits such as the one referred to earlier.

6.2 Conclusion

Everybody has an important role to play and if we all do our part, we can make a difference. Ethical issues relating to HIV/AIDS in developing countries were discussed, and the moral

obligation of the developed countries was outlined. Other ethical issues concern areas such as the laws of the country concerning women in sex industry, universal ethical principles regarding the problem of HIV/AIDS, a question whether these ethical principles are understood in the same way by Africans as they are by Westerners were discussed.

I believe that *developed countries* have a *moral obligation* to help *under developed countries*. Thus making the global AIDS slogan "*One World One Hope*" more true. The South African government on the other hand, must come out clearly in its policy on HIV/AIDS, and take its moral responsibility over its citizens more seriously. On the grassroots level, effective strategies of curbing the spread of HIV/AIDS must be taught and people must be encouraged to go back to traditional ways of living a virtuous life.

I argued that since there is no cure or vaccine for HIV infection and AIDS, prevention is therefore, the only weapon we have at our disposal. As they put it, '*prevention is better than cure*'. To put it in Whiteside and Sunter's (2000:137) words, "*Prevention is more cost effective than treatment*". The present prevention strategies and their limitations were discussed. I went on to challenge the so-called 'safe sex' and proposed that people should be faithful to one uninfected partner and for those who are not married to abstain from sex for as long as possible. Whiteside and Sunter (2000:141) maintain that the ineffectiveness of prevention means that South Africa has to deal with the impact flowing from the illness and death of large numbers of people.

Given how important prevention strategies are in slowing the spread of HIV/AIDS, it is equally important to identify effective prevention methods. Treatment of sexually transmitted diseases is also essential in curbing the spread of HIV/AIDS. Finally, well-designed preventive programmes that are targeted at every person are critically important.

7. Conclusion

South Africa needs a strategy, which will enable the country to do something about what we believe to be right in its fight against the HIV/AIDS problem. I think the *utilitarian approach* would be better suited to practically deal with the HIV/AIDS problem in South Africa. However, elements of deontological approach may also be used. For example, a strict deontologist would argue that the government has a moral duty or obligation to make AZT or nevirapine available for pregnant HIV infected women in order to reduce the chances of *mother-to-child-transmission*.

In this study many aspects of the HIV/AIDS pandemic were covered. They ranged from the need of the international world to develop effective vaccines at an affordable price to behavioural change of high-risk groups and other prevention strategies. I argued that in South Africa, the *main* route of HIV transmission is heterosexual sex. Therefore, in South Africa the victims are *mostly women and children*. I also argued that we have so far failed to make a significant impact in our fight against HIV/AIDS. I went on to discuss some legal and ethical considerations insofar as making HIV/AIDS a notifiable disease is concerned.

Whiteside and Sunter (2000:122) draw our attention to the 1997 national review of South Africa's response to the AIDS pandemic, which was published entitled: *Review the Past, Plan the Future, Work Together*. I would like to summarise the review findings as follows:

- ❖ The need for political leadership and public commitment
- ❖ Responses to be interdepartmental and intersectoral;
- ❖ Meaningful involvement of people living with AIDS and of those infected with HIV;
- ❖ An urgent address of human rights abuses and the reduction of stigmatisation.

During that period, there was a unity of direction and purpose in the fight against HIV/AIDS in South Africa. In 1998, the political leadership committed itself and formed the Government AIDS Action Plan and a major public campaign occurred. This was characterised by President Thabo Mbeki's national address on HIV/AIDS.¹⁰ The President challenged all South Africans

¹⁰ President Thabo Mbeki made this speech while he was still the deputy President on 9 October 1998.

to confront the reality of HIV/AIDS and called for the public and private sectors to pledge themselves to the “*Partnership against AIDS*”. This was indeed a step towards the right direction and various sectors responded positively towards this call. Unfortunately, the South Africa government up until now never committed itself to implementing the programme it initiated in 1998.

I suggested that in the country’s attempt to deal effectively with the problem of HIV/AIDS, ethical principles, such as *informed consent, confidentiality, privacy, autonomy, truth-telling etc.*, play an important role. I went on to suggest that *traditional ethical approaches to ethics* might help in dealing with HIV/AIDS. In making an ethical decision, a strict *consequentialist* would first determine possible alternatives for action and the consequences which each produces. Then alternatives are weighed against each other to determine which produces the greatest possible value in its results. One of the advantages of the *utilitarian approach* is that it takes seriously the future implications of the HIV/AIDS pandemic. In this way the *utilitarian approach* challenges us to look into the future as far as we can and follow the impact of our decision and action as far as possible. The cost-effect approach of *utilitarianism* seems to be the only option South Africa has to curb the spread of HIV/AIDS. *Utilitarianism* demonstrates this by holding a view that the *good* is determined by achieving the *greatest good for the greatest number*.

Finally, in coming to a decision, South Africans ought to include all factors in relation to relevant situation within the proper context. This would mean that the country takes into consideration the *complexities* of HIV/AIDS. Although there is a breakthrough insofar as effective treatment for pregnant HIV infected women (through AZT & nevirapine), we cannot rely on medical solution to reverse the onslaught. Changing one’s life style can stop the transmission of HIV/AIDS. I suggested that in order for preventive strategies aiming at protecting women to be effective, interventions must be aimed at men. Perhaps the answer for HIV/AIDS pandemic comes to us when we sing the South African National Anthem in Sesotho and Zulu, where it says: “*God Save Africa*”.

MORENA BOLOKA SETJHABA SA HESO

8. Bibliography

- Ackerman, T.F. & Strong, C. 1989. *A casebook of medical ethics*. New York: University Press.
- Ankrah, E.M. & Gostin, L.O. 1994. *Ethical and legal considerations of the HIV epidemic in Africa*. In M. Essex, S. Mboup, P.J. Kanki & M.R. Kalengayi (Eds.). *AIDS in Africa*. New York: Raven Press, pp. 547-558.
- Ashley, B.M. & O'Rourke, K.D. 1981. *Health care ethics*, 2nd Ed. St. Louis: Catholic Association Press.
- Beauchamp, T.L. & Childress, J.L. (Eds.). 1994. *Principles of biomedical ethics*, 4th Ed. New York: Oxford University Press.
- Biemiller, L. 1987. Colleges could play a crucial role in halting spread of AIDS epidemic, public health officials say. *Chronicle of Higher Education* 33.
- Biemiller, L. 1985. AIDS on the campuses: Some expect a flood of questions about the disease from frightened students and parents. *Chronicle of Higher Education* 31.
- Black, J.L. 1986. AIDS: pre-school and school issues. *Journal of School Health* 56, 3.
- Cameron, E. "Human Rights: Consequences for the HIV epidemic: Beyond policy consensus to effective activism". (Unpublished Paper delivered at the 12th World AIDS Conference Geneva 28 June- 3 July 1998).
- Chaitow, L. 1999. *The natural way: HIV & AIDS*. Dorset: Element Books Ltd.
- Cilliers, C. 1991. *The role of South African schools in the prevention of AIDS*. In A. van Niekerk (Ed.), in *AIDS in context: The South African perspective*. Cape Town: Lux Verbi, pp. 75-90.
- Cohen, B.G. "Criminalising the sexual transmission of HIV". (Unpublished paper prepared for the AIDS Law Project. Centre for Applied Legal Studies, University of the Witwatersrand. March 1997).
- Colella, U. "HIV-related information and the tension between confidentiality and liberal discovery". *The Journal of Legal Medicine*. March 1995, 33-100.
- Colvin, M. Sexually transmitted infections in Southern Africa: a public health crisis. *South African Journal of Science*. June 2000, 96(6): 335-339.
- Crocker, D. 1991. "Insiders and outsiders in international development ethics". *Ethics & International Affairs* 5, 151-173.

- Department of Education. 1999. *The HIV/AIDS guidelines for educators*. Pretoria: Government Printer.
- Department of Health. 1977. *A guide to the Health Act, No. 63 of 1977*. Pretoria: Government Printer.
- Department of National Health and Population Development 1991. *Health trends in South Africa*. Pretoria: Chief Directorate: Planning Support.
- Department of National Health and Population Development. 1990. *Background and strategy for AIDS prevention*. April 1990. Pretoria: Chief Directorate: Planning Support.
- Epidemiological Comments. 1991a. *First National HIV survey of women attending antenatal clinics*. South Africa, February 1991, **18**(2): 35-50.
- Everett, K. 1995. *Get wise about AIDS*. Swaziland: Macmillan Boleswa Publishers (Pty) Ltd.
- Evian, C. 1995. *Primary AIDS care*, 2nd Ed. Johannesburg: Jacana Education.
- Fine, D., Heywood, M. & Strode, A. (Eds.). 1997. *HIV/AIDS and the law: A resource manual. The AIDS Law Project & Lawyers for Human Rights*. Johannesburg: University of Witwatersrand
- Fraser, N. 1995. From Redistribution to Recognition? Dilemmas of Justice in Post Socialist' Age. *New Left Review*, 212, 68-93.
- Friedland, I.R. & Snipelisky, M. (1991). Vertically transmitted HIV-1 infection in children: a report of 23 cases. *South African Medical Journal* **79**(3): 157-159.
- Gillon, R. 1985. *Philosophical medical ethics*. London: John Wiley & Sons.
- Grosskurth, H., Mosha, F., Todd, J. *et al.* 1995. Impact of improved treatment of sexually transmitted diseases in HIV in rural Tanzania: Randomised controlled trial. *Lancet* 1995, **346**: 530-536.
- Guenter, D., Esparza, J. & Macklin, R. 2000. Ethical considerations in international HIV vaccine trials. *Journal of Medical Ethics*, February 2000, **26**(1): 37.
- Gula, R.M. 1989. *Reason informed by faith: Foundations of catholic morality*. New York: Paulist Press.
- Harrison, A., Smith, J.A. & Myer, L. 2000. Prevention of HIV/AIDS in South Africa: a review of behaviour change interventions, evidence and options for the future. *South African Journal of Science* **96**(6): 285-290.
- Hermann, D.H. 1990. "Criminalising conduct related to HIV transmission". St. Louis University: *Public Law Review*, 351-378.
- Ijsselmuiden, C.B. *et al.* 1988. AIDS and South Africa: Towards a comprehensive strategy. *South African Medical Journal* **73**(8): 455-467.

- Keith-Spiegel, P. & Koocher, G.P. 1995. *Ethics in psychology: Professional standards and cases*. Hilldale, NJ: Lawrence Erlbaum Associates.
- Key, S.W. & DeNoon, D.J. 1999. *More privacy protection needed for people with HIV/AIDS*. *AIDS Weekly Plus*, 04 December 1999, 8.
- Kriel, J. 1991. *AIDS is not a (medical) disease*. In A. van Niekerk (Ed.), *AIDS in context: The South African perspective*. Cape Town: Lux Verbi, pp. 37- 56.
- Kuhse, H. & Singer, P. (Eds.). 1998. *A companion to bioethics*. Oxford: Blackwell.
- London, L. 1999. *(E-mail comments to E. Cameron on Dr. Nkosazana Dlamini-Zuma's proposal to make HIV/AIDS a notifiable disease in South Africa)*.
- Lurie, M. Migration and AIDS in Southern Africa: a review. *South African Journal of Science* **96**(6): 343-347.
- Lindegger, G. & Richter, L.M. HIV vaccine trials: critical issues in informed consent. *South African Journal of Science* **96**(6): 313-317.
- Mail & Guardian**. "Prison Aids policy on trial". July 28 to August 3 2000, p. 15.
- Mail & Guardian**. "R800m to let Aids babies die". July 21 to 27 August 2000, p. 5.
- Martin, D. 1998. "HIV/AIDS and violence against women". *(Unpublished paper delivered at a seminar on HIV/AIDS, August 12, 1998 by Tshwaranang: Legal Advocacy Centre to End Violence against Women)*.
- McIntyre, J. & Gray, G. 2000. Antiretroviral treatment to prevent mother-to-child-transmission of HIV-1. *South African Journal of Science* **96**(6): 277-280.
- Melum, M.M. "Balancing information and privacy". *Hospital Progress* **58**(July 1977): 68-69.
- Nel, J.T. 1995. *Core obstetrics and gynaecology*. Pietermaritzburg: Butterworth Publishers.
- Nussbaum, M.C. & Sen, A. 1989. "Internal criticism and Indian rationalist traditions", in M. Krausz (Ed.), *Relativism: Interpretation and Confrontation*. Notre Dame: Notre Dame University Press.
- O'Grady, F. Lambert, H. Finch, R. & Greenwood, D. (Eds.). 1997. *HIV and AIDS in antibiotic and chemotherapy*, 7th Ed. Edinburgh: Churchill Livingstone Publishers.
- Olowo-Freers, B. 1992. *Socio-cultural aspects of sexual behavioural practices that contribute to the transmission of HIV/AIDS in Uganda*. Kampala: UNICEF.
- Overberg, K.R. (Ed.). 1994. *AIDS, Ethics and religion*. New York: Orbis Books.
- Pierce, C. & van de Veer, D. (Eds.). 1987. *AIDS: Ethics and public policy*. Belmont: Wadsworth.

- Schoub, B.D. *et al.* 1988. Epidemiological considerations of the present status and future growth of the acquired immunodeficiency syndrome epidemic in South Africa. *South African Medical Journal* 74(4): 153-157.
- Schoepf, B.G. 1992. *Women at risk: Case studies from Zaire. In the time of AIDS: Social analysis, Theory and method.* Beverly Hills: Sage 1992: 259-286.
- Sidley, P. 1999. "South Africa plans to make AIDS a notifiable disease". *British Medical Journal*. May 1999, 318(7194): 1308.
- Singer, P (Ed.). 1997. *A companion to ethics.* Oxford: Blackwell Publishers.
- Strauss, S.A. 1991. *Doctor, patient and the law*, 3rd Ed. Pretoria: Van Schaik.
- Steere, J & Wassenaar, D. 1985. *Ethical principles of clinical psychologists.* Stellenbosch: Universiteit Uitgewers.
- Sue, D., Sue, D. & Sue S. 1990. *Understanding abnormal behaviour*, 3rd Ed. Boston: Houghton Mifflin Company.
- Sunday Times.** 2000. "Health minister ducks AIDS question- and thereby answers it: Respected academic versus the government on key issues around the epidemic", 4 June 2000.
- Sunter, C. 1998. *Home truths: what we've got to do!* Cape Town: Tafelberg Publishers Ltd.
- The Constitution of the Republic of South Africa.* 1996.
- Thornton, S. & Catalan, J. 1993. Preventing the sexual spread of HIV infection – what have we learned? *International Journal of STD & AIDS* 1993; (4): 311-316
- UNAIDS. 1998. Global summary of the HIV epidemic: AIDS epidemic update. *December 1998 World Health Organisation*
- United Nations Development Project. *UNDP report AIDS impact 1998.* Geneva: UNDP Press.
- Universal Declaration of Human Rights. *JAMA* 1998, 280: 469-470.
- Update: transmission of HIV infection during an invasive dental procedure-Florida. *JAMA* 1991, (265): 563-568.
- Van den Berg, R.H. & Viljoen, M.J. (Eds.). 1994. *Communicable diseases: A nursing perspective.* Pretoria: Sigma Press.
- Van Hoose, W.H. & Kottler, F.A. 1985. *Legal issues in counselling and psychotherapy.* San Francisco: Jossey-Bass.
- Van Niekerk, A.A. (Ed.). 1991. *AIDS in context: A South African perspective.* Cape Town: Lux Verbi.

- Van Wyk, A. 1991. *The legal implications of AIDS*. In A. van Niekerk (Ed.), *AIDS in context: A South African perspective*. Cape Town: Lux Verbi.
- Webber, L.M., Richards, P.A. & Grey, S.V. 2000. HIV prophylaxis: are South African health-care students being neglected? *South African Journal of Science* **96**(6): 296-296.
- Weekly Epidemiological Record. 1991. *Acquired immunodeficiency syndrome: AIDS data as at 1 June 1991* **66**(23): 165-166.
- Whiteside, A & Sunter, C. 2000. *AIDS the challenge for South Africa*. Cape Town: Human & Rousseau Ltd.
- Wilkinson, D. & Davies, G.R. The increasing burden of tuberculosis in rural South Africa: impact of the HIV epidemic. *SAMJ* 1997, **87**: 447-450.
- World Health Organisation Fact Sheet Number 242 – June 2000. *Women and HIV/AIDS*.
- World Health Organisation & Global Programme on AIDS: Effective Approaches to AIDS Prevention. *Report of a Meeting*. Geneva: WHO/GPA, May 1992.