THE IMPACT OF CONFIDENTIALITY ON HIV AND AIDS TRANSMISSION IN GREATER MAFIKENG SUB- DISTRICT

RESEARCH

BY

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DEDICATION

I would like to dedicate this dissertation to my children Letlhogonolo, Malebo and Matlotlo, my parents Lesegonyane and Dipuo, for their love, support through difficult times and their encouragement that made this research project a success.

DECLARATION

I declare that:

THE IMPACT OF CONFIDENTIALITY ON HIV AND AIDS TRANSMISSION IN GREATER MAFIKENG SUB-DISTRICT

Is my work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete reference.

M.Y. MOKGALAGADI

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ABSTRACT

THE IMPACT OF CONFIDENTIALITY ON HIV AND AIDS TRANSMISSION IN GREATER MAFIKENG SUB-DISTRICT

INTRODUCTION

Confidentiality in the HIV and AIDS field is a controversial issue. Health care professionals are ethically and legally required to keep all information about their patients and clients confidential. Any information about the patient or client's illness or treatment can only be divulged to another person with the patient's or client's consent.

Although South Africans generally know about HIV and AIDS, many do not perceive themselves to be at risk, and are not willing to accept the link between high-risk behaviour and actual HIV infection. The problem arises when the patient or client tests HIV positive and refuses that his or her partner be informed, and at the same time, there is no guarantee that safe sex will be practised, instead, new people will be infected in the process, as some indicate that "they will not die alone".

It is clear that not everyone infected with HIV takes all the necessary steps to protect others or themselves.

The study investigates whether confidentiality facilitates HIV and AIDS transmission or not.

The study used descriptive research design and quantitative research method because of the complexity of the subject matter.

Data was collected by asking close-ended questions where respondents could answer with regard to issues of confidentiality and HIV and AIDS. The population for the study composed of both male and female clients and patients in Voluntary Confidential Counselling and Testing (VCCT) sites, in Greater Mafikeng Sub-district. The sample of 200 was chosen from patients and clients aged from fifteen years and above, at VCCT sites (100), including the general practitioners consulting rooms (40) and home-based care settings (60). Tables, graphs and percentages were used in the analysis of data.

The study confirmed that, there is facilitation of HIV transmission by maintaining confidentiality and not disclosing HIV status to sexual partners and significant others. However, some HIV positive respondents wanted to disclose their status but were prohibited by fear of the reaction of significant others as well as sexual partners, thus making them to continue with their sexual life as if all is well.

Recommendations emerging from the study deal with aspects which include among others, re-looking at the confidentiality clause and extending to other categories of health professionals involved with counselling patients and clients around HIV and AIDS, formal authority to inform sexual partners of patients and clients about their HIV positive status.

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LIST OF ABBREVIATIONS

AIDS - Acquired Immune Deficiency Syndrome
AMREF - African Medical Research Foundation
CBO - Community-based Organization
DPSA - Department of Public Service Administration
HBC - Home-based Care
HIV - Human Immune-deficiency virus
HST - Health Systems Trust
MRC - Medical Research Council
NDOH - National Department of Health
NGO - Non-Governmental Organization
PLWHA - People Living With HIV and AIDS
PMTCT - Prevention of Mother-to-Child Transmission
STATSSA - Statistics South Africa
STI - Sexually Transmitted Infections
UN AIDS - United Nations on AIDS
VCCT - Voluntary Confidential Counselling and Testing
WHO - World Health Organization

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CHAPTER 1

INTRODUCTION AND BACKGROUND OF THE RESEARCH PROBLEM

1.1 INTRODUCTION

According to Statistics South Africa, hereafter referred to as Stats SA, 2001, the South African population was estimated to be about 44 819 782. With HIV and AIDS, the growth rate will fall from 1, 7% to 1.5% by 2010, with the population reaching 47 million. There are about 4,7million South Africans who are HIV infected at present. The irony is that whatever social and democratic goals South Africa may have achieved in the post-apartheid years; these probably will be threatened as the disease becomes fully blown out of proportion. There is so far too much silence and denial surrounding HIV and AIDS and the issue of confidentiality in the country is exacerbating the problem.

Although South Africans generally know about HIV and AIDS, many prefer to treat it with the utmost secrecy, and are not willing to accept the link between high-risk behaviour and actual infection.

Statistics show an increasing number of AIDS orphans where one of the contributing factors is that some women fall pregnant, because they are not informed of the partners' status. Post delivery, they die and leave infected children.

1.2 STATEMENT OF THE PROBLEM

Confidentiality in the HIV and AIDS field is a controversial issue. It is a moral dilemma where a counsellor often becomes involved in endless debates about the rights of HIV infected individuals as opposed to the rights of their sexual partners and the rights of the community in general.

Health care professionals are ethically and legally required to keep all information about their clients or patients confidential. Any information about their clients or patients' illness or treatment can only be divulged to another person with the patient's consent. Because people living with HIV and AIDS often face discrimination and prejudice, it is even more important to keep the information of their infection confidential, sometimes to the detriment of others.

The HIV and AIDS pandemic has given rise to a vast array of ethical, moral and legal issues. In relation to this Van Dyk (2001: 22), explains that "although we need laws that will guide us to make the right decisions about people living with HIV and AIDS, we should be guided as we attempt to do the right thing, not so much by various laws (however valuable they may be), but by our own common sense, our own ethical and moral values, our own compassion and our basic respect for human rights and dignity of all people". On the other side of the coin, practitioners are faced with issues of human rights where it is indicated that every individual has a right to determine his fate. This controversy normally leads to situations where innocent people end up being infected. This is because health care practitioners cannot force patients to bring in their partners for testing. If a patient refuses to bring in the partner, the health care practitioner does not have the right to health practitioners inform the partner. The worst scenario is those patients that prefer not to have their sexually transmitted infections treated at public clinics or health centres because they avoid being told to bring in their partners. This is the category that resort to traditional or no treatment at all. This is confirmed by Van Dyk (2001: 22) indicating that more than 70% of people prefer traditional health practitioners as their first care-givers. The reason for this being that, they will not be required to bring along their partners for treatment.

The danger is that those clients that choose no treatment eventually come to a health facility in an advanced state of complications, and in the process of consultatiion, it will come to the attention of the counsellor that safer sex has not been practised. The problem arises when the client or patient tests positive and refuses that his or her partner or significant others be informed, and at the same time, there is no guarantee that safer sex will be practised. This situation may lead to new people being infected in the process, as some, from professional experience normally indicate that "they will not die alone". It is this controversy that prompted the researcher to investigate the impact of confidentiality on HIV and AIDS transmission.

1.3 AIM AND OBJECTIVES OF THE STUDY

The aim of the study is to explore the impact of confidentiality on HIV and AIDS transmission.

Objectives are more specific, measurable explanation of the aims. Aims enable the researcher to determine whether the problem has been solved and what recommendations are made. Uys and Basson (1998: 28), on the similar issue, De Vos (1999: 6) explains objectives as the end toward which effort or ambition is directed. Objectives are therefore steps to be taken, one by one, realistically at grassroots level, within a certain time span, in order to attain the dream.

The objectives of the study are as follows:

1.3.1 To explore the concept and regulations regarding confidentiality with regard to HIV and AIDS

1.3.2 To determine the impact of confidentiality in the spread of HIV and AIDS

1.4. HYPOTHESIS/ ASSUMPTION

The hypothesis is defined as a tentative prediction or explanation of the connection between two or more variables. The function of a hypothesis is to guide the scientific investigation (Polit and Hungler 1983: 102). As the study is exploratory and quantitative in nature, a hypothesis will not be utilised, instead the study will use assumptions.

An assumption is what one thinks to be true without proof. The assumption for the study is as follows; lack of regulations to compel clients to reveal their positive HIV status to partners facilitates or contributes to the rapid spread of the disease.

1.5 SIGNIFICANCE OF THE STUDY

According to De Vos (1998: 103), there are three broad aspects that contribute to the usefulness of the study and they are explained below:

- The study must contribute to knowledge;
- The relevant policy arenas should find usefulness and meaning in the study; and
- The study must be useful to practitioners

Based on the above, the study will endeavour to do the following:

- Answer the question of whether confidentiality encourages HIV and AIDS transmission or not;
- Promote the theme "knowing liberates" and facilitate informed decision-making; and
- Inform policy-makers about the controversy surrounding confidentiality

1.6 LIMITATIONS OF THE STUDY

- The study cannot be generalised to the whole of North West Province as it is concentrated only in the Greater Mafikeng Sub-district.
- Due to lack of financial resources, the researcher focused only in the public clinics, available private practitioners and home-based care, because of their convenience and proximity;
- Sensitivity of the study serves also as a limitation as not all people living with HIV and AIDS were willing to participate in the study; and
- Hospitalized or admitted patients were excluded from the study.

1.7 DELIMITATION OF THE STUDY AREA

1.7.1. Demographic profile and infrastructure

The North-West Province comprises 9.5% of the total land area of South Africa and 8.3% of the total South African population, with a majority being of Tswana descent (these and the following figures are taken from the South African Health Review, 1998). The population density is 28,8 persons per kilometre square compared with Gauteng with 432 persons per kilometre square. In 1996, 65.1% of the population in the North West Province were classified as rural and 34.9% as urban, which makes the North West Province the province with the second lowest degree of urbanization, after the Northern Province, with an 11% urban population.

North West Province is divided into four districts viz Bojanala, Bophirima, Central and Southern. Focus will be on the Mafikeng sub-district in the Central district as the area where the study was undertaken.

1.7.2 Central District

The Central District is one of the four (4) districts that form the North West Province. It is mostly rural and has farming communities, and it is densely populated.

Mafikeng sub-district which forms part of the Central District, covers an area of approximately 6 315sq/km. It is centrally situated to the other sub-districts namely, Tswaing, Greater Ditsobotla, Ratlou and Zeerust.

Mafikeng Sub-district is predominantly 80% rural and 20% urban. According to 1996 census population, the sub-district has a population of 255 658.

For the purpose of administration and management, the sub-district is divided into five (5) community health areas, namely:

- Montshioa Stadt;
- Modimola;
- Unit 9;
- Ramatlabama; and

- Setlakgobi

1.7.3 Health facilities

Community Health Centres	**Clinics**
Montshioa Stadt	Magogwe
	Dithakong
	Rapulana
	Mafikeng Gateway
	Matlhonyane
	Danville
	Montshioa Stadt mobile
Modimola	Mmasutlhe
	Lekoko
	Tshunyane
	Gelukspan Gateway
	Weltevrede
	Modimola mobile
	Gelukspan mobile
Unit 9	Motlhabeng
	Mocoseng
	Mogosane
	Montshioa Town
	Matshepe

Ramatlabama	Lokaleng
	Tsetse
	Lonely Park
	Miga
	Tlapeng
	Ramatlabama mobile
Setlakgobi	Loporung
	Tshidilamolomo
	Setlagole
	Madibogo
	Tshidilamomlo mobile

1.8 DEFINITION OF CONCEPTS

1.8.1 AIDS

AIDS stands for Acquired Immune Deficiency Syndrome. This acronym emphasizes that the disease is acquired and not inherited. The virus that invades the body, attacks the body's immune system and makes it so weak that it is unable to protect the body from both serious and common infections and pathogens that cause it (Van Dyk 2001: 424).

1.8.2 HIV

The human immuno virus, the virus that causes AIDS (Van Dyk 2001: 424).

1.8.3 ART

ART stands for Anti-retroviral therapy - Drugs which suppress or prevent the replication of HIV in the cells. (Van Dyk 2001: 424).

1.8.4 HIV antibody positive

HIV antibody positive means that the antibodies to HIV are present in the blood stream – an indication that the person concerned has been exposed to (and is therefore infected with) the HI Virus (Van Dyk 2001: 424).

1.8.5 Confidentiality

Confidentiality means the handling of information in a confidential manner. Sieber (1982:145) views confidentiality as a continuation of privacy, which refers to agreements between persons that limit others' access to private information.

1.8.6 Transmission

Transmission is the action or process of passing on from one place to another, Concise Oxford English Dictionary, (2002: 1524).

1.8.7 Privacy

Privacy is defined by De Vos (1998: 26) as "that which normally is not intended for others to observe or analyse". Singleton, R. Straits ,B.C., Straits, M.M. & McAllister, R.J.(1988: 454) further explain that "the right to privacy is the individual's right to decide when, where , to whom and to what extent his or her attitudes, beliefs and behaviour will be revealed".

1.8.8 Disclosure

Disclosure is making secret or new information known,(Concise English Oxford Dictionary, 2002: 408).

1.8.9 Dilemma

Dilemma is a situation where one has to choose between two or more possible actions, each of which will bring difficulties (Oxford School Dictionary). Spradley (1991: 126) gives another definition of dilemmas as situations of ambiguity and conflict with equally unattractive alternatives for choice, decision-making and action.

1.8.10 Stigma

Stigma is undesirable attitude that is deeply discrediting and reduces a person's status and worth in the eyes of society. The underlying causes of this stigma are ignorance, lack of knowledge, irrational fears, societal prejudices and equating HIV and AIDS with death and dying (Bloor 1995: 6).

1.8.11 Ethics

Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behaviour expectations about the most correct conduct towards experimental subjects/respondents, employers, sponsors, other researchers, assistants and students (De Vos 1998:24).

Muller (2002:92) defines ethics as the study of human behaviour in respect of what is considered to be right/wrong in terms of moral judgements. It is therefore the science of morality (moral philosophy), which guides a person's judgement of a moral act.

1.8.12 Patient or client

A patient is a person who is ill or who is undergoing treatment for disease, (Dorland's Illustrated Medical Dictionary 1988:1242). A client is defined in the Concise Oxford English Dictionary (2002: 267), as a person using the services of a professional person or organization. More often, a patient and client are used interchangeably. In this context, a client may not necessarily be ill, but attends a preventative service like family planning or counselling, as examples.

1.9 RESEARCH METHODOLOGY

Methodology is explained as the way in which we proceed to solve problems, i.e. the research process (De Vos 1998:37). Silverman (2002:88) defines methodology as a general approach to studying research topics. Mason (1996:19) further explains that, in this sense, the choice of method should reflect an "overall strategy" as the methodology shapes which methods are used and how each method is used.

1.9.1 Research Design

Uys and Basson (1998:37), define research design as the total strategy for the study, from identification of the problem to the final plans for collection of data. Huysamen (1993:10) on the other hand, defines research design as "the plan or blueprint according to which data are to be collected".

From these quotations, it can be seen that the research design is the guideline within which a choice about data collection methods has to be made, and data collection methods are the ways in which the data are actually obtained.

The study used descriptive research design. This was chosen, as there is limited knowledge about the topic. The exploratory research is the extension of descriptive research and is more directly orientated towards the discovery of relationships. The purpose of such exploration is to gain more insights into the domain phenomena, and to extend a preliminary investigation into a more structured study, to elucidate central concepts and constructs, to determine the priorities for further research and to develop new hypotheses in respect of an existing phenomenon. Exploratory studies are aimed at gaining insight and understanding the impact of confidentiality on HIV/AIDS transmission.

Quantitative research method was used because of the complexity of the subject matter. De Vos (1998: 241) describes quantitative research as a deductive form of reasoning used by researchers.

1.9.2 Methods of data collection

Data collection methods are the ways in which data are actually obtained, De Vos (1998: 82). The following methods of data collection were used:

1.9.2.1 Literature study

A thorough study of literature is essential for all kinds of research. The purpose of literature study is, among others, to become aware of what has already been done, thus assisting the researcher to develop the ability to identify and isolate the significant and relevant facts, Uys and Basson (1998: 17).

1.9.2.2 Questionnaires

De Vos (1998: 290), describes a questionnaire as an instrument with open or close ended questions or statements to which a respondent must react. For the context of this study, it is mentioned as a qualitative data collection method. Uys et al, (1998; 65), explain that the questionnaire is always structured and questions are arranged in a definite order according to the researcher's choice. It may consist of close -ended or open-ended questions. In close-ended questions, a series of possible answers are given, from which the respondent must make his choice. In an open-ended question, a person can formulate his own answers.

For the purpose of this study, close-ended questions were asked where participants could answer with regard to issues of confidentiality and HIV and AIDS.

1.9.3 Sampling

Walker (1985: 22) defines population as a total set of things under consideration for some purpose. Williamson, (1981: 171), further describes the accessible population as the aggregate of cases that conform to the designated criteria and which is accessible to the researcher as a pool of subjects for a study. These concur with Polit and Hungler (1999: 278), who define a population as a group whose members possess specific attributes that a researcher is interested in studying.

The population for the study composed of both male and female clients and patients in Voluntary Confidential Counselling and Testing sites, hereafter referred to as VCCT, in Greater Mafikeng Sub-district, who visit the sub-district health clinics, for the purpose of receiving health care. This population is accessible to the researcher as she is an employee.

A sample is therefore defined as a small portion of the total set of objects, events or persons that together comprise the subject of the study, Seaberg (1988: 240). Sarantakos (2001: 139) in De Vos (2002: 199), state that the major reason for sampling is feasibility. A complete coverage of the total population is seldom possible, and all the members of the population of interest cannot possibly be reached.

Silverman (2002: 102) identified the purpose of sampling as to study a representative sub-section of a precisely defined population in order to make inferences about the whole population. A sample is further defined as a subset of objects drawn from a population.

The sample was chosen from patients and clients, aged from sixteen (16) years and above, who came to test for HIV in a given VCCT site, including the general practitioners' consulting rooms, where there are support groups for HIV and AIDS patients and home-based care settings.

1.9.3.1 Sample size

A sample of 200 clients and patients (n=200) was chosen from the clinics in the five health areas (100), as well as in the home-based care settings (60) and private practitioners' support groups (40). The following non-probability sampling techniques were used:

- **Purposive sampling**

Purposive sampling is described as by Singleton, Straits, and McAllister in De Vos (2002: 207), as based on the judgement of the researcher, in that a sample is composed of elements that contain the most characteristic, representative or typical attributes of the population.

Purposive sampling was used to select a sample. As the topic has a sensitive nature and ethical issues associated with it, the researcher decided to purposively select only those participants who were willing to give information.

- **Snowball sampling**

Snowballing involves approaching a single case that is involved in the phenomena to be investigated, in order to gain information on the similar persons. The researcher proceeds in this way until he or she had identified a sufficient number of cases to make up a sample, De Vos (2002: 208). This was done in the general practitioners' consulting rooms where support groups were established.

- **Accidental Sampling**

De Vos (2002: 208) explains "we simply reach out and take the cases that are at hand, continuing the process until the sample reaches a designated size. Any case that happens to cross the researcher's path and has anything to do with the phenomenon is included in the sample until the desired number is obtained". On the other hand, McBurney (2001: 246), calls this type of sample a convenient or availability or haphazard sample, and adds that the respondents are usually those who are nearest and most easily available. This type of sampling was implemented at the VCCT sites identified, sometimes simultaneously with purposive sampling, and at different home-based care settings.

1.9.4 ANALYSIS OF DATA

Statistical package for social scientists was used to analyse the data. After the details were captured, descriptive statistics was used, which its use is explained by Polit and Hungler (1999: 439), as to describe and synthesize data. Averages and percentages that were used are examples of descriptive statistics.

1.9.5 ETHICAL ISSUES

Ethics are concerned with the rules and principles that would harmonise the aims and desires of all men. Since human beings are the subjects of this study, in the social sciences, this brings its own unique ethical problems to the fore, which would never be relevant in the pure, clinical laboratory settings of the natural sciences (De Vos 1998: 23).

According to the ethical standards for Nurse Researchers (Nursing Update: 2002), which serve as criteria for the judgement of all proposed research projects wherein patients/ clients would be the study subjects, all the standards thereof were adhered to in this study, through the following strategies:

- Justice: all the respondents were treated with respect and fairness, without prejudice, for example, their socio-cultural or political status were not interfered with.
- Beneficence: no respondent was exploited in any way, nor harmed and even be exposed to any discomfort, physically, emotionally and psychologically.
- Confidentiality and anonymity were highly maintained

1.9.5.1 Confidentiality and anonymity

Confidentiality entails that no information provided by the client or patient should be divulged or made available to any other person.

The researcher ensured that the anonymity of any person or institution was protected. It was assured due to the fact that respondents' names were not filled in the questionnaires, and only clients that were willing to be open about their status were included in the study.

1.9.5.2 Privacy

Privacy means that a person can behave and think as he or she pleases without interruption and without the possibility that private conduct or thoughts may later be misused to embarrass the client or patient. The researcher took the necessary precautions to ensure that the self-respect and dignity of the clients or patient were maintained, by conducting interviews in privacy.

1.9.5.3 Informed consent

This is explanation and full disclosure given to the respondents on the purpose and objectives of the study and how the study will be conducted.

The research project was explained to all respondents in order to get informed consent. This is the principal mechanism for ensuring that individuals' rights are respected. The participant agrees in writing where possible, to participate as a subject in the research project and that this decision is made with adequate knowledge of potential and real risks or benefits. Informed verbal consent was obtained from all participants.

1.9.5.4 Trust

The trust between the researcher and respondents is vital throughout the whole project. The respondents provide valuable information if trust is maintained at all times. Trust is maintained by following all ethical considerations for health research, such as respect, acceptance, non-judgemental attitude and allowing patient and client self-determination.

1.9.5.5 Withdrawal and termination

Respondents were informed that if they felt uncomfortable at any stage of the project, they were allowed to withdraw from the project. The research should be terminated if an individual person chooses to withdraw, regardless of the fact that he/ she initially agreed to participate or the project is no longer proceeding with the standards set during its planning (Uys and Basson1985: 100).

The rights of the respondents were respected with regard to self-determination and freedom of choice. There was no victimisation or coercion by the researcher.

1.10 CONCLUSION

HIV infection remains and continues to be a challenge to national communities, households and economies. The confidentiality in HIV and AIDS is quite a complex issue. In addition to these complex issues, there are practices in the homes and within the health institutions, which comprise confidentiality in the prevention, management and care of HIV and AIDS.

It is a known factor that the principles of confidentiality are protected by the Constitution and it is so that it was designed to protect the citizens of the country beyond the HIV status. Much as this is appreciated, confidentiality dilemmas and disclosure present a number of problems and challenges.

1.11 STRUCTURE OF THE REPORT

Chapter 1: General orientation of the study and methodology

Chapter 2: Literature review

Chapter 3: Analysis and interpretation of data

Chapter 4: Findings, recommendations and conclusion

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

A common problem experienced in many countries in addressing the HIV and AIDS epidemic is that people often avoid learning or admitting to being infected with HIV because of the stigma attached to the disease and fear of discrimination. Such avoidance limits diffusion of knowledge about HIV in the general population and increases the risk of transmission to loved ones and others.

Stigma and discrimination often follow when HIV status is disclosed hence confidentiality. Voluntary Confidential Counselling and Testing (VCCT) is done with informed consent and clients need to be confident that the results will remain private. In turn, HIV positive individuals have a responsibility to notify spouses and / or sexual partners. However, this is not always the case.

Literature review is aimed at contributing towards a clear understanding of the nature and meaning of the problem that has been identified, by enabling a person to acquaint himself with the range and depth of scholarly and professional activity that exists within the general area in which the problem falls, as well as identifying some deficiencies in previous research (De Vos 1998: 64).

Uys and Basson (1998: 20), identify two kinds of literature review as (a) conceptual literature review, which helps the researcher to assess and appreciate the correctness or validity of theories, and also reveals gaps in existing knowledge in a particular field, and reveals significant points of departure for research or areas of research which may be linked to the researcher's current research and (b) research literature, which includes reports on research that has already been adequately completed in a particular field and highlights issues that have already been adequately demonstrated and proved in a particular field, and those matters that call for further research. For the purposes of this study, literature review will focus on the above.

2.2 CONFIDENTIALITY AND RELEVANCE TO THE STUDY

2.2.1 What is confidentiality?

Bok in Callahan (1988: 231) explains that confidentiality refers to the boundaries surrounding shared secrets and to the process of guarding these boundaries. The word confidentiality has by now become a means of covering up a multitude of questionable and often dangerous practices. In the context of this study, it means that some people engage in dangerous sexual practices without using any protective measures and end up with HIV infection. As a result of the nature of this diagnosis, they then pass it on to unsuspecting partners, knowing that they will not be notified unless they give consent. It is upon their decision whether to protect or infect others.

2.2.2 Confidentiality circle

A circle of confidentiality consists of those people with whom the confidential information can be shared without breach of confidentiality (Brown, Kitson and McKnight, 1992: 92). Where there is a good reason to disclose information beyond the circle of confidentiality, there may be an opportunity to obtain the patient's consent.

2.2.3 Importance of confidentiality

The following elements in the table 2 below, outlined by Brown et al (1992: 94), highlight the importance of confidentiality in HIV and AIDS:

Table 2: The importance of confidentiality

ELEMENT	DESCRIPTION
Consequences	The practice of keeping personal information about patients and clients secret may have good consequences. This makes people more likely to present themselves for health care when they need it and more likely to be open in giving health care professionals the necessary information. On the other hand, information that is kept confidential may be detrimental to other unsuspecting partners.
Information is property	Personal information is a kind of property. The right to personal property is regarded by many as a fundamental human right. Confidentiality is important because intimate information about oneself is an especially personal kind of property, only as far as it does not hurt other people.

Confidentiality is decency	Maintaining confidentiality is important because it is the prevention of the indecent exposure of private information, however, it is indecent to knowingly spread the virus and violate other people's rights to life or health.
Confidentiality is privacy	Maintaining confidentiality is a way of protecting a person's privacy. Privacy in turn is important because there is a profound human need for it. On the contrary, breaches of confidentiality and privacy cause distress, particularly to health care professionals, in the same way as maintaining confidentiality and privacy, and the process, the cycle of infection and re-infection continues.
Confidentiality as respecting persons	Respecting a person's autonomy involves respecting those choices hence having reason to treat as intimate and private those things that, in the person's chosen way of living, are intimate and private. However, the right and respect of the other party must be taken into consideration.

If confidentiality is appreciated, an individual's rights would not be violated, though the argument is that this is done at the expense of unsuspecting significant others. If environment, especially socially, could benefit those infected and those affected, the spread would be somehow controlled.

2.3 HIV AS INTERTWINED WITH SECRECY

Certain features about HIV infection conspire to make it be intertwined with secrecy. As indicated below:

- HIV can be hidden, i.e. HIV has no telltale signs until it has developed into AIDS;

- HIV can be hidden for many years, during which the person with it may infect a large number of people;
- HIV is infectious. More importantly, the mechanism by which it is spread means it tends to be linked to practices that are publicly condemned, but privately practised; and
- HIV infection cannot be eliminated from the body and is associated strongly with the unpleasant terminal syndrome AIDS.

As HIV antibody testing must occur only with free and informed consent, persons who test HIV positive should have access to continuing support and health services. At the same time, persons with HIV or AIDS have the right to confidentiality and privacy concerning their health and HIV status, as information regarding their positive HIV status must not be disclosed without that person's consent. Even after death, except when required by law, consent of his or her family or partner must be solicited, except in cases of clear threat to and disregard for an identifiable individual's life interests.

The issue of confidentiality or secrecy becomes more apparent because most of the time the individual will be well. He or she continues living and working normally, and pretends that all is well. The problem crops up when the incumbent continues with his or her sexual relations without protecting his/ her sexual partner. This poses a dilemma to the health professional that is aware of the HIV status of the patient. The dilemma is caused by whether to disclose to the sexual partners or to keep quiet until the partners are also infected. It is because of this dilemma that most countries are experiencing a drop in life expectancy. By 2010, life expectancy in most of the Southern Africa countries is expected to be no more than fourty years. The scary part of it is that the pandemic is affecting those in their most economically productive years (HIV and AIDS Perspective 65: 2000).

It has been estimated that 4-6 million people are living with HIV and AIDS (South African Health Review 2003/4: 191). Based on the Ante-natal survey conducted in October 2002, 26% of pregnant women were HIV positive. Kwa-Zulu Natal was the province that recorded the highest HIV prevalence rate among Ante-natal care (ANC) attendees, with the rate of 36%. The province with the second highest prevalence rate among pregnant women was Gauteng (31%), followed by Free State (28%), Mpumalanga (28,6%), North West (26%), Eastern Cape (23,6%), Limpopo (15%), Northern Cape (15%) and lastly Western Cape (12.4%).

Young people, especially young women, are at high risk of HIV infection from partners who do not disclose their status. In a study conducted on herpes and HIV infection among youths in South Africa, published in Afro-Nets, the authors found, for example, an extremely increased prevalence of HIV among young women (34%) and men (9%) aged between 14-24 years from a township in the Carletonville district in North West. In this study, 41% of men and 42,5% of women reported never having used condoms irrespective of their status.

This confirms that young people can continue with their sexual life without any qualms because they are well aware that nobody can outwardly divulge their status. Because of the issue of Human

Rights that reinforce the fact that everybody has a right to confidentiality, health personnel find themselves trapped, as they cannot do anything to stop a particular person from spreading the epidemic. The least they can do is to advise, give counselling and assurance. More than that they are expected to remain lipped tight.

A study was conducted in China, indicating that HIV was first detected in young pregnant women who are nulliparous. Gradually it increased to older mothers, aged between 30-34 years.

In a study conducted in Kwa Zulu-Natal by Leclerc- Madlala in 1997, one of the frightening response by some youth, to finding out that one is infected with the virus was not just the acceptance of a death sentence but seeing it as a passport to sexual licence. The chilling comment of one twenty-four year old was: "You lose hope. You know that you will be rejected; you know you are going to die. All you can do is go off and spread it. It's your only hope knowing that you won't die alone". The study aimed to look at the reasons why the spread of HIV was accelerating amongst people under the age of 25. The study discovered a shocking mutation of Ubuntu, where infected youth deliberately seek to spread the infection as much as possible.

This shows that simply notifying people of their positive HIV status is not adequate intervention. The study above recommended that the attitudes and reported behaviour of those young people warrant consideration by all those involved in the AIDS prevention effort. In a similar effort, Winiarski (1997: 117), states that a study conducted by Cleargy in 1991, found that after a group of blood donors were notified of their positive serostatus, more than a quarter still engaged in unsafe sex. A counsellor or health professional will be in a dilemma as respecting the confidential nature of patient and client information helps build trust in the professional-patient relationship, however when the patient or client demonstrates attitudes and behaviours correlated with the risk of HIV infecting others, and the professional cannot notify sexual partners, this perpetuates the spread.

Parish, Mandel, Thomas and Gomprets cited in Winiarski, (1997: 118), allude that it is not known how often HIV infected people put someone else at risk, although studies have indicated that up to 40% might have unprotected sex after notification of their positive HIV serostatus. This may be happening because regulations on the notification of a positive HIV status were withdrawn by Government due the wide-spread resistance to such a step. People know that their HIV positive status will not be disclosed unless they give consent.

From the above information, it can be deduced that emphasis on confidentiality is two faced i.e. it can protect the rights of the infected and at the same time expose the innocent people to the virus, and thus contribute to the spread of the pandemic. Many decisions require balancing legal or health concerns against other clients' or patients' interests. This means that crucial professional decisions involve value choices. In most instances, partners know little or nothing about the risk they face, and not being able to talk with a partner directly is a barrier for the counsellor or health professional.

2.4 CONFIDENTIALITY AND SOCIO-CULTURAL FACTORS

Being HIV positive has a tremendous impact on the medical, psychological, social, spiritual, educational and economic life of the infected person, his or her affected others and the community as a whole. This means that the socio-cultural factors have an enormous impact on the issue of confidentiality and exposure to the HI Virus.
The World Health Organization (WHO: 1996), asserts that women are essentially at more risk in cultures that remove their control over their own bodies. Women are blamed incorrectly as the source of HIV infection and carry the dual burden of infection and caring for the infected family members. Further, women in some cultures have no right to ask their partners to use condoms even if they are aware that they have extra-marital affairs.

Cultural practices and pressures therefore prevent women from taking the necessary precautions to guard against infection. The cultural desire and social pressure to reproduce make it difficult for women to practise protected sex. For example, in the African culture, a wife or a woman in a relationship cannot insist on a condom and can also not determine for the husband not to make more babies because of HIV. On the other hand, the husband who is aware of his positive HIV status will pretend as if nothing is happening and continue with his sexual life.

Even after the diagnosis of HIV infection, most women will not change their reproductive choices. Although there are some reports of increased termination of pregnancy in HIV positive women, the majority of women will prefer to continue with the pregnancy. Thus knowledge of HIV infection has little effect on reproductive trends, (WHO: 1996). This is because the husband can continue with his sexual preferences without informing the wife or the partner, since there is no law that forces him to disclose to the wife. This may make him feel not obligated to confide in his own wife or partner. The syndrome that "I don't know where I got it from, so I will continue with my life as usual", still prevails. This is further exacerbated by the knowledge that nobody will tell until I give them permission to disclose.

Families, especially in times when members need all the comfort, peace and support they can get, often rely on women to ensure that they cope with the tragedy of HIV and AIDS. If it is the women themselves dying, what hope is there for those who need their tender care?

Socio-culturally women are disempowered to exercise their democratic and constitutional right to co-decide on matters relating to sex in partnerships. As a result, in cases where their partners are involved in reckless sexual behaviour, it is the women who are often exposed to risk.

Eversole, (1999: 265), emphasizes that it is important for the counsellor or health professional to understand the composition of the family and the dynamics of the relationships. However, this does not assist in anyway, only knowing what is going on but no formal authority to disclose the positive HIV status to the sexual partner of the patient or client, protecting confidentiality of the status but exposing innocent partners to HIV infection. This is an experience of many counsellors who are not medical practitioners.

2.5. Confidentiality and the Constitution of the Republic of South Africa Act No 108 of 1996

The issue of confidentiality emanates from the concern for human rights enshrined in the Constitution, which is the supreme law of the Republic of South Africa. Law or conduct inconsistent with it constitutes the violation of human rights, and the obligations imposed by it must be fulfilled.

The Bill of Rights, Chapter 2 of the Constitution, is a cornerstone of democracy in South Africa. It enshrines the rights of all people in the country and affirms the democratic values of human dignity, equality and freedom (Sub-section 7[1]). It further explains in sub-section (11) that everyone has the right to life.

Emphasis is put for the purpose of the study on sub-section 14(d), which emphasises that everyone has the right to privacy. The right to privacy is safe-guarded by the ethical and legal rules regarding confidentiality on the same token.

Sub-section 32(1) (b) states that everyone has the right of access to all information held by the state or any organ in any sphere of government in the exercise or protection of any rights. At the same time, a high standard of professional ethics must be promoted and maintained. High on the list of professional ethics is the issue of confidentiality and respect for all individuals.

Adherence to professional ethics becomes difficult for health professionals, if the partner insists that he or she is entitled to information of what is wrong with the other party. On the contrary, the law insists that information cannot be divulged to the partner, unless the patient gives consent. This at the same time is contravening the partner's rights to information, which can be useful to him or her to protect him or herself from further cycle of HIV infection. This eventually turns into a vicious circle with no beginning and end.

In an effort to abide by the Constitution, several policy regulations were put in place. These will be discussed hereunder.

2.5.1 Batho- Pele Principles

Batho-Pele means People First. It is the name of the government's programme for transforming its public service delivery from an inefficient bureaucracy with focus on the rules, to a culture of customer care, in which the needs of all citizens of South Africa are truly served, irrespective of their race, gender or creed. This programme is set out in the White Paper on Transforming Public Service Delivery (Government Gazette No: 18340, October 1997). There are eight guiding principles, and for the purpose of this study, only four will be emphasised, and outlined or explained in Table 3 on the next page.

Table 3: Batho-Pele Principles:

PRINCIPLE	EXPLANATION
1.Consultation	Citizens should be consulted about the level and quality of the public service they receive, wherever possible, should be given a choice about services that are offered. For HIV and AIDS, a patient must be consulted prior to disclosure of the diagnosis of a positive HIV status. He/ she must give informed consent to disclose or not to disclose.
2. Service Standards	Citizens should be told what level and quality of public services they would receive so that they are aware of what to expect. For HIV and AIDS, this means that pre- and post-test counselling services will be offered, with a particular time frame for results and continued support.
3. Information	**Citizens should be given full and accurate information about the public service they are entitled to receive. For HIV and AIDS, after the diagnosis or results, even before, people are informed about continuous counselling, programmes like prevention of mother-to-child transmission (PMTCT), Voluntary Confidential Counselling and Testing (VCCT), Anti-Retroviral Therapy (ART) as well as availability of resources e.g. social grants etc.**
4. Access	All citizens should have equal access to health services to which they are entitled. For HIV and AIDS, failure to disclose may disadvantage unsuspecting partners to access services timeously, e.g. testing and appropriate treatment.

The concept of Batho-Pele emanates from the Public Service Administration policies (DPSA 1997:22). It is an idea and a promise to the public, which had to be established to redress the public service standards in all public and private sectors of service delivery, for the benefit of the citizens of this country. In these principles, the consumer of any service must be given first priority in the service that is rendered.

The patient has a fundamental right to be informed of any health treatment and be able to make an informed decision in this regard. Everyone has the right to be given full and accurate information about the nature on one's illness, diagnostic procedures, the proposed treatment and costs involved, for one to make a decision that affects any of these elements. This is called ***INFORMED CONSENT***, which is further described by Van Dyk (2001: 423), as the kind of consent to medical testing or treatment that is accompanied by ***information and permission.*** On the contrary, the principle of informed consent does not take into consideration the rights of the partner to know or have access to information or diagnosis.

Medical records consist of information detailing what is known about the medical condition and history of patients. In this case, access to these records is somehow restricted to health professionals, who are obliged to keep all information confidential.

2.5.2 Patients Rights' Charter

For many decades the vast majority of the South African population has experienced either denial or violation of fundamental human rights, including rights to health care services.

To ensure realisation of the right of access to health care services as guaranteed in the Constitution of the Republic of South Africa (Act No 108 of 1996), the Department of Health is committed to upholding, promoting and protecting this right. For the purpose of this study, the following have been selected from the Patients' Rights Charter.

2.5.2.1 A healthy and safe environment

Everyone has a right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection. This is linked with the right to information, where a partner is not informed of what is wrong with the other partner, and the partner has not disclosed. The end result is that the partner will unknowingly get infected, as the cycle of HIV infection continues, there is no protection, and the partner is forever exposed to an unsafe environment.

Justice Edwin Cameron has been an activist for human rights for many years. In 1993 he founded the AIDS Law Project in the Centre for Applied Legal Studies (CALS), at Wits University. He has been diagnosed HIV positive in December 1986. It was only in 1999, after 13 years, that he disclosed or declared his positive HIV status known.

The underlying reason for his decision to go public was based on his involvement in the formulation of Public Policy on AIDS. In 1997, he fell ill with AIDS, but there was no question about being unable to do his duties just because he had HIV. **He had intense support and love from family, friends and colleagues** (HIV and AIDS Perspectives 2000: 76). These are elements that are expected in the environment that make it easier for people to disclose.

2.5.2.2 Participation in decision-making

Every citizen has the right to participate in the development of policies and decision-making on matters affecting one's health. People have good knowledge of HIV and AIDS, how it is spread and how it can be prevented, but often fail to act on this knowledge. Prevention of HIV and AIDS is fundamentally dependent on sexual behaviour (Lovelife 2004). Despite considerable efforts aimed at public education about the risk of HIV and AIDS, ***HIGH RISK SEXUAL BEHAVIOUR REMAIN THE NORM***. The issue of confidentiality deprives the partner of the diagnosed partner to make decision about her or his sexual life.

The fact that the diagnosed patient is normally given indefinite time to decide to disclose, can constitute danger to the other partner. In the process of making up his or her mind, the other partner may demand sexual intercourse. Fear may make the affected partner not to insist on the condom, especially if the condom has never been a norm. This is even worse in the case where the infected party is a woman or wife.

African women are considered to be at least 1.2 times more likely to be infected with the virus than African men (UNAIDS and WHO 2003). The impact of HIV and AIDS and access to treatment are markedly different for men and for women. Typically, women are more stigmatised and discriminated against, often being denied access to health care services, especially if they present for diagnosis or treatment of STIs without a male partner (International HIV and AIDS Alliance 2002a).

According to Ntuli, Padarath, McCoy and Berthiaume (2003), the epidemic is fuelled among women for a number of reasons. Many women exchange sex for material favours and as a means of daily survival.

2.5.3.3 Access to health care

Failure to disclose one's positive HIV status to the partner deprives the partner from seeking or accessing health care timeously. There will be delays and complications set in and little can be done for something that could have been prevented. This can be linked with Batho-Pele principles where failure to disclose one's positive HIV status to the partner and otherwise, will deprive oneself of available resources that can be of benefit to those infected and affected, like care and support, prevention of new infections etc., as HIV and AIDS are not merely medical problems, but require a broader multi-faceted response.

In a situation where there is no disclosure to the partner, the other unknowingly infected and affected partner will not be in a position to access health services, to be counselled and be able to share information around preventative measures and to alleviate further spread.

2.5.3 HIV and AIDS Charter

The HIV and AIDS Charter promotes the inclusion of PLWHA in the fight against HIV and AIDS which play a certain role in personalising the epidemic, and promoting destigmatisation of individuals, families and others affected by AIDS, UNAIDS (1999: 51).

The Charter further sets out those basic rights which all citizens must enjoy and which should not be denied to persons affected by HIV or AIDS, as well as certain duties. For the context of this study, the following aspects of the charter will be discussed:

2.5.4.1 Duties of persons with HIV or AIDS

At the Durban conference on AIDS, Nkosi Johnson alluded that "I want people to understand about AIDS –you can't get AIDS if you touch, hug, kiss, hold hands with someone who is infected. **Care for us and accept us** – we are all human beings. We are normal. We can walk, we can talk, we have needs just like everyone else – don't be afraid of us- we are all the same!" In these words Nkosi Johnson was trying to show that the community has a responsibility towards PLWHA, and also advocating that PLWHA have rights like any other person.

However, in as much as patients have rights, these go with responsibilities, e.g. it is the responsibility of the patient to check with their health care worker about confidentiality and advice about what may be disclosed to a third party.

It can be further emphasized and expanded that, in as much as PLWHA need to be cared for and accepted, they also have a duty to take care of others in their environment. However, this has not been the case, as evidenced by the new infection rates reported. Persons with HIV or AIDS have a duty to respect the rights, health and physical integrity of others, and to take appropriate steps to ensure this where necessary. When HIV people disclose, their teachers, care-takers, playmates etc, are in a better position to know how to handle them, like when they accidentally bleed.

If the person did not disclose, then, no precautionary measures would be taken and the other parties would be exposed to the risk of being infected. For example, if the child bleeds during play, whoever tries to assist and has a laceration, the likelihood is that that person will be infected by that blood through the laceration, if no protection like gloves were used. The same goes for relatives who are taking care of an HIV person at home. Most of them may be ignorant or be unaware of what is wrong with the patient, and not protect themselves. This is common where there is denial of the diagnosis or the patient did not disclose.

2.6 NOTIFICATION OF HIV INFECTION

The media response to people living with HIV has been varied, and often disempowering, as it overemphasises death and dying, emotive articles and headlines, and visual portrayal of people dying of AIDS. One of the central requirements of positively addressing the HIV and AIDS epidemic is to discourage the cloudiness and encourage open discussion of issues of sex and sexuality, as well as the nature of the disease progression and the associated complexity of disclosing one's positive HIV status (Palmary 2000: 4).

It is important to treat HIV and AIDS as a communicable disease like cholera and chicken pox, to encourage disclosure. Up to this point, it has not been made a 'notifiable' disease because of the stigma attached to it.

While HIV and AIDS do not discriminate, people still do, (www.aidsinfo.co.za). Palmary (2000: 7), indicates that advocates for the use of partner notification, state that it is of benefit to the public as it allows partners of HIV positive individuals to learn their HIV status early and reduce high-risk behaviours, as well as receive appropriate care if they test HIV positive. On the same note, critics of partner notification state that it violates the rights of the HIV positive individuals and expose them to stigmatisation and discrimination.

The reasons and implications, according to Van Dyk (2002: 413), of classifying a disease as notifiable, are to give medical and health care professionals the opportunity to do the following:

- Positively identify the disease as soon as possible;
- Treat patients; and
- Attempt to prevent the disease from spreading to other members of the community.

Regulations on the notification of HIV and AIDS disease and death were published for public comment by the South African Department of Health in 1999. Because of the widespread resistance to such a step and fears for the safety of HIV infected people, the Government decided in January 2001 to abandon the notification proposal.

UNAIDS and WHO encourage the appropriate use of HIV case reporting and suggest that HIV case reporting, including named HIV case reporting (i.e. the reporting to public health authorities of each individual identified as HIV positive), could provide accurate information on the spread of HIV, and allow effective action to prevent further infections and ensure access to care services. However, in resource-poor settings, certain conditions result in HIV case reporting not providing accurate data for surveillance purposes and does not result in better prevention and care. In such countries where such conditions exist, it is recommended that HIV case reporting not be carried out.

Notwithstanding, notifiability might however be useful because it might give health authorities an opportunity to suggest to infected people that they seek treatment to opportunistic infections and educate themselves about sexual behavioural changes (such as safer sex) as quickly as possible.

The argument is that ethical and medical principles are the same for HIV and AIDS as any other sickness. The problem with HIV and AIDS is that it gets to the root of social relationships and put other people or partners at risk.

This is confirmed by Bott 1986 in a letter to the editor of the British Journal, where a medical practitioner describes a situation in which he felt he had unnecessarily placed police at risk of HIV infection by not informing them of the HIV status of a violent patient when calling them to restrain him.

Van Dyk (2002: 414) argues that notification may simply drive people in need of care underground, as a way to escape punishment, stigmatisation and other negative consequences of having their status known. On the other hand, immediate disclosure may expose infected people to a wide range of available resources that may assist them to cope with their condition and not be isolated.

Currently there are still too many gaps in the process of making HIV and AIDS a notifiable disease in South Africa. Ways of addressing discrimination, as well as infrastructure required to be in place before AIDS can be made a notifiable disease, are being investigated. These need to include how notification will curb further spread and reduce the rate of new infections, but not violating human rights like confidentiality and privacy.

According to the International Guidelines on HIV and AIDS and Human Rights, Public Health Legislation should authorise, (on the basis of each individual case and ethical considerations), to inform patient's sexual partners of the HIV status of their patient. Such a decision should be made in accordance with the following criteria:

- The HIV positive person in question has been thoroughly counselled;
- Counselling of the HIV positive person has failed to achieve appropriate behavioural changes;
- The HIV positive person has refused to notify, or consent to the notification of his or her partner(s);
- A real risk of HIV transmission to the partner(s) exists;
- The HIV positive person is given reasonable advance notice;
- The identity of the HIV positive person is concealed from the partner(s) if this is practically possible; and
- Follow-up is provided to ensure support to those involved.

Suffice to say that such criteria or information is normally not made available to health professionals at grass-roots level, where there is a problem of communication in most health facilities, thus impacting on conveyance of important information timeously and implementing policies that have been developed. This therefore creates an information gap as some health professionals remain ignorant on new developments and therefore continue to adhere to the confidentiality clause irrespective of the danger involved.

According to UNAIDS and WHO (2000), particular concern has been expressed regarding the vulnerability of women to being infected by husbands or partners who do not know their status, or refuse to disclose it, or refuse to practise safe sex. This has led to calls to adopt policies such as named HIV case reporting, mandatory disclosure of status, and criminalizing the deliberate transmission of HIV.

The following case study is cited as an example of how confidentiality adds to the spread of HIV:

A 33-year-old unmarried urban Zambian woman died from AIDS related illness. Although she suspected that she was sero-positive after she discovered that her previous boyfriend had recently lost a wife and was himself sick, no tests were conducted to confirm her suspicion. However, she had a number of miscarriages and two infant deaths, with severe complications at one of the births. From this onwards, she was continually being treated for many opportunistic infections. When she became terminally ill, she was taken back to her parents in the village whom she had rarely visited while healthy. Her parents nursed her until her death (Caldwell 1999).

This means that the boyfriend knew that he was HIV positive but did not disclose to the wife and girlfriend, nor did he use any form of protection like condoms. As the wife was exposed to the same environment, she was continuously being infected, and due to socic-cultural pressures, could not negotiate condom use, irrespective of her suspicion. The girlfriend was in denial though she had a number of miscarriages that could have been investigated, as no disclosure was made. Most HIV positive women who are not on ART tend to lose their pregnancies, as they are not monitored.

Until her final days, her parents did not know what was wrong with her; one of them could have been infected during the time of nursing her, by not taking precautionary measures. This is how silence and confidentiality expand the infection to innocent people, irrespective of the mode of spread.

2.7 DISCLOSURE AND SILENCE

Disclosure of HIV positive status has been a source of controversy in the established literature from as early in the epidemic as 1983. Much of the focus has however, been on the disclosure by the third party such as health care worker to the sexual partner or significant others, and not advocating for disclosure by the patient or client to his or her sexual partner(s), looking at the most common mode of transmission.

For example, there has been a great deal of debate between the rights of the HIV positive person to privacy, and the duty of the health care worker to warn those who face possible infection from the patient (Kohn 1983), cited by Palmary (2000: 7). This is not always easy as the health care worker needs to keep information entrusted to him or her by the client or patient, however, predisposing other people to possible infection at the same time.

Nelson Mandela, at the closing ceremony of the Barcelona Conference in July 2002, indicated that many people suffering from AIDS are not killed by the disease itself, but are killed by the stigma associated with suffering from HIV and AIDS (Nursing Update November 2003: 31). This is because infected people prefer to remain silent about their status and therefore fail to avail themselves for proper treatment. As a result of silence and failure to disclose, stress and depression compromise the functioning and well-being of the individual in all areas of family life, work performance and relationships.

The Department of Health published an article on the "Living Openly Project" in 2000 in which it was discovered that disclosure is difficult because of the social stigma attached to it.

The intention of the project was therefore to give voice to the experiences of people in South Africa who have openly declared their HIV positive status and to encourage recognition that openness about HIV status is central to the fight against HIV epidemic.

In the "Living Openly Project", participants, according to Palmary (2000: 14), described their disclosure as something that gave them access to support, which in turn improved their physical and psychological well-being. In spite of evidence of rejection by some people, no participants regretted their decision to live openly. Living openly was seen as a way of influencing the public to internalise the risk of HIV infection and to provide support and assistance to those who are infected. It was also seen as a way to challenge stereotypes that blame the HIV positive person for their infection.

The fact that a patient's HIV and AIDS status is protected creates a dilemma for health workers. Health workers feel torn between patients and their loved ones, as they may not disclose a patient's HIV status to partners and families, without their consent. On the other hand by not disclosing the status, they cannot protect innocent people from the infection.

In a study conducted by the American Medical Research Foundation (AMREF) (2002: 19), on the impact of HIV on the households, about half of the households (n=366), reported that they were not aware that the index case was suffering from AIDS. Many other diseases were mentioned by those who were not aware of the HIV or AIDS diagnosis, the more commonly mentioned being TB and pneumonia, instead of HIV and AIDS.

In a similar survey, among AIDS affected households in four South African provinces (Free State, Mpumalanga, Gauteng and Kwa-Zulu Natal), family members were not aware that a person was suffering from AIDS, Health Systems Trust (HST), 2003/4: 204). The implication is that patients did not disclose their positive HIV status, and blame was shifted to other diagnoses. The repercussions are that relatives were ignorant and did not take precautionary measures when handling these patients at home. The other is that services that the patients could benefit from, were not optimally utilised, like ARVs and other social grants. Again, it also depends on the nature of the relationship. If that patient was in a relationship, the spouses or partners were exposed to the infection and were not aware of it.

In a study conducted in the mining community in Carletonville by African Medical Research Council (AMREF) in 2001, respondents answered all questions correctly about the risk factors for HIV infection. However, there was a weak relationship between perceived risk of infection and actual infection. Twenty two percent (22%) of those who thought that they were at low risk were already infected with HIV, compared with twenty nine percent (29%) who thought they were at high risk. The greatest barriers to achieving HIV prevention are fear, denial and ignorance. HIV prevention efforts have been plagued, above all, by **SILENCE**, resulting from stigma associated with the disease.

On the contrary, Van Dyk (2001: 125), reports that as recently as January 1999, the brutal killing of an HIV positive woman from Kwa- Mashu (Kwa-Zulu Natal), was reported in the South African newspapers: Gugu Dlamini was beaten to death by her neighbours for disclosing that she was HIV positive in December 1998. The critical issue according to Lie and Biswalo, 1994, is who should be informed and how. This showed an extreme act based on ignorance and the prejudice surrounding the disease, thus encouraging infected people to maintain silence.

Pieter Dyk Uys quoted in HIV and AIDS Perspectives (2000: 65), when empowering youth,: " secrecy is the enemy. We need to face this head-on, and we can't do that by hiding behind comfortable facades. HIV is not death. It is part of life".

There has been an investigation into the role that HIV and AIDS counsellors can play in encouraging partner notification as well an investigation into the factors that facilitate disclosure. Marks, Richardson, and Maldonado (1991), suggested that disclosure is directly correlated with the number of sexual partners that one has, with an increase in disclosure being associated with fewer partners. This can be disputed because if that was the case, one would begin to identify a decline in new infections recorded. Although in some monogamous relationships where there is a history of condom use, individuals are more likely to disclose their HIV positive status than those with multiple partners (Niccolai, Dorst, Myers and Kissinger: 1999), this would be an ideal situation, where it is a fact that not all HIV infected people disclose their status to partners, and this again proves how lack of disclosure perpetuates the spread of HIV infection.

There has been an investigation into the role that HIV and AIDS counsellors can play in encouraging partner notification as well as an investigation into the factors that facilitate disclosure. It has been suggested by Marks, Richardson and Maldonado in Palmary (2000: 7), that disclosure is directly correlated with the number of sexual partners that one has, with an increase in disclosure being associated with fewer sexual partners. In monogamous relationships where there is a history of condom use, individuals are more likely to disclose their HIV positive status than those with multiple partners (Niccolai, Dorst, Myers and Kissinger: 1999), in Palmary (2000: 7). This again proves how lack of disclosure perpetrates the spread of HIV.

Stein, Freedberg and Sullivan (1998), in Lachman (1999: 572), interviewed 203 consecutive patients presenting for primary care for HIV at two urban hospitals. One hundred and twenty-nine (129) reported having sexual partners they had been living with over the past six months. An analysis was made on the relationships between socio- demographic, alcohol, social support, sexual practice and clinical variables, and whether patients told their partners they were HIV positive. The results showed that sixty percent (60%) had disclosed their positive HIV status to all sexual partners. Of the 40% who had not disclosed, half had not disclosed to the one and only partner.

Among patients who did not disclose, 57% did not use condoms at all times, thus a considerable number of HIV infected individuals do not disclose their status to sexual partners, at the same token non-disclosures are not likely to use condoms regularly than disclosers. Sexual partners of HIV infected individuals continue to be at risk of HIV transmission, thus perpetuating the spread of HIV.

The above study recommended that HIV infected individuals disclose their sero-positive status and or protect their partners through behaviour change. They suggest disclosure interventions could be implemented in clinics, primary care offices and through special counselling programmes.

The implication is that people may be putting themselves at risk of acquiring HIV without knowing it, and that the medical and health care personnel may have great difficulty improving the situation.

Disclosure is one strategy that specifically indicates self-acceptance whilst also helping to relieve the stress associated with non-disclosure. Disclosure also represents a marked commitment to adopt safer sexual practices. One of the tasks of those working in the field of HIV and AIDS, in the words of Professor William Makgoba, president of the Medical Research Council, "is to promote the culture of 'breaking the silence' around this silent killer of our nation".

2.8 VALUES, MORALITY AND ETHICS

2.8.1 Values

It is important to point out that the concepts of values, ethics and morality differ from one another without necessarily being mutually exclusive. Levy (1993: 2), views values as preferences for a certain form of conduct. They (values), indicate what is good and desirable, and when compared with ethics, it is about what is right and correct. Ethics is a set of moral principles which is suggested by an individual or group, and is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct. In as far as confidentiality in HIV and AIDS is concerned, both the values held by the health care practitioners and ethical principles set by the profession create a dilemma, where the practitioner or counsellor may consider it necessary to inform the sexual partner of his patient or client, in order to prevent further transmission, may be prohibited by the ethical principles of not disclosing that information to the sexual partner as that will constitute breach of confidentiality, especially when the patient or client does not give consent.

2.8.2. Morality

Morality is defined as principles concerning the distinction between right and wrong or good and bad behaviour, Concise Oxford English Dictionary (2002: 925). The patient or client who is HIV positive, should look at morality, i.e. in terms of not disclosing the status to the sexual partner and continuing with sexual intercourse as if all is well, at the same time infecting the unsuspecting party (ies), whether that constitutes good or bad behaviour, or whether in his or her opinion it is right or wrong. That will also be linked with questions of value and value dilemmas faced by health professionals for disclosing the status to sexual partner(s) of the patient or client in question. Dilemmas include deciding to preserve or protect one value or set of values. Morality includes the sacrifice of some other value or a set of values is equivalent to deciding in favour of the competing value or set of values (Callahan 1988: 6).

To further demonstrate this, Bennett and Erin (1999: 157), share a case of a woman, who is HIV positive and does not tell her present partner. In her view there is no point in doing so; their sexual contacts are safe and the reasons for her not to tell him are plenty. Following an accident, a broken condom, she tells him about her status and insists he be tested. He is found to be infected. In terms of morality, the questions asked are, should she have told him earlier? Does she have a moral duty to inform any sexual contact she has? And did the health professional have a duty to insist on her telling? One can argue that immoral situations should be set apart by clear regulations.

Morality is not reducible to law. Finding out what the law permits or requires is not necessarily to find out what is morally right, and morality (sometimes) may permit or require breaking a just law. The law itself is always subject to moral scrutiny or moral criticism, and the question of whether one should obey the law is always in principle, an open one (Callahan 1988: 11).

In terms of this study, the society we live in, determines the morals, which, in most cases are not adhered to as there are no law enforcements. This becomes complex as it can be interpreted that it is immoral for one HIV positive patient or client to, knowingly infect or expose a partner to HIV, at the same time the victim does not have any legal footing to charge the perpetrator for willingly and knowingly infecting him or her as this is not considered a criminal offence as opposed to breach of confidentiality, which is considered as a criminal offence. It is these dilemmas that encourage the spread of HIV and fail to protect innocent unsuspecting citizens.

2.8.3 Ethics

A health professional has a manifold role-based obligation, which can be subdivided into the specific duty to inform his or her patient or client about the positive HIV status (results), the general duty to promote health, e.g. by preventing the spread of HIV in society, and possibly the specific duty to warn or protect third persons.

Ethical principles require health care practitioners to become advocates for their patients. The right to privacy (section 14 of the constitution) is safeguarded by the ethical and legal rules regarding confidentiality.

Ethics, a formal field of philosophical inquiry is the philosophical study of morality. It includes three conceptually distinct but closely related enterprises or projects namely, metaethics, theoretical normative ethics and applied ethics (Callahan 1988: 7). Medical ethics, which is part of applied ethics, is seen as the moral principles that govern the practice of medicine by doctors and other health care professionals McQuoid-Mason, Pillemer, Friedman and Dada (2000: 80). As a result, breaches of ethical rules may result in disciplinary action being taken by employers and or professional bodies.

For the purpose of this study, emphasis will be placed on applied ethics because its main task is to resolve specific moral issues and morally problematic cases which arise in different areas of life.

Applied ethics borrows insights from metaethics and theoretical normative ethics and thus, concentrate on finding acceptable resolutions of moral problems. Bennett and Erin (1999: 2), indicate that confidentiality is not an absolute obligation. Situations arise where the harm in maintaining confidentiality is greater than the harm brought about by disclosing confidential information. In this instance, it is the health professional maintaining confidentiality about the positive HIV status of the client or patient and not warning the sexual partner, predisposing the unsuspecting sexual partner to more harm of being infected.

Public discussion has paid a great deal of attention to conflicts between parties in terms of rights (patients' rights), such as autonomy, privacy and confidentiality, and the related responsibilities of health professionals, such as (not) breaking confidentiality.

There are other important themes to be considered, in situations in which conflict arise less sharply. In those cases, third parties (patients' sexual partners) can be served best by an improvement of the caring relationship, in which the general health is promoted or protected by the 'empowerment' of people to choose and act in a morally responsible way. Without patronizing, the health professional can play a role in which moralizing is justified in a situation in which someone has to face sexual partners interests.

While there may be cases where the health professional or counsellor feels compelled or sees it right to share information regarding the patients' health and prognosis with, for instance, the patients' inquiring spouse, without explicit permission from the patient, it is generally unjustifiable to do so. Except in cases where the spouse is at specific risk of harm directly related to the diagnosis, it remains the patients', rather than the health professional's obligation to inform the spouse. Although provisions for medical doctors are made to disclose to the sexual partner, this is not a blanket provision for all professionals, this excludes those who are not medical doctors, but are faced with ethical dilemmas on a day-to-day basis in contact with HIV positive clients and patients.

Ethical principles require health professionals to become advocates for their patients. The right to privacy (section 14 of the constitution) is safeguarded by the ethical and legal rules regarding confidentiality. The following table outlines the different ethical systems and how the ideal situation would be in terms of dealing with HIV and AIDS issues.

2.8.3.1 Ethical systems

Table 4:

SYSTEM	DESCRIPTION
Relativism	All moral principles are valid and relative to cultural tastes. The rules of society serve as a standard
Utilitarianism	Actions are judged right or wrong solely by their consequences. Right actions are those that produce the greatest balance of happiness over unhappiness. Each person's happiness is equally important. [One person's good is another's evil]. The majority's happiness is overruled by an individual's happiness.
Deontology	Emphasises on moral rules and duty. Moral rules are universal. Emphasis is also on autonomy, justice and kind acts.
Devine command	Moral standards depend on God who is all knowing. Any act that conforms to the law of God is right, and an act that breaks God's law is wrong.
Virtue ethics	Morals are internal. Virtue ethics seek to produce good people who act well out of spontaneous goodness. Emphasises living well and achieving excellence.

Source: Woodrow 1992

The above table emphasises that the society we live in sets the rules and moral expectations. However, when PLWAH disclose their positive HIV status out of good will and trying to conscientise others about their standing, the very society rejects them, which in turn, make most of them decide to keep their status a secret, in the process harming other innocent, unsuspecting individuals, by infecting them with the virus, as safer sex cannot be guaranteed.

At the same time, the health professionals' duty to respect confidences, derives from the foundational principle of respect for individual autonomy which is standardly taken to justify attenuation of a strict duty of confidentiality in cases where others will be put at risk of harm.

On the contrary, there is great difficulty to predict the probability of harm to third parties, ***except,*** perhaps, where we have good reason to suppose that HIV positive people will neither inform their sexual partners (third parties) and not take measures to minimize the chances of HIV transmission, Vedder in Bennett and Erin (1999: 9).

Winston (1988: 1-104), presumes that the duty to respect the confidentiality of personal medical information, derives from a more basic duty to respect autonomy of individuals. Because it is generally assumed that the autonomy of individuals may be legitimately restricted in cases where they expose others to risk of harm, Winston argues, it may likewise be assumed that medical confidentiality may be restricted in cases where the individuals concerned put others at risk of harm.

Winston further argues that the vulnerability of the third parties (partners), should be considered sufficient justification for breach of medical confidentiality, not only in cases where HIV infected persons evidently refuse to protect their partners by informing them, but also as a general policy, whether or not HIV infected persons appear to be willing to take measures to protect their partners from contracting the disease.

Recent international consultations on these matters have confirmed that the principles of confidentiality and informed consent are not obstacles to effective prevention and care programmes. In fact, if employed appropriately, they are not only valid ethical principles, but are also pragmatic tools by which to best protect both the non-infected and the infected. Rather, it is HIV-related denial, stigma and discrimination, and the secrecy that results from these that compromise major impediments to an effective response to HIV.

2.8.3.2 Breaching confidentiality

Patients discuss intimate and personal details about themselves with health care workers and have a right to expect that their disclosures will remain in confidence, McQuoid-Mason, Pillemer, Friedman and Dada, (2002: 91).

Van Dyk (2002: 408), concurs with the above statement by stating that people with HIV and AIDS have the right to confidentiality and privacy about their health and HIV status. Health care professionals are ethically and legally required to keep all information about the clients or patients confidential. After death, the HIV status of the deceased person may not be disclosed to anybody without the consent of his or her family or partner – except when required by law.

Van Dyk (2000: 409), further explains that a client's right to confidentiality and privacy should be respected at all times. The health care professional or counsellor may therefore not disclose the HIV positive status of a client to his or her sexual partner. The counsellor should rather convince the client to disclose his or her status to the sexual partner and to use condoms. However, the counsellor or health professional cannot conclusively say this will be done.

There is a 50/50 chance that the partner will be infected, whereas if the counsellor had a right to immediately involve the partner, there will be 100% surety that the partner will not be infected.

Fine, cited in Van Dyk (2002: 409) is of the opinion that if a counsellor, against all advice, decides to disclose a client's positive HIV status to a sex partner, the counsellor should explain this decision to the client first and offer the client the opportunity to inform the sexual partner him or herself, with or without the help of the counsellor. If a health care professional or counsellor discloses a client's positive HIV status to anybody without the client's consent, he or she must also be prepared to accept full responsibility for the decision as well as possible legal consequences. For example a Florida State health worker was sentenced to one year of probation for breaching AIDS patient's confidentiality by providing a former lover with a list of names of 4000 AIDS patients in the State (United Press International News).

The European Court of Human Rights has found the publication of a person's identity and HIV statistics can violate the right to respect for private and family life. What this means is that the court found out that publishing the patient's identity as well as his or her positive HIV status in terms of notifying the disease, was violating the patient's confidentiality and human rights, which will impact negatively on his private and family life.

Confidentiality may only be breached under the following circumstances:

- Court order to make a disclosure;
- Act of parliament;
- Moral/legal obligation; and
- Consent by patient.

On the contrary, health professions Council allows doctors to breach confidentiality in cases where their HIV positive patients, or patients suffering from AIDS, put other health care practitioners or the patients' spouse or sexual partners at risk. In such cases, the doctor should first try to persuade the patients to consent to the disclosure being made. If the patient refuses consent, the doctor should counsel the patient and explain that he or she is ethically bound to warn the other parties on a confidential basis.

The problem with the above provision is that it creates a gap, as it is not only doctors, who deal with HIV and AIDS patients, and most of the doctors are not involved in the counselling of patients. The challenge is to make the Health Professions Council aware of the gap in order to create a mechanism to cover other health professionals including lay counsellors.

2.10 CONCLUSION

This chapter detailed what the South African Government is offering its citizens in terms of the legal provisions for respecting their privacy, confidentiality and other rights. The different health programmes are available as evidence. Despite all these, the principle of confidentiality is widely endorsed in the epidemic, but its limits and practical application are subject to controversy.

Generally, patients who are HIV positive or suffering from AIDS are entitled to have their right to confidentiality respected. However, if they are a threat to the health and life of others, it may be necessary to disclose their positive HIV status.

Much still needs to be done where most PLWHA must in turn respect the very society they live in. It is understood that being diagnosed with HIV or AIDS is traumatic, but there are services available that clients can use, for them to cope better. However, most community members do not know that they are HIV positive as a result of the confidentiality surrounding the infection, especially those in "monogamous" relationships, as they think that they are safe, and others cannot negotiate condom use because of their socio-economic and cultural status.

The spread of the infection can only be contained if the rights of all citizens can be respected. The question in making disclosure mandatory may prevent many people from going for testing and may defeat the whole exercise. People are encouraged to disclose during counselling sessions but the behaviour change is not as expected. This leaves the counsellor to be tempted to disclose to the sexual partner, which is unethical, when the patient does not consent. As a result, it may be easy for all counsellors, if they are authorised, to disclose to sexual partners. Legislation in this country may need to be geared in that direction, because it is becoming difficult to win this battle, as currently only breach of confidentiality between health professionals is allowed, as 'shared confidentiality', and only medical doctors have a standing provision by their Council to disclose to partners after counselling the patient, which does not assist in any way, as the person to whom confidentiality must be breached, is the sexual partner, looking at the most common mode of spread of this infection.

Many HIV positive people who do not disclose their HIV positive status, are guilty of murder or culpable homicide or assault as they do not practise safer sex and expose other partners to HIV, who are unfortunately dead or still alive, and are still in relationships and are unaware of their partners' status.

CHAPTER 3

ANALYSIS AND INTEPRETATION OF DATA

3.1 INTRODUCTION

In data analysis, accumulated or collected information is manipulated for the purpose of drawing up conclusions that will reflect on ideas and interests that initiated the original research undertaking. A close-ended questionnaire was used to collect data from 200 respondents. The questionnaire was self-administered to the respondents by the researcher, general practitioners and home-based carers, thus assuring 100% of its return.

A sample of 200 respondents was determined by saturation of the information selected from the population of HIV and AIDS patients attending health care in Greater Mafikeng sub-district, in the clinics, general practitioners' consulting rooms and home-based care (HBC).

Data is therefore presented as follows:

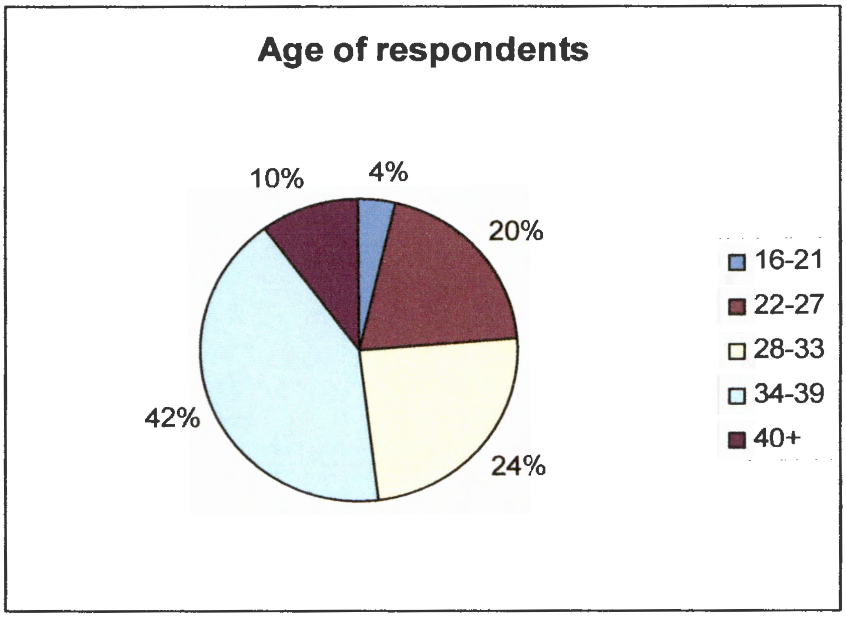
3.2 Profile of respondents

3.2.1 Age distribution of respondents

Table 5: Age of respondents (N=200)

Response	Frequency	Percent
16 – 21	8	4
22 – 27	40	20
28 – 33	48	24
34 – 39	84	42
40+	20	10
Total	200	100

Figure 3.2.1: Age of respondents (N=200)



The study reflects that the respondents were young individuals aged between16-39. This age group is associated with high-risk behaviours and bad life-styles, (Health Systems Trust 2003/4: 191).

The age group between 34-39 showed the highest percentage (42%), followed by age group of 28-33, which comprised 24%, then age group of 22-27 at 20%. This shows that these categories are the most highly affected by HIV and AIDS and are in their reproductive stage, as well as in the working category.

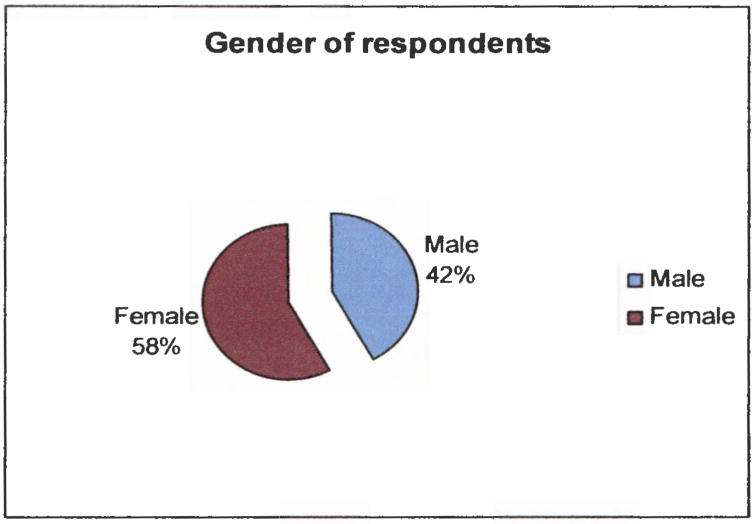
Most respondents are in some kind of a relationship, whether living alone or with parents, and this means that when this age category does not take care of itself, the economy of the country will be affected, as their health will later on deteriorate and not be able to function anymore. With children produced in those relationships, where there is lack of disclosure of positive HIV status, there will be more child-headed families later on, and that will put more demand on the state and the community to look after them.

3.2.2 Gender distribution

Table 6: Gender of respondents (N=200)

Response	**Frequency**	**Percent**
Male	84	42
Female	116	58
Total	200	100

Figure 3.2.2: Gender of respondents (N=200)



The gender distribution reveals predominance of females at 58% and 42% male. This is an indication that for HIV and AIDS, females are at the highest risk. This confirms the findings of Ntuli, Padarath, McCoy and Berthiaume (2003), who indicated that the epidemic is fuelled among women for a number of reasons, for example, some women exchange sex for material favours and as a means of daily survival, most women are not empowered to negotiate condom use with the partner or husband as it is the husband that sets rules around sexual matters. Even if the husband or sexual partner knows his HIV status, he will continue to infect the woman without disclosing his status. (Bennett and Erin 1999: 9).

The anatomical difference between females and males has implications, as women seem to be more vulnerable, and more women die from AIDS as compared to men. This is from a professional observation made as patients and clients were coming into the health facility.

3.2.3 Marital status

Table 7: Marital status of respondents (N=200)

Response	Frequency	Percent
Married	36	18
Single	88	44
Widowed	16	8
Separated	28	14
Divorced	32	16
Total	200	100

Figure 3.2.3: Marital status of respondents (N=200)

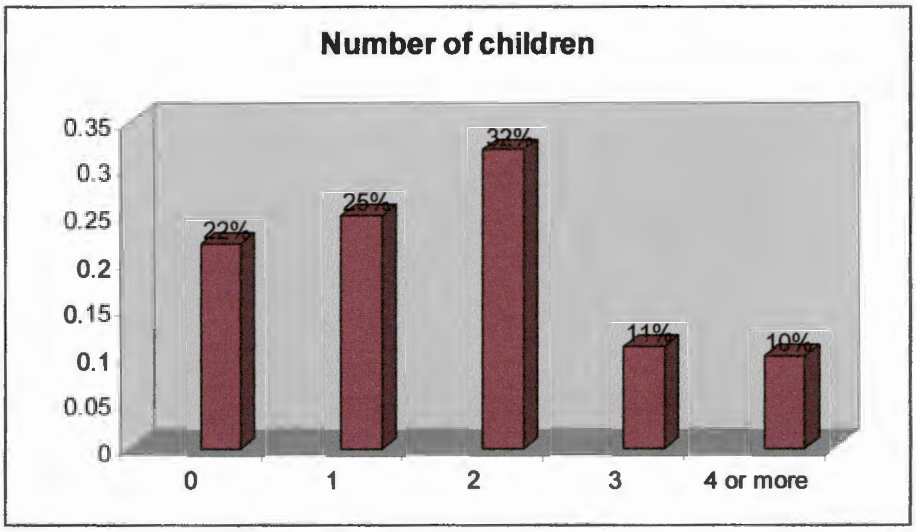
In terms of the marital status, only 18% of respondents reported being married. The majority (44%) identified themselves as single and 2% reported being divorced. Single respondents had the highest percentage compared to married ones. This means that single people are more prone to HIV and AIDS. This may be due to indiscriminate sexual activities and failure to use condoms or practise safe sex. Only 14% of respondents were separated from their partners and 22% lost their partners through death as they were widowed.

3.2.4. Number of children of respondents

Table 8: Number of children respondents have (N=200)

Response	Frequency	Percent
0	44	22
1	50	25
2	64	32
3	22	11
4+	20	10
Total	200	100

Figure 3.2.4: Number of children respondents have (N=200)



Respondents were asked to state the number of children they had. Most respondents (32%) reported that they had two children, followed by 25% with one child, and 11% with three children, and 10% with more than four children.

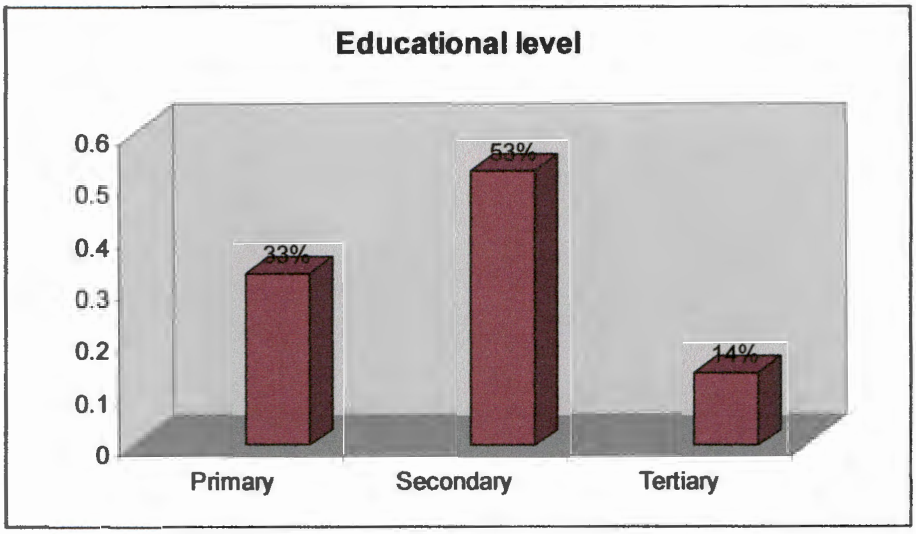
This can be interpreted as failure on the part of respondents to inform their partners that they are HIV positive. This also proves that after the diagnosis, condoms are not often used, thus creating children that are infected, spreading and increasing the number of HIV and AIDS patients. However, it must be indicated that the study did not ascertain whether the children were born prior or after the diagnosis.

3.2.5 Level of education

Table 9: Level of education of respondents (N=200)

Response	**Frequency**	**Percent**
Primary	66	33
Secondary	106	53
Tertiary	28	14
Total	200	100

Figure 3.2.5: Level of education of respondents (N=200)



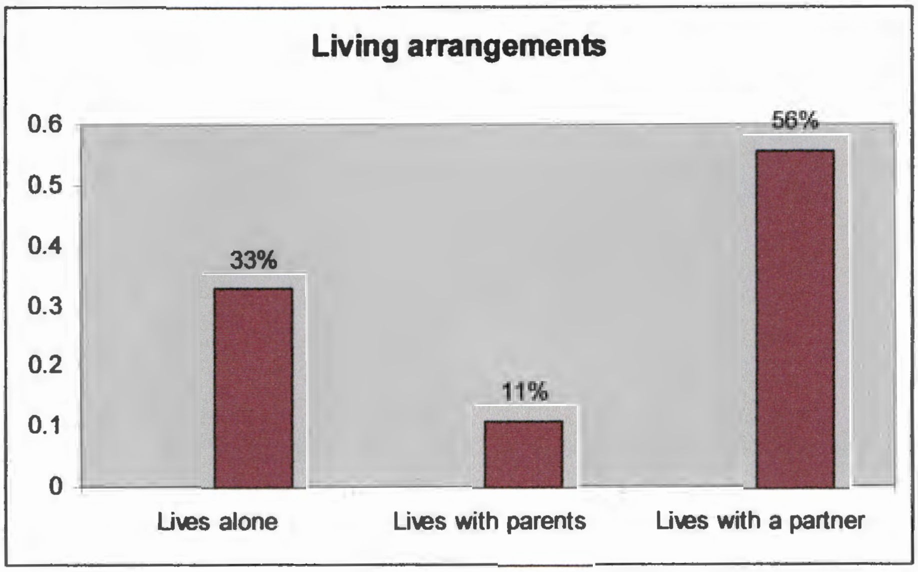
The above table 9 and figure 3.2.5 depict that 53% of respondents have secondary education, and only 14% of respondents have tertiary education. The remaining respondents (33%) attained primary school level of education. The fact that the majority of respondents have secondary education, one would assume that they are literate enough to understand the pros and cons of not disclosing their status to their partners or at least to be responsible enough to practise safe sex. Looking at figure 4 above, it can be concluded that the level of education of respondents does not influence the use of condoms as the majority of respondents have at least one child. This behaviour can be expected from people who have no form of education and therefore regarded as stark illiterate.

3.2.6 Living arrangements

Table 10: Living arrangements of respondents (N=200)

Response	Frequency	Percent
Partners	112	56
Alone	66	33
Parents	22	11
Total	200	100

Figure 3.2.6: Living arrangements of respondents (N=200)



The majority of respondents (56%) live with their partners, whether married or not, and 33% live on their own. Only 11% are under parental care. The figure confirms that most of the people with HIV and AIDS live in some form of a relationship where they are expected to share intimate information which should make it easy for one to divulge their status to each other. However, considering the fact that most respondents have one or more children as according to figure 3.2.4, gives an indication that partners do not divulge their positive HIV status, thus spreading the virus.

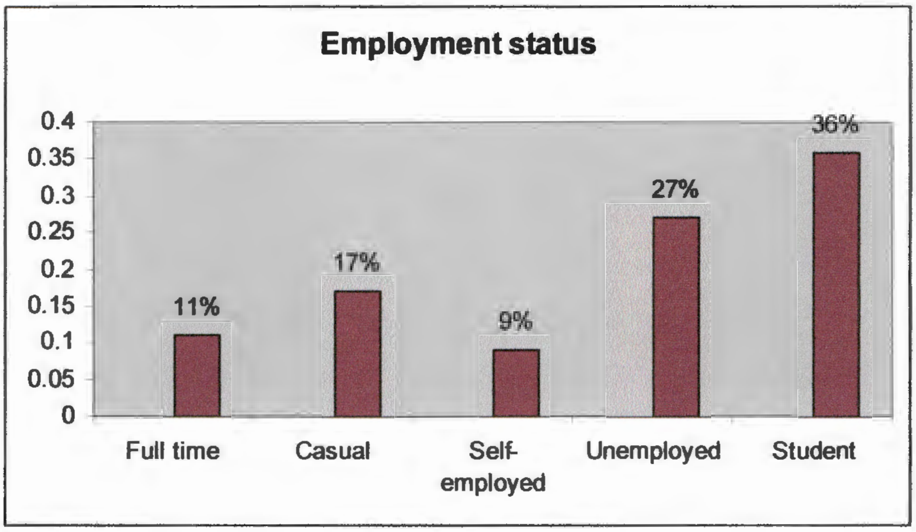
The fact that most of the respondents are single as portrayed in Table 7, indicates that single young people practise cohabitation without considering safe sex.

3.2.7 Employment status

Table 11: Employment status of respondents (N=200)

Response	Frequency	Percent
Full Time	22	11
Casual	34	17
Self Employed	18	9
Unemployed	54	27
Retired	0	0
Student	72	36
Total	200	100

Figure 3.2 7: Employment status of respondents (N=200)



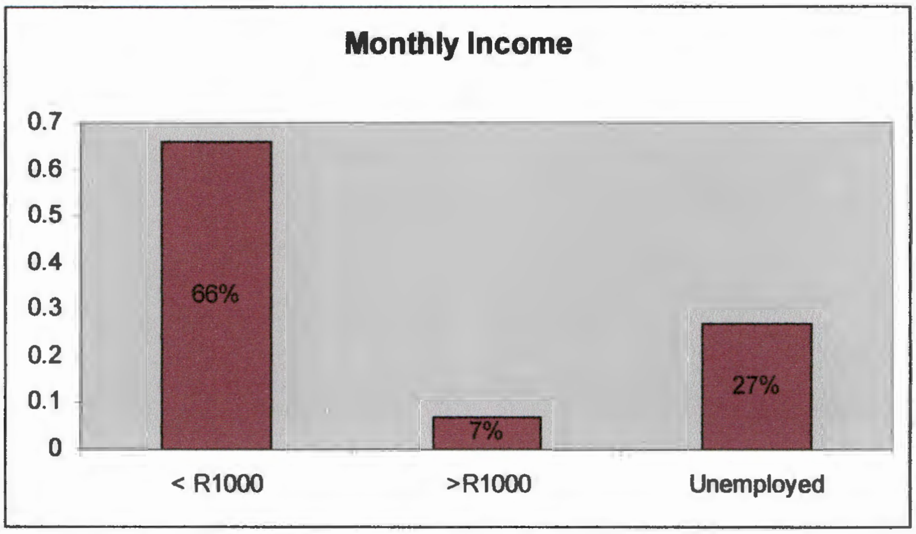
Of the total number of respondents, 36% are students, followed by 27% who are unemployed. This figure correlates well with figure 3.2.3 that indicates that the majority of respondents are single though they all have children as indicated in figure 3.2.4. Another feature of interest is that though the majority of respondents are students, figure 3.2.6 confirms that they live full-time with a partner, either married or cohabitating. From personal experience as a professional, many students drop out of school or tertiary institutions because of HIV and AIDS. This is an indication that young people fail to disclose their HIV status to their partners.

3.2.8 Monthly Income

Table 12: Monthly income of respondents (N=200)

Response	**Frequency**	**Percent**
Less than R1000	132	66
More than R1000	14	7
Unemployed	54	27
Total	200	100

Figure 3.2.8: Monthly income of respondents (N=200)



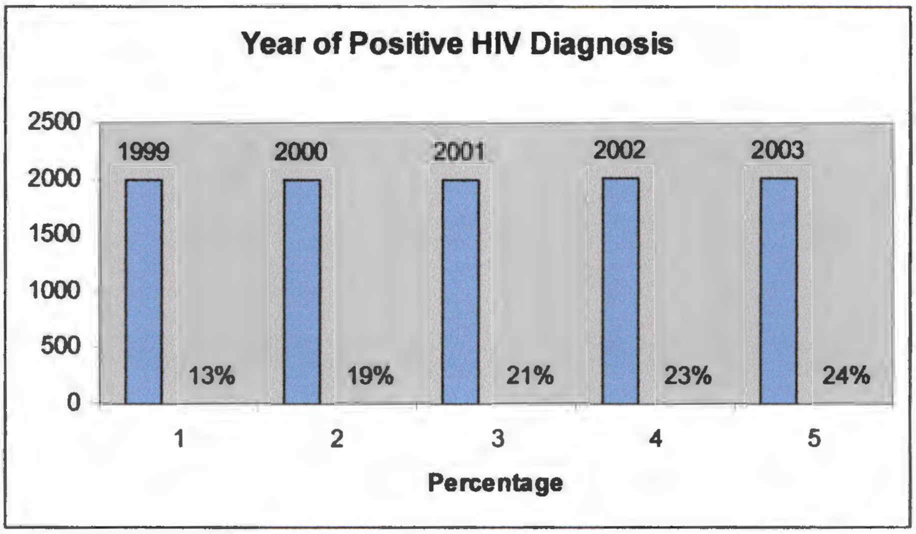
Respondents were asked to state their monthly income. Most respondents (66%) who earned less than R1000.00 were students, single and still looking for a permanent partner to take care of them and in the process making more children, thus spreading the virus. Only 7% earned more than R1000.00 and 27% were unemployed.

3.2.9 Year of diagnosis

Table 13: Year in which respondents were diagnosed HIV positive (N=200)

Response	Frequency	Percent
1999	26	13
2000	38	19
2001	42	21
2002	46	23
2003	48	24
Total	200	100

Figure 3.2.9: Year in which respondents were diagnosed HIV positive (N=200)



Respondents were asked about the year in which they were diagnosed HIV positive. Most were diagnosed in the last 4-5 years, with the majority (24%) diagnosed in 2003, followed by 23% diagnosed in 2002 and 21% in 2001. Only 13% were diagnosed in 1999 and 19% in 2000 respectively. This is linked with figures 3.2.16 and 3.2.17, where irrespective of the diagnosis; some respondents still had not disclosed their positive HIV status to their partners. Given the epidemiology of HIV and AIDS, one can go on symptomless for some years (depending on one's immunity), and this contributes to the spread of the virus to partners.

3.2.10 Knowledge about positive HIV status

Table 14: How respondents came to know about their positive HIV status (N=200)

Response	Frequency	Percent
Self referral	64	32
Medical reasons	102	51
Other	34	17
Total	200	100

Figure 3.2.10: How respondents came to know about their positive HIV status (N=200)

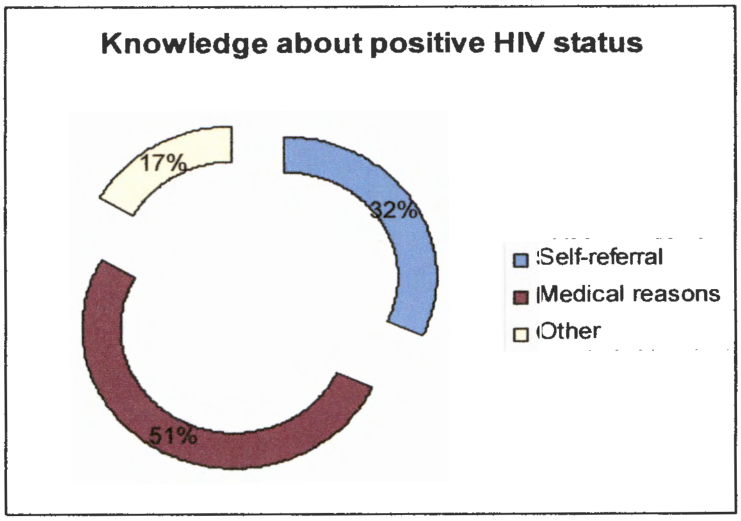


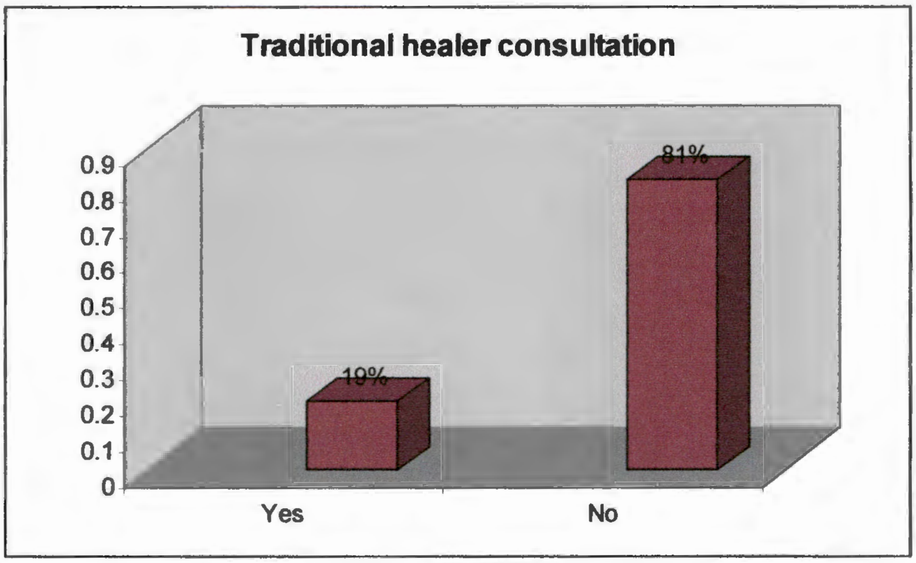
Table 14 and figure 3.2.10 above show the main reasons given by respondents for having an HIV test. Majority of respondents (51%) came to know about their positive HIV status due to medical reasons and 32% were self-referrals. Only 17% acknowledged other reasons, like having engaged in unprotected sex due to alcohol consumption, and condoms not being available at that time. It should be noted that other respondents broke down to tears when answering this question and could not go on to further explain. None reported having been encouraged by the disclosure of the positive HIV positive partner. This further confirms that young people do not voluntarily check their status. They wait until they have a medical condition that compels them to be tested.

3.2.11 Traditional healer consultation

Table 15: Traditional healer consultation (N=200)

Response	Frequency	Percent
Yes	162	81
No	38	19
Total	200	100

Figure 3.2.11: Traditional healer consultation (N=200)



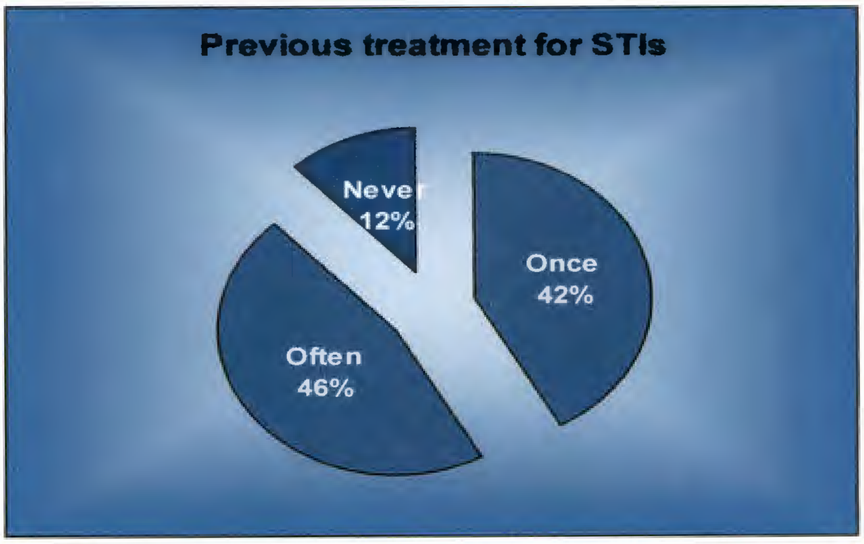
Fewer respondents (19%) agreed to have consulted traditional health practitioners in secret with the hope that nobody will get to know of their status as some traditional health practitioners do not insist on treating partners. This is one way of keeping the status to oneself and not disclosing it to the partner. This is significant as traditional health practitioners are considered to be part of the health system and in the literature review, it was evident that some respondents would rather disclose to a traditional health practitioner as he or she is more likely to keep a secret as there is no official record of the disease that are kept. On the contrary, the majority of respondents (81%) have never consulted a traditional health practitioner.

3.2.12 Previous treatment of sexually Transmitted infections (STIs)

Table 16: Previous treatment of sexually Transmitted infections (STIs) (N=200)

Response	**Frequency**	**Percent**
Once	84	42
Often	92	46
Never	24	12
Total	200	100

Figure 3.2.12: Previous treatment of sexually Transmitted infections (STIs) (N=200)



Most respondents (42%) of respondents were once treated for STIs, and 46% were often treated for STIs. Only 12% were never treated for STIs. Other sexually transmitted infections are of concern because they can increase the risk of transmission or acquisition of HIV. The figure above confirms that being exposed to repeated STIs increases the likelihood that one will get HIV infection.

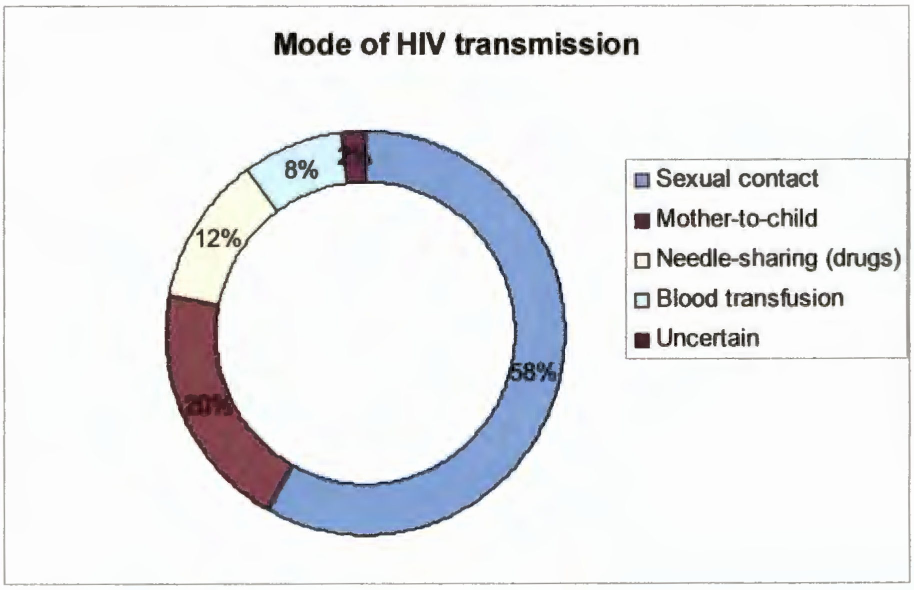
3.2.13 Mode of transmission of HIV

Table 17: Knowledge of the mode of transmission of HIV (N=200)

Response	Frequency	Percent
Sexual Contact	116	58
Mother to child	40	20
Needle sharing	24	12

(drugs)		
Blood transfusion	16	8
Uncertain	4	2
Total	200	100

Figure 3.2.13: Knowledge of the mode of transmission of HIV (N=200)



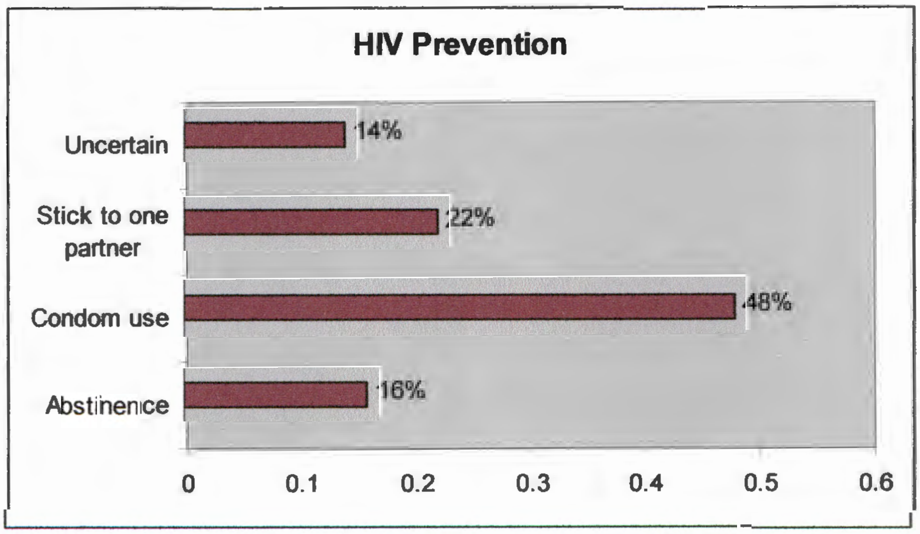
Respondents were asked to indicate their knowledge of how HIV is transmitted. The majority of respondents (58%) knew that the most common mode is through sexual intercourse, followed by 20% of mother-to-child transmission. Blood transfusion and needle sharing were reported as the lowest by 12%. Table 17 above proves that most respondents are were of the most common mode of transmission and therefore one would expect the rate of infections to be controlled by taking appropriate precautionary measures, like condom use, but that was not the case. Globally, the major mode of HIV transmission is through sexual intercourse. The fact that the majority were aware that HIV is sexually transmitted, one would expect that those respondents would be more open with their partners by insisting on the use of condoms to prevent the spread of HIV. Contrary to this, the study by African Medical Research Foundation in 2003, showed less commitment to the use of condoms even after diagnosis.

3.2.14 HIV Prevention

Table 18: Knowledge of HIV prevention (N=200)

Response	Frequency	Percent
Abstinence	32	16
Condom use	96	48
Stick to one partner	44	22
Uncertain	28	14
Total	200	100

Figure 3.2.14: Knowledge of HIV prevention (N=200)



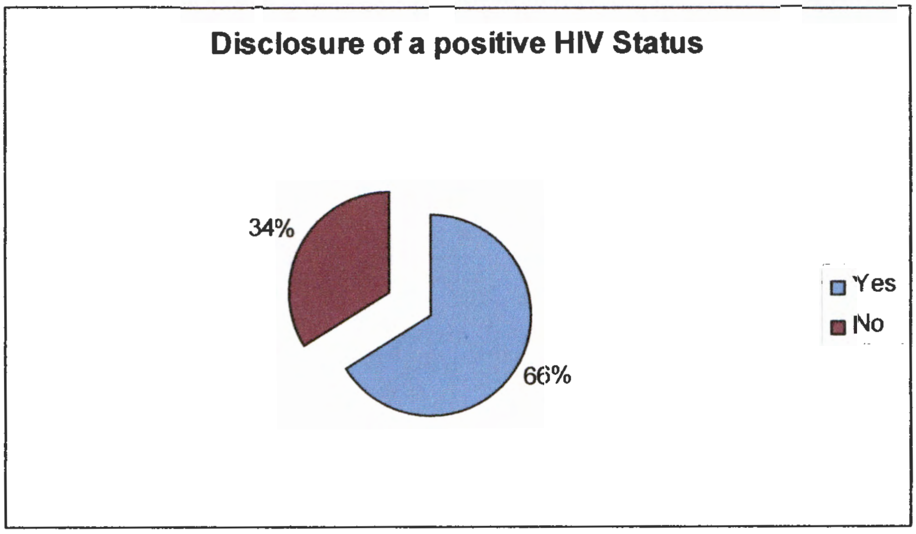
Overall, knowledge around HIV and AIDS prevention was relatively good. Most respondents (48%) were aware of condom use as the most common means of prevention of HIV and AIDS. However, 16% and 22% valued abstinence and sticking to one partner (being faithful) respectively. The figure showed 14% of respondents who remained unsure, the percentage is significant, as respondents might have knowledge on certain issues. Notwithstanding the fact that HIV infected people were aware of the need to use condoms to protect their partners, this study had shown that condoms were not readily used during sexual intercourse.

3.2.16 Disclosure of a positive HIV status

Table 19: Disclosure of a positive HIV status (N=200)

Response	Frequency	Percent
Yes	132	66
No	68	34
Total	200	100

Figure 3.2.16: Disclosure of a positive HIV status (N=200)



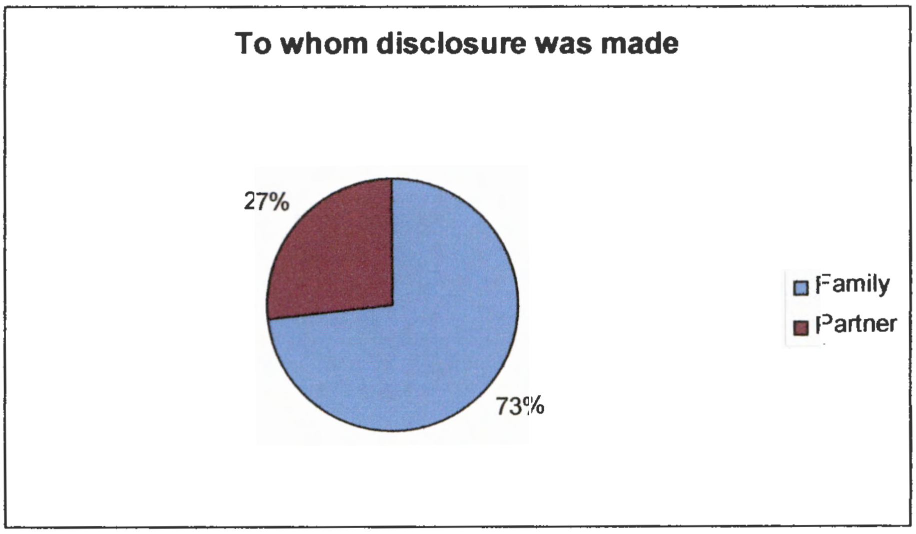
Asked whether they had disclosed their positive HIV status, 66% of respondents had readily disclosed, however 34% did not disclose and confirmed going on with sexual activities as if nothing had happened. The percentage of those who did not disclose was significant, as that meant that some innocent people were at risk of being infected, as safe sex through condom use was not always guaranteed. That was the percentage that preferred to keep their status confidential and at the same time continued with their sexual lives as if all was normal. Thirty four percent of non-disclosure was a high percentage that was enough to perpetuate the spread of the virus.

3.2.17 Disclosure to whom

Table 20: To whom disclosure was made (N=132)

Response	Frequency	Percent
Family	96	73
Partner	36	27
Total	132	100

Figure 3.2.17: To whom disclosure was made (N=132)



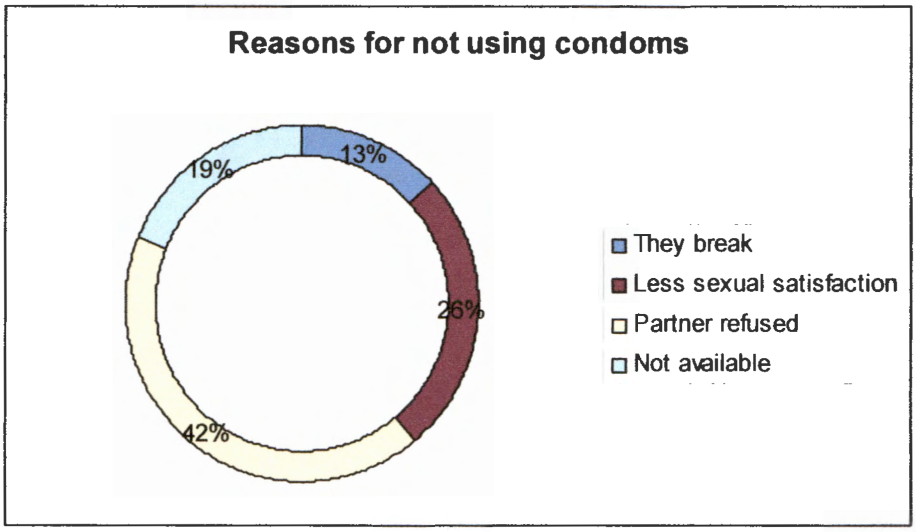
The majority of the respondents (73%) disclosed their status to the family and not to their partners. Only 27% disclosed to their partners. The implication was that family members normally kept that information within the family as confidential as possible. Normally they were strictly warned not to tell anybody about the status, not even the partner. That situation posed the problem of loyalty where the family felt compelled to protect the member of the family by keeping information from outsiders. A partner in this instance might be seen as an outsider. Looking at the most common mode of transmission, the ideal scenario was that the partner would be the first to be informed so as to protect unsuspecting individuals and that was not the case.

3.2.18 Condom use

Table 21: Reasons for not using condoms (N=200)

Response	Frequency	Percent
They break	26	13
Less sexual satisfaction	52	26
Partner refused	84	42
Not available	38	19
Total	200	100

Figure 3.2.18: Reasons for not using condoms (N=200)



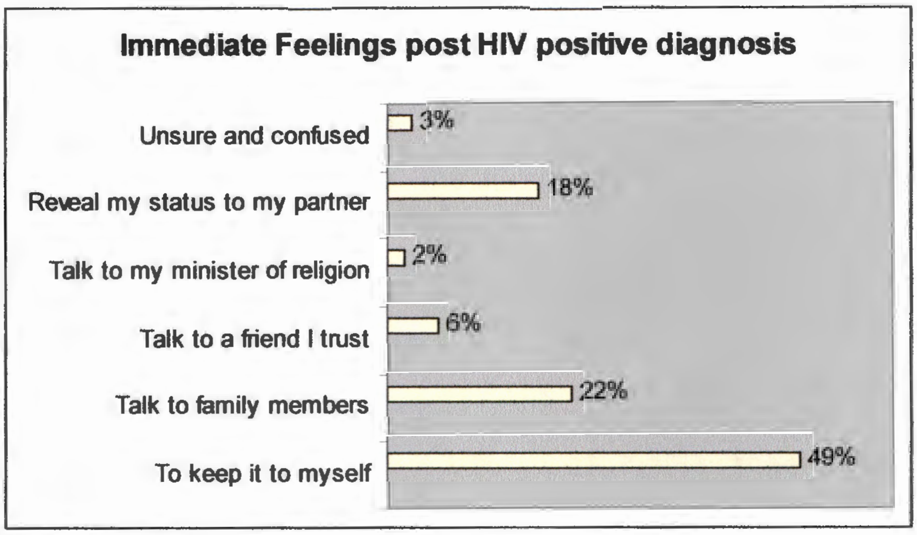
Since all participants were HIV positive, it was expected that 100% of them would indicate positive use of condoms at all times. Figure 3.2.18 and Table 21 proved that respondents were not doing well in terms of condom use, and when co-related with findings in Table 19, which indicated that 34% of partners were not informed of their partners' status, it meant that partners would refuse the use of condoms to pretend as if all was good and well. That proved how silence could perpetuate the spread of HIV. Normally refusal to use condoms was one way of pretending to the partner that one was faithful and therefore there was no need to use a condom. It was that pretence that kept the statistics high.

3.2.19 Immediate feelings post HIV positive diagnosis

Table 22: Immediate feelings about HIV immediately after the diagnosis (N=200)

Response	**Frequency**	**Percent**
Keep it to myself	98	49
Talk to family members	44	22
Talk to a friend I trust	12	6
Talk to my minister of religion	4	2
Reveal my status to my partner	36	18
Unsure and confused	6	3
Total	200	100

Figure 3.2.19: Immediate feelings about HIV immediately after the diagnosis (N=200)



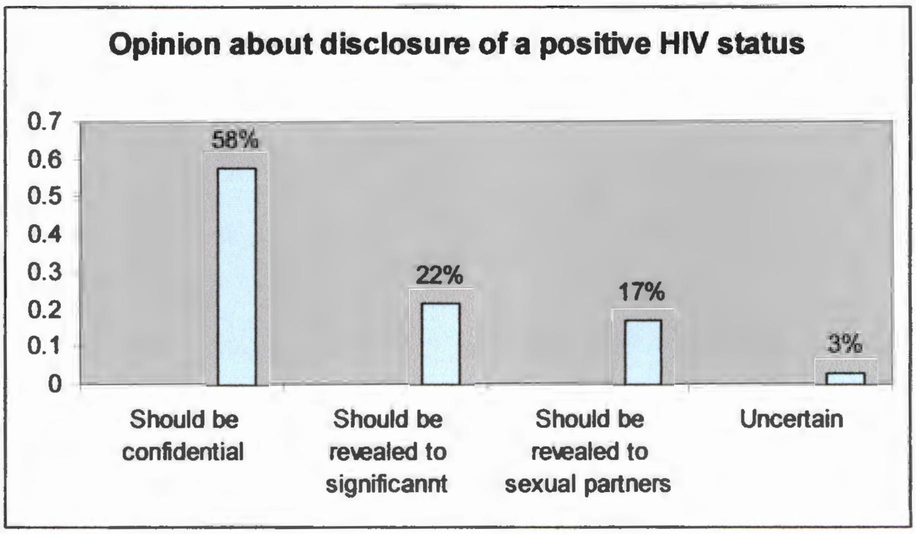
When asked about their feelings after being diagnosed HIV positive, 49% of respondents preferred to keep it confidential, though figure 3.2. 6 confirmed that, 56% of respondents lived with partners. That meant that there would be no disclosure to the partner(s) and more people would continue to be at risk of infection as most respondents were single, according to figure 3.2.3, and only 48% i.e. less than 50% were aware of condom use, figure 3.2.14. A significant number (22%), indicated talking to family members where the information would be treated in confidence. Normally very few trusted family members were informed.

3.2.20 Opinion about disclosure

Table 23: Opinion of whether people should disclose their positive HIV status (N=200)

Response	Frequency	Percent
Should be confidential	116	58
Should be revealed to significant others	44	22
Should be revealed to sexual partners	34	17
Uncertain	6	3
Total	200	100

Figure 3.2.20: Opinion of whether people should disclose their positive HIV status (N=200)

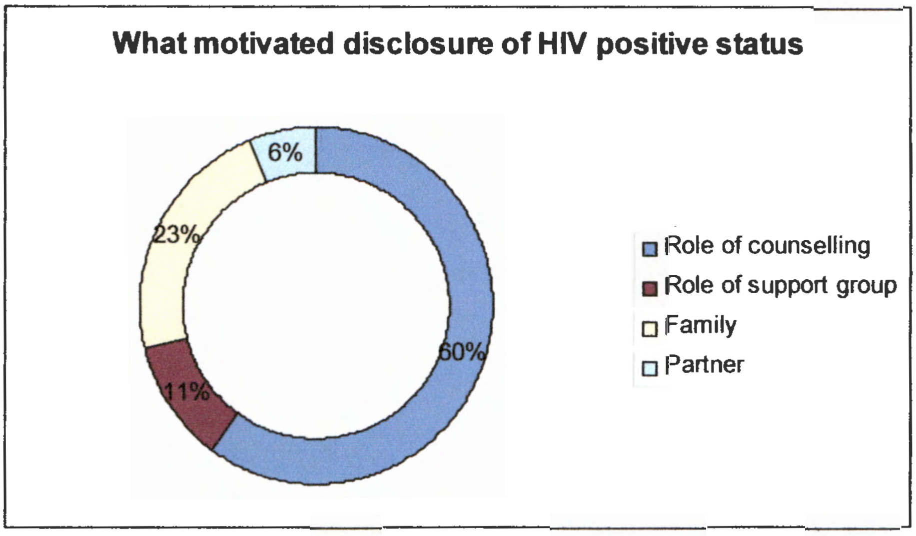


Unfortunately, disclosure of positive HIV status continued to be an issue, with 58% of respondents confirming that one's status should be confidential. Only 17% were of the opinion that partners should be informed. Twenty-two percent (22%) felt they would disclose their positive HIV status to significant others. That implied that the majority of respondents prefer not to disclose to their sexual partners and would preferred to keep the diagnosis to themselves and continued to pretend that all was well. The repercussion for the silence was that the circles and chains of infection would not be broken. That was complicated by the lack of any regulation that compelled partners to disclose their positive HIV status. Patients were furthermore aware of the confidentiality clause and therefore took advantage.

3.2.21 Motivation for disclosure

Table 24 and Figure 3.2.21 present the number and percentage of respondents who indicated how they were motivated to disclose to another person their HIV status.

Response	**Frequency**	**Percent**
Role of counselors	120	60
Role of support group	22	11
Family	46	23
Partner	12	6
Total	200	100



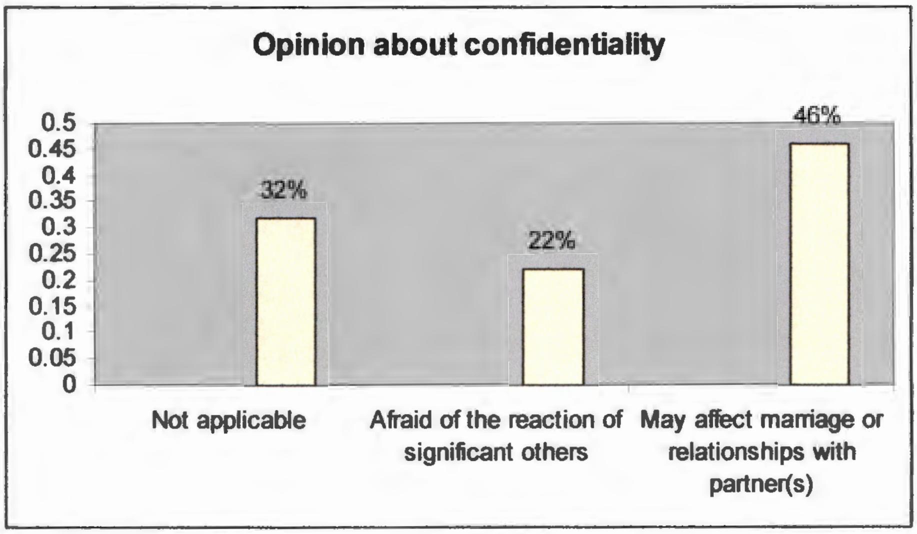
The respondents that disclosed their HIV positive status were asked to indicate what motivated them to disclose their positive HIV status. Of the total that disclosed 60% believed that counselling played an important role, 23% indicated family, followed by 11% for support groups. It was not surprising that only 6% of respondents' partners gave support. That was attributed to the fact that being diagnosed with HIV, one was subjected to prejudice, discrimination and ultimately rejection, which most HIV positive feared, as a result, most relationships were secured by denial and life continues as if there were no problems, especially where respondents are symptomless. Only 11% of respondents alluded to support groups. More use of support groups could be utilised to promote disclosure and facilitate acceptance of a positive HIV status.

3.2.23 Opinion about confidentiality

Table 25: Opinion about confidentiality (N=200)

Response	Frequency	Percent
Not applicable	64	32
Afraid of the reaction of significant others	44	22
May affect marriage/relationship with partner(s)	92	46
Uncertain	0	0
Total	200	100

Figure 3.2.23: Opinion about confidentiality (N=200)



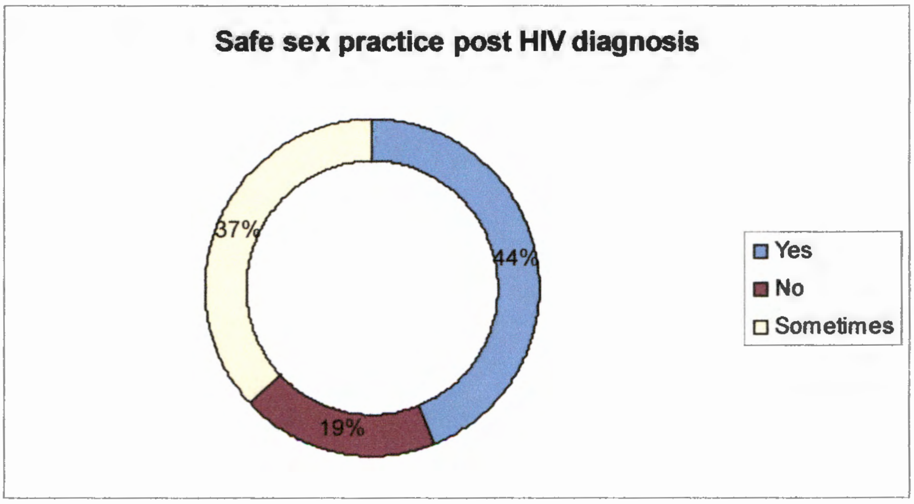
The majority of respondents (46%) agreed that confidentiality might affect marriage or relationships. That concurred with Table 19, which showed that 34% of respondents did not disclose their status and Table 20 in which 27% of respondents did not disclose to their partners. The other respondents 32% indicated that confidentiality was not an issue for discussion, meaning that they had not considered disclosure. The implication was that it might take a while for some people to disclose, and in the mean time new infections occurred.

3.2.24 Safe sex practice

Table 26: Practise of safe sex post diagnosis of positive HIV status (N=200)

Response	Frequency	Percent
Yes	88	44
No	38	19
Sometimes	74	37
Total	200	100

Figure 3.2.24: Practise of safe sex post diagnosis of positive HIV status (N=200)



Of the total respondents 37% sometimes practised safe sex even if they knew that they were HIV positive, and 19% did not practise safe sex at all. That actually meant that 56% of respondents did not always practise safe sex and yet according to Table 10, 56% lived with partners. Well, below half of respondents (44%) considered safe sex. The 19% who did not practise safe sex at all was quite significant. That meant that the spread of HIV and AIDS continued as partners were not aware of the status of their partners. Considering that it did not take several sexual encounters for one to be infected, showed how easy a partner could be infected. That was an indication of how confidentiality can facilitate the spread of the pandemic.

Table 27: Consequences of keeping a positive HIV status confidential (N=200)

Response	**Frequency**	**Percent**
There is no support	50	25
Continuous isolation	70	35
Remaining depressed	64	32
Other	16	8
Total	200	100

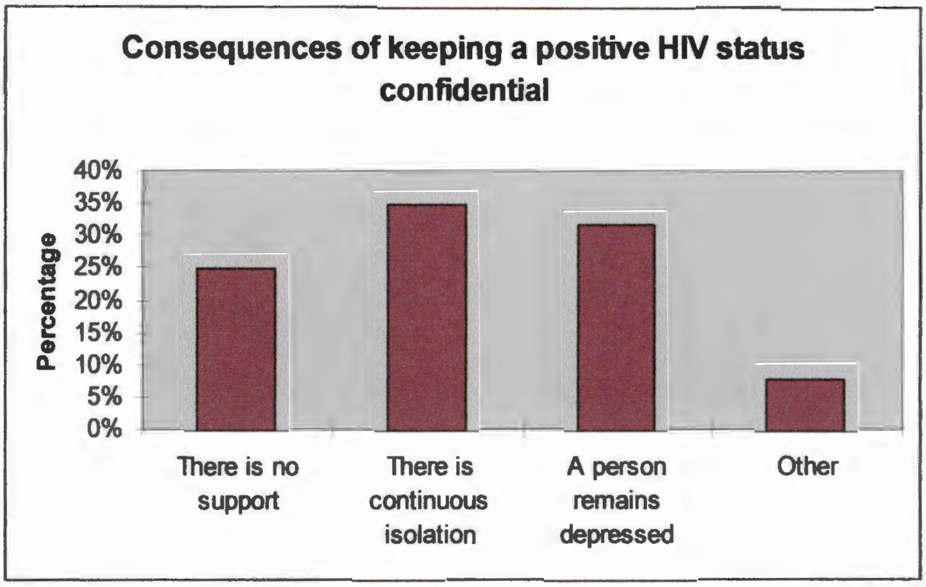


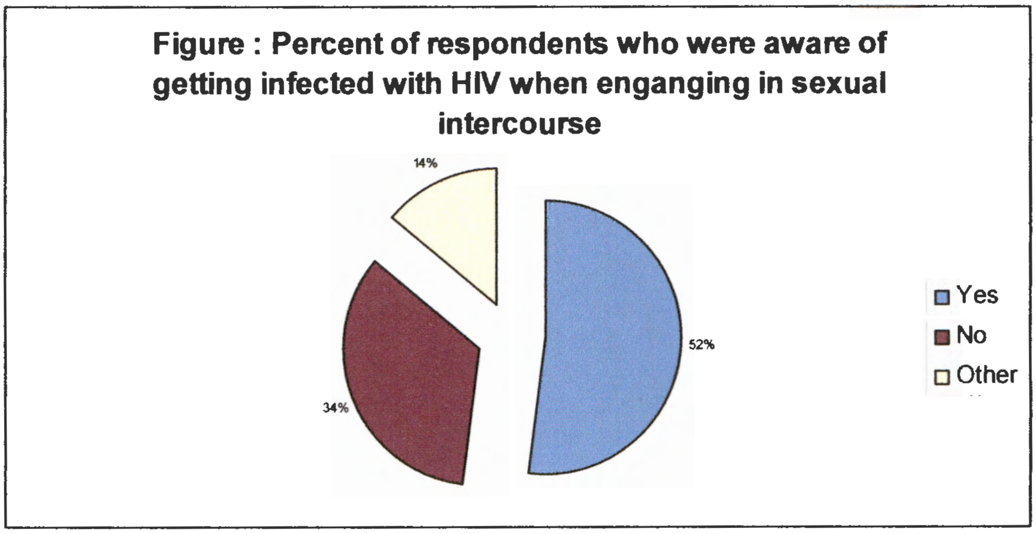
Figure 3.2.26: Consequences of keeping a positive HIV status confidential (N=200)

Keeping one's HIV status confidential had several implications for the infected as 35% of the respondents alluded to continuous isolation, 32% alluded to being depressed and 25% said they lacked support. From that it could be argued that the unsympathetic environment helped maintain the silence. That was linked with what had been reported in papers, where Gugu was brutally killed by community members for disclosing that she was HIV positive. The discrimination and prejudice that prevailed, as well as fear, made most people living with HIV not to disclose their status (Van Dyk 2002), thus perpetuating confidentiality.

Table 28: Awareness of possible consequences of HIV when engaging in sexual intercourse (N=200)

Response	**Frequency**	**Percent**
Yes	104	52
No	68	34
Other	28	14
Total	200	100

Figure 3.2.27: Awareness of possible consequences of HIV when engaging in sexual intercourse (N=200)



Respondents were asked if they were aware of possible consequences of HIV infection when engaging in sexual intercourse. Of the 200 respondents, 52% were aware and 34% were not aware. The remaining 14% could not identify with being aware or not aware and thus were categorised as “other” as the responses included the following: - “Even if I was aware, I had no choice but to sleep with my husband without a condom being a married woman", and "I don't want my partner to leave me as he is providing for me and my children, so if I insist on a condom, that will be the end of the relationship").

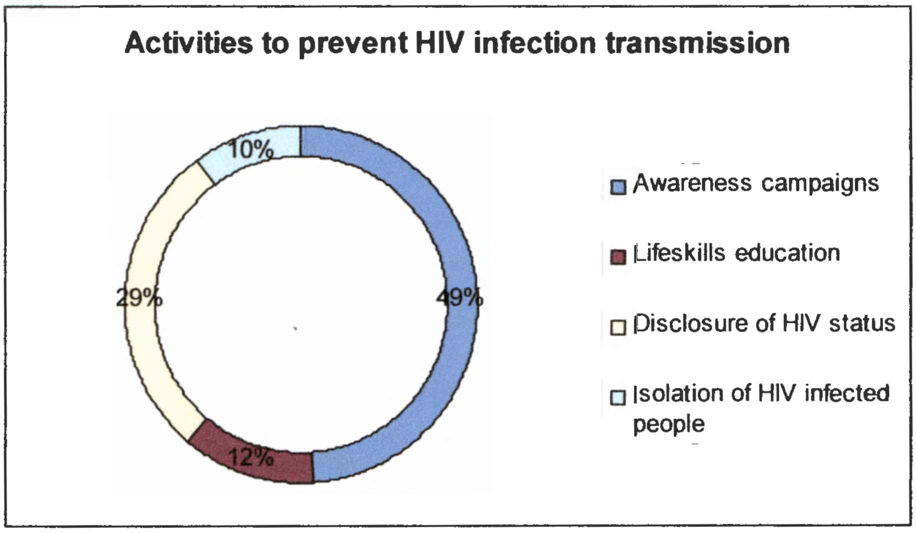
52% respondents who were aware, indicated that they were not in a position to negotiate the use of condom as they are women and feared that their partners would be suspicious as to the reasons why a sudden emphasis on condoms. On the other hand, those who were not aware, took it for granted that they were not at high risk of contracting the infection as they considered themselves safe as a result of a 'monogamous' relationship. That affirmed what (WHO: 1996) indicated in respect of socio-cultural factors having an enormous impact on the issue of confidentiality and exposure to HIV, where women were essentially at more risk in cultures that removed their control over their own bodies.

3.2.28 Activities to prevent HIV infection transmission

Table 29: Activities to prevent HIV infection transmission

Response	Frequency	Percent
Awareness Campaigns	98	49
Life skills Education	24	12
Disclosure of HIV status	58	29
Isolation of HIV infected people	20	10
Total	200	100

Figure 3.2.28: Activities to prevent HIV infection transmission



Just over half of respondents were able to name some activities which could assist in prevention of HIV transmission. Table 29 and Figure 3.2.28 above showed that 49% of respondents knew that awareness campaigns could be of help because more people could be reached and knowledge about HIV and AIDS could be intensified. Only 10% of respondents still believed that isolation of HIV infected people would be of benefit. The other 29% acknowledged that if people could disclose, HIV infection transmission would be reduced and only 12% advocated for life-skills education.

3.3 CONCLUSION

From the responses above, it could be deduced that respondents showed varying degrees of fear, stigma and denial of HIV positive diagnosis. Stigma was believed to be one of the greatest barriers in the management of HIV and AIDS, including treatment. It had been said to foster the growth of the epidemic, as prevention efforts were undermined, due to people' unsafe and risky behavioural patterns, including lack of disclosure of a positive HIV status and not practising sex. A small percentage of respondents had disclosed their HIV status. Those who had not disclosed, lived with fear, shame and secrecy, they even kept their medicines (ARTs) hidden. It therefore made it difficult to take the doses at the right time of the day, especially for those who felt they needed to hide their status from their partners and significant others.

An institutionalised system of patriarchy and financial dependence on men often meant that women could not control when, with whom and under what circumstances they had sex. In addition, women were not expected to discuss or make decisions about sexuality. It therefore became difficult for women to request for, let alone insist on using a condom or any form of protection. If they refused to have sex or request condom use, they often risked abuse, as suspicion of infidelity might arise.

CHAPTER 4

FINDINGS, RECOMMENDATIONS AND CONCLUSION

4.1 INTRODUCTION

This chapter presents the research findings, conclusions and recommendations based on the empirical study and literature review. It will also review the statement of the problem and ascertain whether the objectives of the study have been achieved and assumption proven right or wrong.

The main objective of the study is to determine how confidentiality impacts on the transmission of HIV and AIDS. The other objective is to explore the confidentiality clause in relation to the dilemma and controversy based on the following assumption:
Regulations compelling confidentiality with regard to HIV and AIDS status facilitate or contribute to the rapid spread of the disease.

4.2 FINDINGS

4.2.1 The main finding of the study is the confirmation that confidentiality does contribute to the spread of HIV.

4.2.2 In this study it has been confirmed that most respondents more often than once, have been exposed to STIs. This is an indication that people who contract STIs are at a high risk of HIV infection.

4.2.3 Females are more at risk to contract HIV as compared to males.

4.2.4 The level of education has no impact on the disclosure or use of condom to prevent the spread of HIV.

4.2.5 There is still a lot of denial around accepting one's status. This is perpetuated by resistance to voluntary testing as most people learn about their status because of medical reasons.

4.2.6 The use of traditional healers is used as a way of maintaining the secrecy of the disease.

4.2.7 Generally there is resistance to informing sexual partners about the disease. Partners prefer to pretend as if all is well as they are convinced that no professional will disclose their secret without their consent.

4.2.8 Safe sex is certainly not guaranteed after diagnosis, though the use of condoms is understood as a means of prevention.

4.2.9 Some PLWAH still believe that one's status should be kept confidential and are aware that the confidentiality clause protects their secret. This is perpetuated by fear that disclosure may affect marriage or relationship with partners.

4.2.10 There has been a change in HIV infection among young people. Previously, in most parts of the world, the majority of new infections were in young people between the ages of 16 – 24, sometimes younger. In this study, it is people of ages 34 -38 who are mostly infected. Females remain vulnerable to infection.

4.3 CONCLUSIONS

The study has confirmed that there is facilitation of HIV transmission by maintaining confidentiality and not disclosing a positive HIV status to sexual partners and significant others.

However, some HIV positive respondents wanted to disclose their status but were prohibited by fear of the reaction of significant others as well as sexual partners, and as a result, opted to continue with their sexual life as if all was well, knowing that nobody would breach confidentiality without their consent.

People who are HIV infected, have a moral duty towards other people like their sexual partners and are expected to act in a responsible way, although the extent of this duty and how strong it is, is still open for discussion.

Respecting the confidentiality of personal medical information has its point in respecting the autonomy of individuals, which shows reverence for them as being capable of taking up moral responsibility and leaves them with the possibility of looking after vital interests in an appropriate way.

Counsellors and health professionals in most health facilities lack authority to disclose the HIV positive status of their patients and clients to their sexual partners with an exception of some medical practitioners (doctors), who are authorised by the Health Professions Council. Confidentiality is "shared" among health professionals only when the patient or client is referred for other services, and only upon consent given by the patient or client. Counsellors and other health professionals who are not medical practitioners are left out as they are not covered by this provision.

Condoms, while being a valuable contraception method, are more commonly promoted as an important means of preventing STIs, especially HIV infection. The noted trend is that their use among some PLWHA, who are unemployed young women with secondary level of education, staying with partners, is not satisfactory. While STIs generally increase an individual's chances of contracting HIV, to decrease this risk, STIs must be prevented and if contracted, treated rapidly and effectively. All bacterial STIs are curable. People with STIs are more likely to be exposed to HIV, and become infected with HIV if exposed.

Literature indicated that condom use should be encouraged and accelerated, irrespective of whether a person is HIV positive or not. Even when one has been counselled post HIV diagnosis, it is not easy to disclose one's HIV status and advocate condom use, especially for women, who are mostly affected and are infected by their sexual partners, and are in relationships where their basic right of exercising control over ones' sexuality, fertility and reproduction, is continuously violated.

The overall knowledge about HIV and AIDS mode of spread or transmission is quite impressive, whilst stigma around the diagnosis makes disclosure difficult if not impossible. The notable exception is where there are a few PLWHA who have disclosed their HIV positive status to their partners, whereas others are in denial or live in fear.

The duty to respect confidentiality derives from a more basic duty to respect the autonomy of individuals. The Constitution and other policy documents advocate for confidentiality, respect and privacy for the citizens. In maintaining confidentiality about the positive HIV status, and leaving the individual with the discretionary authority over access to this information, one shows reverence for the autonomy of the individual in a significant respect. This considers the individual to be the master of his or her own well-being.

It is clear from the responses that some HIV positive people are not doing well in terms of condom use, in as far as protecting third parties is concerned. The specific vulnerability of sexual partners needs to be considered to yield sufficient justificatory grounds for putting aside medical confidentiality, not only in cases where the HIV infected persons evidently refuse to protect their partners by informing them, but as a general policy, whether or not HIV infected people appear to be willing to take measures in order to protect their partners from contracting the infection.

It is therefore important to look at what may be harmful to sexual partners of HIV infected people. Dimensions considered essential are the extent, seriousness and probability of occurrence of that harm, and whether it consists of loss of health and life. In the case of HIV and AIDS, as opposed to many communicable diseases, the probability of transmission of the virus or the probability of the harm occurring, depends largely on the willingness of the person already infected to change his or her habits or inform his or her sexual partners.

Generally patients who are HIV positive or suffering from AIDS are entitled to have their right to confidentiality respected. However, if they are a threat to the life of others, it may be necessary to disclose their positive HIV status to prevent the spreading of the disease.

From the literature review, it was found that The Health Professions Council requires doctors to breach the confidentiality rule in cases where their HIV positive patients suffering from AIDS, put other health care workers or the patient's spouse or sex partner at risk. In such cases it is the role of the doctor to persuade the patient to consent to the disclosure being made, and if the patient refuses consent, even after extensive counselling, the doctor should explain that he or she is ethically bound to warn the other parties on a confidential basis. Currently HIV and AIDS have not been made notifiable. The controversy here is that it is not only doctors who deal with PLWHA. Counsellors and other health professionals do not have the mandate. This therefore means they cannot begin to disclose the status of the patient even if they are aware of promiscuous behaviour. It is in such cases that confidentiality tends to have an impact on the transmission of HIV and AIDS. This point proves right the assumption that lack of regulations to compel clients to disclose their HIV status to their sexual partners perpetuates the spread of HIV infection and also achieves the objective that confidentiality perpetuates the spread of HIV and AIDS.

Policy-makers and development agents face significant challenges as they plan around the delivery of HIV and AIDS programmes, in the mist of controversy and dilemma surrounding confidentiality.

4.4 RECOMMENDATIONS

Recommendations emerging from the study deal with aspects which include among others, relaxing the confidentiality clause and extending it to other categories of health professionals involved with counselling patients and clients around HIV and AIDS, formal authority to inform sexual partners of patients and clients about their HIV positive status.

There is an increasing consensus that involving community groups and representatives, peers and family members is a crucial component for successful large-scale roll out of public health programmes, including HIV and AIDS.

In light of the findings and problems identified in this study, the research makes the following recommendations:

1. The government, for example, is doing much enacting laws and regulations, and implementing legal and social support services that protect against discrimination. Further research is essential on the community readiness to accept disclosures made by HIV positive people, particularly their sexual partners.

2. People or couples need to be tested together where possible, because refusal to do so can result in the onward transmission of HIV.

3. Counselling programmes need to be strengthened and should involve strong and professional efforts to encourage, persuade and support HIV positive persons to notify and counsel partners (develop safe disclosure plans), as it was indicated in one study by Palmary (2000), that half of the respondents reported that no one at a public health clinic had ever discussed disclosure of positive HIV status to sex partners.

4. Notification of HIV and AIDS as a communicable disease will ensure accurate statistics. It is currently not known exactly how many patients die because they have progressed from HIV to full blown AIDS, as a result of the confidentiality issue. The decision not to report HIV was the pivotal break with the traditional disease control.

5. Follow-up of contacts is recommended to ensure that partners are informed; barrier methods are employed, to protect the partner and give each other support.

6. The authority to breach confidentiality under exceptional circumstances must be formally acknowledged and apply a blanket approach, where counselors other than medical doctors, need also to be covered, in disclosing the status to sexual partners who are known. Relaxation of confidentiality clause and enforcement of this legislation will provide an opportunity for counselors to be empowered to disclose the status to sexual partners and will help reduce the spread or

transmission of HIV infection, as more people are getting infected.

7. In as much as PLWHA need their rights to be respected, they also have a responsibility to respect the rights of their partners, as outlined by the HIV and AIDS Rights Charter.

4.5 CONCLUSION

The research yielded positive results. Although the mortality rate due to HIV infection has decreased significantly, in the era of potent anti-retroviral therapy, the incidence of new infections has not seen such a dramatic downturn. Most people living with HIV do not know they are infected. More people disclose to family and other significant others, rather than sexual partners, which should not be the case, considering the most common mode of transmission of the infection.

The other challenge is that relationships are not stable and the numbers of sexual partners are almost impossible to establish with any accuracy.

The earlier people know that they are infected, the greater the opportunities for them to access treatment, and make informed responsible decisions about child-bearing, transmission to spouses, and plans for their families' welfare after they fall ill or die.

The experiences of the past decade show that as long as HIV spreads silently and unnoticed, it remains at best a theoretical threat to people and is not taken seriously.

One counselor explains her frustration and is concerned that her counseling efforts have not resulted in behaviour change. *Regarding confidentiality and HIV/AIDS, she said:* ***"you know an HIV positive person going out with someone and you cannot disclose to the other person that status. Some of them go out with more than one person and you feel guilty not telling them. I don't have a solution to this problem. Should we tell the police it is criminal because we have counselled these people. They appear as if they understood, but they still are behaving the same old way".***

The International Guidelines on HIV/AIDS and the Human Rights support voluntary partner notification, but with provision for exceptional cases. They recommend that public health legislation should authorize, but not require, health care professionals to notify sexual partners of their patients' HIV status in carefully defined situations. The discretion granted to health care professionals would also protect against breach of confidence actions by their client, and from civil liability for failure to notify a partner.

Many countries have specific criminal offences for the intentional exposure or transmission of HIV. The existence of these offences has little impact on the spread of the virus, given that the vast majority of cases of transmission occur at a time when the infected person is unaware of his/ her infection. By placing blame on one party, the criminal law undermines public campaigns aimed at placing responsibility for adopting preventive measures on both parties engaging in risky behaviour.

The confidentiality clause needs to be relaxed as professional bodies discipline breaches of confidentiality or unreasonable invasion of privacy as professional misconduct. In the case of legal proceedings, the guidelines propose that it should be possible for any court to issue privacy or confidentiality orders protecting identity in case where HIV status of an individual is likely to be raised. On the contrary, in some countries, evidence laws require rape victims to disclose their HIV status to establish cases of aggravated assault.

Discrimination is one of the most significant human rights abuses in the area of HIV and AIDS. The most effective legal remedy is the enactment of general anti-discrimination legislation, which prohibits unfair and irrelevant distinctions being made on specified grounds. Such laws exist in many countries including South Africa, in various forms, either constitutionally based or under special civil or criminal legislation, so that it is treated like other analogous diseases, and has the benefit of broad-based community lobbying, particularly as HIV can be asymptomatic. The focus of anti-discrimination laws is educative rather than punitive.

The question is: does it suffice to maintain medical confidentiality even in those particular cases where the health of the third parties might be threatened?

It should be understood that the health care or health research professional who finds oneself in a situation in which a person explicitly expresses her or his intention not to inform her or his partner about her or his positive HIV status, whereas the professional knows the name of the partner and has a way of reaching her or him, is confronted with a tragic dilemma. On the one hand, one has a duty to respect confidentiality; on the other hand, one has a duty to prevent serious harm, a duty that could be fulfilled by violating the confidentiality rule.

It is important and disheartening to note that most women, are expected to passively accept their husband's behaviour and decisions, and are unlikely to negotiate in sexual relations.

The belief is that human rights and ethical principles provide a framework by which the dignity and health of those who are infected by HIV are safeguarded. UNAIDS and WHO allude to the fact that adherence to human rights and ethical principles is essential to create an effective public health environment in which most people are encouraged to, and indeed do, change their behaviour, prevent their own infection or onward transmission and receive care.

Finally, general implications of the findings are that beneficial disclosure of HIV status is encouraged, which is voluntary, respects the autonomy and dignity of the affected individuals, maintains confidentiality as appropriate, leads to greater openness in the community about HIV and AIDS and meets ethical imperatives so as to maximize good for both the uninfected and the infected. In America, some states have made partner notification mandatory, so many infected persons decline to nominate partners. However, in the Soviet Union, 64% of known HIV cases was identified as a result of aggressive contact tracing. This means that more work needs to be done in South Africa in that aspect.

It is intended that the findings will help to promote the use of information by managers and policy-makers in the planning of services; review of processes and thus allow them to decide on priority interventions and assist them to appropriately target areas where intervention is most required. This may involve changing the focus and prioritization of HIV and AIDS confidentiality and vulnerability of sexual partners.

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APPENDIX A

P.O.BOX 3403
Mmabatho
2735
14/ 10/ 2003

The Assistant Director
Community Health Services
Greater Mafikeng Sub- District
Mmabatho
2735

RE: APPLICATION FOR PERMISSION TO CONDUCT RESEARCH

I hereby request permission to conduct research in the clinics of Greater Mafikeng Sub-district, offering Voluntary Confidential Counselling and Testing (VCCT) services, on **"THE IMPACT OF CONFIDENTIALITY ON HIV AND AIDS TRANSMISSION"**. I am employed by the Department of Health, stationed at Unit 9 Health Centre, Mmabatho.

The purpose of the study:

- To determine the concept and legislation regarding confidentiality in HIV and AIDS
- To specifically find out the relationship between confidentiality and HIV transmission
- To explore the confidentiality clause for review

The study is supported and supervised by Professor L. Qalinge, of the University of North West.

Hoping that my request will be considered.

Yours truly,

……………………………………
M.Y. Mokgalagadi

Cc Unit 9 Health Centre Facility Manager
Area Manager
Sub-district Manager

APPENDIX B

TITLE: THE IMPACT OF CONFIDENTIALITY ON HIV AND AIDS TRANSMISSION IN GREATER MAFIKENG SUB-DISTRICT

The purpose of this study is to determine whether confidentiality facilitates the spread of HIV and AIDS or not.

INTERVIEW SCHEDULE

Clinic	General Practitioner	Home-based Care/NGO

1. Age

16 – 21	
22 – 27	
28 – 33	
34 – 39	
40+	

2. Gender

Male	
Female	

3. Marital status

Married	
Single	
Widowed	
Separated	
Divorced	

4. Number of children

0	
1	
2	
3	
4 or more	

5. Educational level

Primary	
Secondary	
Tertiary	

6. Living arrangements

Lives alone	
Lives with parents	
Lives with a partner	

7. Employment status

Full time	
Casual	
Self Employed	
Unemployed	
Retired	

Other...

8. Monthly income

Less than R1000,00	
More than R1000,00	
Unemployed	

Other...

9. Year of diagnosis

1999	
2000	
2001	
2002	
2003	

10. How did you know about your positive HIV status

Self referral	
Medical reasons	

Other...

11. Have you ever consulted a traditional healer for your condition

Yes	
No	

12. Have you suffered/ were you ever treated for sexually transmitted infection(s)?

Once	
Often	
Never	

13. How is HIV spread?

Sexual contact	
Mother-to-child	
Drug abuse (needle sharing)	
Blood transfusion	
Uncertain	

14. How is HIV prevented?

Abstinence	
Condom use	
Stick to one partner	
Uncertain	

15. Have you disclosed your positive HIV status to someone?

Yes	
No	

16. If yes to the question above, to whom did you disclose?

Family	
Partner	

Other..

17. What could be the reason(s) for not having used condoms?

They break easily	
Less sexual satisfaction	
Partner refused	
Not available	

Other..

18. Immediately after knowing that you are HIV positive, what was your feeling with regard to confidentiality?

To keep it to myself	
Talk to family member(s)	
Talk to a friend I trust	
Talk to my minister of religion	
Reveal my status to my partner	
Unsure and confused	

19. In your opinion, should people disclose their positive HIV status?

Should be kept confidential	
Should be disclosed to significant others	
Should be disclosed to sexual partner(s)	
Uncertain	

20. Who motivated you to disclose your HIV positive status?

Role of counselling	
Role of support group	
Family	
Partner	

Other..

21. What is your opinion about confidentiality?

Not applicable	
Afraid of the reaction of significant others	
May affect marriage or relationships with partner(s)	

Other..

22. After learning that you are HIV positive, do you practise safe sex?

Yes	
No	
Sometimes	

23. What are the consequences if a positive HIV status is kept a secret?

There is no support	
There is continuous isolation	
A person remains depressed	

Other...

24. Were you aware of possible HIV infection when engaging in sexual intercourse?

Yes	
No	

Other...

25. What activity (ies) should be carried out to prevent HIV infection?

Awareness campaigns	
Life-skills education	
Disclosure of HIV status	
Isolation of HIV infected people	