FACTORS INFLUENCING HIV STATUS DISCLOSURE

Ceridwyn Elza Klopper

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Supervisor: Dr. E.L Stellenberg

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Declaration

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Abstract

Understanding the incidence and prevalence of HIV/AIDS is important in addressing the ongoing epidemic. Understanding which factors influence the rate of transmission of the virus is critical in attempting to contain and ultimately eradicate the disease.

Determining which factors influence a person's decision to disclose his/her positive status to others, particularly the sexual partner, is essential in understanding this complex process and thereby improving disclosure rates.

The aim of the study was to investigate which factors influence the disclosure of someone's HIV positive status.

The objectives were to determine whether aspects such as socio-demographic factors, stigma and discrimination, religion, culture, fear of abandonment and rejection as well as knowledge of the disease influences disclosure rates.

These objectives were met through an in-depth descriptive correlational research design with a quantitative approach. The target population (N=1200/100%) consisted of all the HIV infected clients who attended a Community Health Clinic (CHC) for HIV management in the Cape Metropolitan area. The convenience sampling method was used to select the sample of participants (n=150/12.5%) who met the criteria and voluntarily agreed to participate in the study.

A self-administered questionnaire was used consisting of mainly closed-ended questions, with a limited number of open-ended questions.

Ethics approval for the study was obtained from the Health Research Ethics Committee at the Faculty of Health Sciences, Stellenbosch University. Permission was obtained from the City of Cape Town: City Health, to conduct the research. Informed consent was obtained from each participant.

Reliability and validity were supported by a pilot study which was conducted on (n=15/10%) of participants at this CHC to assure the feasibility of the study.

The data was analysed with the support of a statistician and was presented with histograms and frequency tables. Statistical associations were determined between the various variables. The qualitative data obtained from the open-ended questions were grouped in trends and analysed thematically and then these trends were quantified.

The results show that there are numerous factors which influenced HIV status disclosure.

The fear of stigmatisation was identified as a factor which influences HIV disclosure to others, especially among the male participants. The results revealed that this was the major reason for delayed or non-disclosure, as well as the fear of rejection and blame.

The results showed that awareness of the sexual partner's HIV status remained relatively low (n=64/43%), with awareness of the partner's status highest among married participants.

The recommendations were to assure that HIV positive individuals have access to support groups and are given an opportunity to attend multiple counselling sessions. Community based initiatives are needed to reduce stigmatisation of individuals with HIV and to improve access to social support systems.

It was concluded that disclosure is a multifaceted process and one particular factor does not necessarily influence disclosure of a HIV positive status but most often a combination of factors.

Opsomming

Dit is belangrik om die verspreiding en voorkoms van MIV/VIGS te verstaan om die gesprek rondom die voortdurende epidemie aan te roer. Kennis van watter faktore die snelheid beïnvloed waarteen die virus oorgedra word, is krities in ’n poging om dit onder beheer te hou en uiteindelik uit te wis.

Om te bepaal watter faktore ’n mens se besluit beïnvloed om jou positiewe status van MIV aan andere bekend te maak, veral aan ’n seksuele maat, is dit belangrik om die kompleksiteit van die proses te begryp en sodoende die pas van bekendmaking te verbeter.

Die doel van die studie is om te bepaal watter faktore beïnvloed die bekendmaking van ’n MIV positiewe status.

Die doelwitte is om vas te stel of aspekte soos sosio-demografiese faktore, stigma en diskriminasie, godsdiens, kultuur, vrees vir verlating en verwerping en kennis van die siekte, die insidensie van bekendmaking beïnvloed.

’n Beskrywende korrelatiewe navorsingsontwerp met ’n kwantitatiewe benadering is toegepas. Die teikengroep (N=1200/100%) het bestaan uit al die MIV geïnfekteerde persone wat ’n Gemeenskapgesondheidskliniek vir die bestuur van MIV in die Kaapse Metropolitaanse area besoek het. Die gerieflikheidssteekproef metode is gebruik om die steekproef van deelnemers (n=150/12.5%) te kies wat vrywillig ingestem het om aan die kriteria vir die studie te voldoen.

’n Self-geadministreerde vraelys was gebruik wat hoofsaaklik uit geslote vrae met ’n beperkte aantal ope vrae bestaan.

Etiese goedkeuring vir die studie is verkry van die Gesondheidsnavorsing se Etiese Komitee by die Fakulteit van Gesondheidswetenskappe, Universiteit van Stellenbosch. Toestemming is verkry van die stad Kaapstad: Stad Gesondheid, om die navorsing uit te voer. Ingeligte toestemming is van die deelnemers verkry.

Betroubaarheid en geldigheid is ondersteun deur ’n loodsstudie wat op (n=15/10%) van die deelnemers beoefen is by die Gemeenskapsgesondheidkliniek om die uitvoerbaarheid van die studie te verseker.

Die data is geanaliseer met die ondersteuning van ’n statistikus en is deur histogramme en frekwensie-tabelle voorgestel. Statistiese assosiasies is vasgestel tussen die verskeie veranderlikes. Die kwalitatiewe data is geneem vanuit ope vrae wat gegroepeer is in neigings en tematies geanaliseer is en die neigings is hierna gekwantifiseer.

Die uitslae bewys dat daar heelwat faktore is wat die bekendmaking van MIV statusstatus beïnvloed.

Die vrees vir stigmatisering is geïdentifiseer as ’n faktor met betrekking tot die bekendmaking van MIV aan andere, veral onder die manlike deelnemers. Die uitslae bewys dat dit die hoofrede vir terughoudendheid of nie-bekendmaking van die siekte is, asook die vrees vir ververwerping en blaam.

Die resultate bewys dat die bewustheid van die seksuele maat se MIV statusstatus relatief laag bly (n=64/43%) met bewustheid van die maat se status die hoogste onder getroude deelnemers.

Die aanbevelings is om te verseker dat MIV positiewe individue toegang het tot ondersteuningsgroepe en dat hulle geleentheid gegee word om veelvuldige voorligtingsessies by te woon. Gemeenskapgebaseerde inisiatiewe is nodig om stigmatisering van individue met MIV te verminder en vir die verbetering van toegang tot maatskaplike ondersteuningsisteme.

Ter samevatting kan die gevolgtrekking gemaak word, dat; die bekend making van MIV positiewe status word nie noodwendig beïnvloed deur ’n spesifieke faktor of meervlakkige besluitnemings proses nie, maar eerder deur ’n kombinasie van faktore.

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Acronyms

ART - Anti retroviral therapy

CHC - Community Health Clinic

CNP - Clinical nurse practitioner

GHO – Global Health Organisation

HATC - Health Assessment, Treatment and Care

HIV/AIDS - Human immunodeficiency virus/acquired immunodeficiency syndrome

MSM – Men who have sex with men

RNA – Ribonucleic acid

SA – South Africa

TB – Tuberculosis

USA - United States of America

VCT – Voluntary counselling and testing

WHO - World Health Organisation

Appendices

CHAPTER 1

SCIENTIFIC FOUNDATION OF THE STUDY

1.1 Introduction

Chapter 1 provides an overview of the rationale, aims and objectives of the study. This chapter also briefly describes the methodology which was applied for the purpose of the study including the ethical considerations, definitions and summary of the chapter.

1.2 Rationale and literature review

Understanding the incidence and prevalence of the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) is important in addressing the ongoing epidemic. Understanding which factors influence the rate of transmission of the virus is critical in attempting to contain and ultimately eradicating the disease.

Globally, the HIV/AIDS pandemic has accounted for the death of almost 30 million people (WHO Global Health Observatory, 2009:1). In South Africa, it is estimated that 5.24 million people are living with HIV (Statistics South Africa, 2010:6). The transmission of the virus is mostly through sexual transmission or intravenous drug use. At present, the highest mode of transmission is through sexual contact worldwide (Quinn, 2008:7).

Pinkerton and Galletly (2009:698) identified that the effect of disclosure of HIV status to sexual partners has significant implications in the transmission of the virus. Furthermore, individuals who fail to disclose their HIV status are less likely to change sexual behaviour and practice safer sex than individuals who have disclosed.

Historically, most research which has been conducted on HIV and AIDS has been in the United States of America (USA). The rate of disclosure in the developed world ranges from 42% to 100% (World Health Organisation (WHO), 2004:1). Current casual partners and prior casual partners were found to have the lowest rates of disclosure (Deribe, Woldemichael, Wondafrash, Haile & Amberbir, 2007:81; Gaskins, 2006:39 and King, Katunta, Lifshay, Packel, Batamwita, Nakayiwa, Abang, Babirye, Lindvist, Johansson, Mermin & Bunnell, 2007: 232).

Limited studies on disclosure have been completed in South Africa. In these studies, the researchers mostly applied convenience sampling. Convenience sampling, according to Burns and Grove (2009:353), are those subjects included in the study because they happened to be at the right place at the right time. An example of readily available subjects would be females who attended antenatal facilities during pregnancy, as indicated by Wong, van Rooyen, Modiba, Richter, Gray, McIntyre, Schetter and Coates (2009:216).

Studies which have been completed on men have mostly focused on male to male sexual relationships. Gaskins (2006:39) reported that disclosure to the sexual partner by men who have sex with men (MSM) was 67% - 88%. This rate decreased with casual partners and also if the individual had more than one sexual partner. Again, there was no time period specified from the time of diagnosis to disclosure.

During the researcher's clinical practice it was identified that the majority of HIV positive clients who were treated for minor ailments or injuries, failed to disclose their HIV positive status to their sexual partner. The prevention of new HIV infections does reduce the incidence of HIV and the disclosure of HIV status has been proved by numerous studies to reduce the transmission of the virus (Pinkerton and Gattetly*,* 2007:698; Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007:31 and Wong *et al.,* 2009: 214).

The time period between diagnosis and disclosure is therefore an important factor, although this has not been researched in any detail. Studies reviewing the length of time from diagnosis to HIV disclosure have differed significantly ranging from one day to four years. Often these studies do not specify to whom individuals disclosed their status (Brou, Djohan, Becquet, Allou, Ekouevi, Viho, Leroy & Desgrees-du-Lou, 2007:1912; Deribe *et al.,* 2007:81 and WHO, 2004: 3).

The most frequent time that pregnant women disclose their status according to Brou *et al.* (2007:1916) is just before delivery, during early weaning and upon resumption of sexual activity. Medley, Garcia-Moreno, McGill and Maman (2004:4) established that younger women who had fewer sexual partners and a higher level of education are more likely to disclose. A permanent relationship also had higher disclosure rates of HIV status.

Deribe *et al.* (2007:81) noted that the factors which influence disclosure are the awareness of the partner's status, living in the same home and the phase of the disease. Simbayi *et al.* (2007:31) determined that 42% of participants indicated that they had not disclosed to their sexual partners. It appears that the higher rate of non-disclosure was among married men who had more than one sexual partner. Most research suggest that the barriers to disclosure include fear of abandonment, loss of financial support, discrimination, violence and fear of being accused of infidelity (Gaskins, 2006:39 and Medley *et al.,* 2004:1).

Disclosure to non-sexual partners is important, as it has been shown to increase emotional and social support, improves access to medical care, namely anti retroviral therapy (ART) and reduces stress according to Medley *et al.* (2004:1). This aspect does not directly influence the transmission of the virus nor reduces the incidence of HIV.

According to Pinkerton and Galletly (2009:698) disclosure to the sexual partner does reduce the transmission of the virus by allowing for safer sexual practice, namely increasing condom use, reducing the number of sexual partners and abstinence. The use of condoms was found to be between 60% – 70%, but with the use of substances, mostly alcohol, this decreased dramatically.

Limited research has been conducted on the process of HIV disclosure. A study completed by Eustace and Ilagan (2010:2100) found that although health care professionals may have high quality training in testing and counselling techniques, there is minimal understanding of the concept and elements of HIV disclosure. There are multiple factors associated with disclosure and these rates remain low.

1.3 Significance

The completion of this study provided scientific evidence regarding the factors which influence a person's decision to disclose his/her HIV positive status to others, particularly the sexual partner. This information may assist health care professionals in understanding the complex elements of disclosure. Disclosure is an important prevention goal emphasised by the WHO in their protocols for HIV testing and counselling (Medley *et al.,* 2004:3).

1.4 Research problem

As described above there is evidence that the rates of HIV disclosure remain low. It was noted in a systematic review completed by WHO (2004:3) that research is needed to answer a number of outstanding questions, one of which is to describe the process and length of time that people require to disclose results to sexual or network partners. The consequences of non-disclosure, specifically to sexual partners, increase the transmission of the virus. It is therefore important to scientifically investigate the various factors that influence the disclosure of a positive HIV status.

1.5 Research question

The question explored in this study was: What are the factors that influence disclosure of a person's HIV positive status?

1.6 Research aim

The overall aim was to investigate the factors which influence the disclosure of a person's HIV positive status.

1.7 Research objectives

The specific objectives set for this study were to determine whether the following factors influence HIV status disclosure:

- Socio-demographic factors
- Stigma and discrimination of HIV positive individuals
- Religion
- Culture

- Fear of abandonment and rejection
- Knowledge and understanding of the disease.

1.8 Research Methodology

A brief overview of the research methodology applied in this study is described, with a more detailed account in chapter 3.

1.8.1 Research design

A descriptive correlational design with a quantitative approach was applied to determine the factors influencing disclosure of HIV.

1.8.2 Population and sampling

The target population, for the purpose of this study, was all the HIV infected clients who attended a Community Health Clinic (CHC) for HIV management in the Cape Metropolitan area. A total number (N=1200) HIV infected clients receive their treatment at this particular clinic, approximately 60 clients per day. The sample was selected from this clinic and the convenience sampling method was applied. This included the first 150 clients who met the criteria and voluntarily agreed to participate in the study.

1.8.3 Measurement instrumentation

A closed-ended questionnaire, with a limited number of open-ended questions, was used to determine the factors which influence the decision to disclose one's HIV positive status. A self-administered questionnaire was developed for the purpose of this study (Appendix A). Dichotomous and categorical questions were utilized.

1.8.4 Pilot study

A pilot study was conducted using (n=15/10%) of the anticipated number of participants of the main study conducted at the CHC to test the questionnaire for validity and reliability of the questions, including the feasibility of the methodology of the study. The data obtained from the pilot study was not included in the final analysis.

1.8.5 Reliability and validity

The questionnaire was distributed to five experts to verify content, face, criterion and construct validity, as described by de Vos, Strydom, Fourie and Delport (2009:160-162) in the field of HIV/AIDS.

A statistician was consulted for the statistical feasibility of the instrument and was consulted throughout the study.

1.8.6 Data collection

A self-administered questionnaire based on the objectives of the study was distributed to the participants to complete. The researcher assisted the participants when required, specifically when a respondent had a language or literacy problem and had any questions relating to the questionnaire.

1.8.7 Data analysis

A statistician was consulted with regards to the analysis. The quantitative data was captured on a Microsoft Excel spreadsheet and STATISTICA version 9. Distributions of variables were presented with histograms and frequency tables. Statistical associations were determined between the various variables using tests such as CHI-square, Spearmen and t-tests.

1.9 Ethical considerations

Ethical approval for the study was obtained from the Health Research Ethics Committee at the Faculty of Health Sciences, Stellenbosch University (Appendix B). Permission was obtained from the City of Cape Town: City Health (Appendix C). Informed consent was obtained from the participant (Appendix D) and a participant information leaflet (Appendix E) was distributed to each one. The participant’s identity remained anonymous and they had the right to withdraw from the study without consequences at any time.

Due to the sensitivity of disclosing one's HIV status, a counselling service was provided for participants who become emotional or who found it difficult to disclose. Support was provided to the client who desired to discuss various aspects of the condition. Contact numbers for counselling were provided and where necessary clients were referred to appropriate services with their permission.

The ethical aspects are discussed in more detail in paragraph 3.8.

1.10 Operational definitions

Human immunodeficiency virus (HIV) – HIV type 1 is responsible for the global pandemic. HIV-1 is a rapidly evolving virus, due to the error-prone nature of reverse transcriptase and the high viral turnover. (Wilson, Cotton, Bekker, Meyers, Venter & Maartens, 2008:16).

Sero-conversion – The development of antibodies in response to infection (Evian, 2010:341). The status may be seropositive or seronegative for a particular antibody, i.e. the HIV antibody is present via ELISA and WESTERN BLOT or through HIV Ribonucleic acid (RNA) (viral load) measurement (Wilson *et al.,* 2008:16).

Disclosure – Disclosure is the process of making known to others the seropositive or seronegative status with specific regard to HIV infection (Zunniga, van Cutsem & Saranchuk, 2010:239).

1.11 Time frame

The time frame for the completion of the entire study was 1 year.

1.12 Chapter outline

Chapter 1: Scientific foundation of the study

Chapter 1 describes the rationale and background of the study. It also provides an overview of the literature, research question and objectives, methodology and the definitions applied in the study.

Chapter 2: Literature review

In chapter 2, the literature review, regarding factors influencing the disclosure of a HIV positive status is discussed, as well as the conceptual framework.

Chapter 3: Research methodology

Chapter 3 describes the research methodology applied in the study.

Chapter 4: Data analysis, interpretation and discussion

Chapter 4 describes the data analysis, interpretation and discusses the results of the study.

Chapter 5: Discussion, conclusions and recommendations

Chapter 5 summarizes the findings and recommendations that are formulated.

1.13 Summary

It is interesting to note that the rate of disclosure has only increased marginally over the years and that the rates of disclosure also varied vastly in a single study and across different studies, from approximately 20% to 80%. Numerous studies indicate that an individual has disclosed but does not specify the time period between diagnosis and disclosure, and to whom (Brou *et al.,* 2007:1912; Deribe *et al.,* 2007:81 and WHO, 2004:3). The rates of disclosure, particularly to casual sexual partners, remain low. This puts numerous people at risk of contracting the virus and thus continuing the relentless transmission of the disease.

Identifying factors which influence this decision could lead to an enhanced understanding by health care professionals and thereby utilizing this information to improve disclosure rates.

1.14 Conclusion

HIV disclosure and the associated processes that influence a person's decision to disclose or not to disclose were described. A better perspective of the concept of HIV disclosure is required to support and meet the needs of people living with HIV/AIDS (Eustace *et al.,* 2010:2100).

Chapter 2 will present the findings of the literature review of existing evidence, which underpinned the development of the research focus and approach.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

Chapter 2 presents the results from an extensive review of the relevant literature. According to De Vos *et al.* (2007:123) the literature review is aimed at contributing towards a clearer understanding of the nature and meaning of the problem that has been identified. The literature review was therefore undertaken to determine which factors influence HIV status disclosure and to describe the conceptual framework which guided the study.

New research has found that the Human Immunodeficiency Virus (HIV) diversified from chimpanzees to humans and can be dated to the beginning of the twentieth century. Assistant Professor of Ecology and Evolutionary Biology, Michael Worobey, reported that evolutionary genetic studies were conducted from a paraffin-embedded lymph node biopsy specimen obtained from an adult woman in 1960, which had been preserved by doctors in Kinshasa. He discovered that the diversification of HIV-1 occurred long before the AIDS pandemic was acknowledged (Worobey, Gemmel, Teuwen, Haselkorn, Kunstman, Bunce, Kabongo, Kalengayi, Muyembe, Van Marck, Gilbert, & Wolinsky, 2008:661).

Since the beginning of the epidemic, more that 60 million people have been infected with the HIV virus and nearly 30 million people have died of AIDS. In 2009 there was an estimated 33.3 million people living with HIV (WHO Global Health Observatory, 2009:1) In South Africa, it is estimated that 5.24 million people are living with HIV (Statistics South Africa, 2010:3). The transmission of the virus is mostly through sexual transmission or intravenous drug use (Quinn, 2008:7).

In Sub-Saharan Africa more than 65% of the population is infected with HIV, despite being only 10% of the world’s population (Quinn, 2008:7).

2.2 Disclosure

The incidence of the disease is aggravated further by the effect on disclosure or non-disclosure of HIV status to sexual partners which has implications for the transmission of the virus. Empirical evidence proposes that delayed or non-disclosure of individuals with HIV continue to practise unsafe sexual behaviour and high risk drug-sharing behaviour (Eustace & Ilagan, 2010:2095). A number of people who are on tuberculosis (TB) treatment and ARV's revealed that TB treatment makes it possible for them not to disclose their HIV positive status, as they are able to conceal this under the guise of TB, preventing perceived stigmatisation (Gebrekristos, Lurie, Mthethwa & Karim, 2009:1).

HIV/AIDS is considered to be a socially degrading illness which results in stigmatisation of an individual who is HIV positive. Furthermore, this study found that despite the fact that disclosure is considered to be important as it increases emotional and social support; it may place an individual at an increased risk of abuse and discrimination (Chaudoir, Fisher & Simoni, 2011:1618).

Simbayi, Kalichman, Strebel, Cloete, Hendra and Mqeketo (2006:31) determined that 42% of participants in a study indicated that they have not disclosed to their sexual partners. This study also found that non-disclosure is associated with a higher number of sexual partners and that there is also an increased correlation of high risk sexual behaviour in these individuals.

Pinkerton and Galletly (2009:702) identified that an increase in the use of condoms resulted predominantly after disclosure. The use of condoms reduces the transmission of the virus from 17.7% to 40.6%.

The implications of disclosure were investigated by Brou *et al.* (2007:1915) who identified that the rate of disclosure by HIV negative women is as high as 96.7%, while only 46.2% of the HIV positive women disclose their status to sexual partners. The researchers also found that 'HIV-infected women are less likely to disclose their HIV status when they live with their own family, but without their partner, than when they live with their partner only'. It was also noted that the most frequent time of disclosure was just before delivery, during early weaning and upon resumption of sexual activity (Brou *et al.,* 2007:1912).

Medley *et al.* (2004:300) established that younger women who have fewer sexual partners and a higher level of education are more likely to disclose. A permanent relationship also yielded more encouraging results.

According to Deribe *et al.* (2007:81) it was estimated in 2007 that almost one million people were HIV positive in Ethiopia. This study found that 90.8% disclose to their current main partner but in 14% this is delayed with no specific time period stated from diagnosis to disclosure. These results are supported by a study conducted in four antenatal clinics in South Africa which shows that women have difficulty in disclosing their HIV status to their partners. It is a consistent finding in developing countries where most women are dependent on their partners for financial and social support. Often women are diagnosed HIV positive when they present at the antenatal clinic because of pregnancy. This is an overwhelming and distressing experience for many of these women (Visser, Neafeld, de Villiers, Makin and Forsyth, 2007:1138).

Medley *et al.* (2004:299) identified in a systematic review on HIV disclosure to sexual partners, the rates amongst women who disclose their positive HIV status varied from 16.7% to 86%.

2.3 Time of disclosure

Deribe *et al.* (2007:85) found that the time from diagnosis to disclosure varied from one day to two years. It was found that 73% disclose on the day of the results, but it is not specified to whom. These results are supported to some extent by Wong *et al.* (2009:217) who identified that 13% never disclose to anyone and 36% do not disclose to their sexual partner. The average time of disclosure is 16 months. Visser *et al.* (2007:1141) stated that 59% of women disclose soon after diagnosis (time not specified) to one other individual, though to whom specifically is unknown. According to Medley *et al.* (2004:300) 22% of pregnant women disclose two months after diagnosis and 41% by the fourth year. Research thus indicates that over time more women reveal their HIV positive status. This would indicate that as times increases so does the rate of disclosure.

2.4 Factors which may influence disclosure

Numerous factors may influence disclosure of a positive HIV status. These include age, sex, race, relationship status, financial aspects, religion, culture, educational level and awareness of the partner's status. The common barriers to disclosure include fear of discrimination, stigmatisation, fear of blame, rejection and abuse and lack of understanding of the disease (Gaskins, 2006: 39; Medley *et al.,* 2004:1).

Two types of HIV disclosure were assessed by Wong *et al.* (2009:261), using the dependent variables as sex partners and network disclosure. The sexual partner was a spouse, boy/girlfriend, casual partner or commercial sex worker. The network disclosure was to immediate family, other relatives, friend, health practitioner, religious leader or employer.

The study found that 87% of HIV positive individuals disclosed their status to at least one person, but that 36% of these individuals did not disclose their HIV status to their sexual partner. There is no differentiation whether it is a long-term partner or a casual partner.

2.5 Socio-demographic factors

2.5.1 Age

The age of the individual who is HIV positive and the rates of disclosure thereof vary slightly. It seems that younger people are more likely to disclose to their sexual partner than older people. According to O'Brien, Richardson-Alston, Ayoub, Magnus, Peterman and Kissinger (2003:732) participants older than 22 disclose most often to sexual partners or an immediate family member, while participants older than 35, seem more willing to disclose to a friend. Women younger than 24 years of age are more likely to disclose than older women and specifically to their sexual partners (Medley *et al.,* 2004:300).

The results of a study completed in Uganda by Kadowa and Nuwaha (2009:28) were however different. The study shows the mean age of those who disclose are 38 years and 31 years for those who never disclose. This may be due to associated factors, such as relationship status and the number of sexual partners in the previous two years (Kadowa & Nuwaha, 2009:28).

2.5.2 Gender

The relationship between gender and HIV/AIDS become significant as it is influenced by gender inequality and discrimination. Gender is a social construct and relates to roles and responsibilities of a male or female (Türmen, 2003:411). The financial and social status of women in many communities is lower due to the fact that they are women. A study completed in Nigeria noted that the rapid transmission of HIV included numerous aspects, one of which is the low status of women (Akpa, Adeolu-Olaiya, Oulsegun-Odebiri & Aganaba, 2011:19).

In some societies it is not considered masculine to access health care services so men often access treatment later than women. They are often at an advanced stage of HIV and present with severe opportunistic infections. In these societies the value of women's health is minimal due to power inequalities which result in subordination of women (Greig, Peacock, Jewkes & Msimang, 2008:S36).

2.5.3 Race

Trust has always been a crucial part of health care provider and client relationships, especially among different race groups. Benkert, Peters, Clark and Keves-Foster (2006:1532) stated that it is known that African Americans experience racism within the health care system. Empirical evidence has indicated racial disparities in quality and outcomes of treatment. The perceived racism is not influenced by age or gender.

'Racism is insidious, cumulative and considered to be a chronic stressor in the life of most African Americans' (Benkert *et al.,* 2006:1532).

Discrimination often results against a group of people, such as a specific racial group, that are most affected by a condition such as HIV (Akpa *et al.*, 2011:19).

2.5.4 Relationship status

The relational status of individuals does influence the willingness to share or not share their HIV status. According to Gaskins (2006:38) people do not always disclose to their partner's. This is also influenced by the number of partners. As the number of partners increase, the rate of disclosure decreases.

Married women are more likely to disclose to their sexual partners than women in cohabitating relationships (Gari, Habte & Markos, 2010:9).

According to Chaudoir *et al*. (2011:1622) disclosure rates were higher to steady partners in comparison to those who have casual partners. This was supported by O Brein *et al.* (2003:731) who found that disclosure was significantly higher to steady partners. This rate also increases according to the stage of the disease, where individuals who are ill are more likely to disclose than those who are asymptomatic.

Research from South Africa reveals 'poorer women are more likely to have experienced early sexual debut, a non-consensual first encounter and higher rates of physically forced sex for money, goods, or favours – all significant risk factors for HIV' (Greig *et al.*, 2008:S38).

2.5.5 Religion and culture

Religion and cultural aspects have also been considered in a limited number of studies with regards to attitude about HIV and Anti-retroviral drugs (ARVs). According to Zou, Yamanaka, John, Watt, Ostermann and Thielman (2008:81) it appears there is still a strong belief that people with HIV have done something wrong and are now being punished by God. Of the over 400 parishioners included in the study, 80.8% state that prayer could heal HIV, although believers accept the power of prayer and the healing thereof, 93.7% still prefer the option of medical treatment.

Zou *et al.* (2008:75) found that religion and the perceived fear of stigmatisation are closely related, yet 84.2% of the sample feels that they will disclose their HIV positive status to their partner. This is the intention to disclose, not actual disclosure.

Clients reported cultural mistrust in mental health counsellor-client relationship, which has resulted in the client discontinuing counselling, possibly affecting support of HIV disclosure (Benkert *et al.,* 2006:1532).

In Nigeria the results of a logistic regression showed that Muslims are stigmatized more often if their partners die from AIDS. Culture prevented Muslims, especially women, from even attending HIV/AIDS clinics (Akpa *et al*., 2011:24). The cultural differences are also described by Eustace and Ilagan (2010:2098). In countries such as India and Africa, individuals mostly disclose to family, whereas in the West, disclosure is most often to friends.

Another aspect of concern is the cultural norms of a society. In some instances it is considered that promiscuity is acceptable in men, combined with the encouragement to drink alcohol or abuse drugs, which increase high risk sexual behaviour (Türmen, 2003:412). Individuals are less likely to disclose their HIV status if they have multiple sexual partners and more likely to engage in unprotected sex (Eustace & Ilagan, 2010:2098).

2.5.6 Educational level

There are two aspects to consider when attempting to determine whether education influences HIV status disclosure.

The first is the educational level of the individual i.e. the academic achievement level in school or tertiary education. Secondly, the knowledge of HIV/AIDS and educational opportunities the individual has access to. Male participants of a study completed in a small rural area claimed that ignorance about HIV made disclosure difficult. As one man quoted ‘People look down on you real bad. They are not educated’. These men also related that more knowledge on HIV and treatment options are urgently required (Gaskins, 2006:43).

Lack of knowledge of HIV is directly related to the educational level of an individual and may be related to cultural practices in some instances. According to Türmen (2003:411) ‘many cultures value ignorance about sexual interaction as a feature of femininity, jeopardizing their education’. This study completed in Cameroon revealed that women aged 15-24 have heard about AIDS but only 16% understand the implication of HIV infection. Substantiated further, a study in the Philippines shows that 91% have heard of the disease, but only 4% have substantial knowledge about the infection (Türmen, 2003:411). Individuals with a higher level of education are more likely to disclose which often results in safer sexual practice (Medley *et al.,* 2004:300).

The choice to commence on ARV's was found to be directly related to an educational level and knowledge of the medication. The higher the level of education the more likely the individual would be inclined to start treatment (Zou *et al.*, 2008:74).

It has been reported that individuals with higher education are more likely to disclose their HIV status than those with a basic education or those who are illiterate. (Deribe *et al.,* 2007:82). However, other studies have noted that there is no significant difference in disclosure rates with regards to a level of education (Gari *et al.,* 2010:9; Kadowa & Nuwaha, 2009:28).

2.5.7 Awareness of partner's status

The rates of disclosure are influenced by awareness of the partner's status and in most studies it has been established that individuals are less likely to disclose if they are unaware of the partner's status.

Knowledge of one's partner's status empowers an individual to make safe choices with regards to sexual behaviour such as abstinence and condom use (O'Brein *et al.,* 2003:731). A study conducted by King *et al.* (2007:232) found that, in summary, the highest rates of disclosure are among married participants who have attended an Aids support organization for more than two years and are aware of their partner's status.

Deribe *et al*. (2007:81) stated that 20% of the participants are not aware of their sexual partner's HIV status and at times disclosure was made after sexual contact with the partner. When an individual knows that the status of their partner is negative, the disclosure rates are low. Simbayi *et al.* (2006:33) found that 39% of people are unaware of their partner's status. Unprotected sexual contact is most common when both individuals are oblivious of each other’s status. A related factor is that these individuals are more likely to engage in unsafe sexual behaviour and have more partners. The reasons for non-disclosure are mostly cited as fear of discrimination. There is an attitude of ‘not asking and not telling’.

Women are more likely to disclose to their HIV positive partner than those who do not know the status (Gari *et al.,* 2010:11).

2.6 Barriers to HIV status disclosure

2.6.1 Discrimination of HIV positive individuals

Skinner and Mfecane (2004:161), are concerned with the level of care people can access when many individuals felt that they are unable to tell anyone of their positive HIV status. Goudge, Ngoma, Manderson and Schneider (2009:94) also looked at the individual’s ability to deal with being discriminated against as a way of increasing the individual’s willingness to disclose. Fear of discrimination reduces the willingness to disclose and this reduces the potentially important sources of support, such as family and friends (Skinner & Mfecane*,* 2004:161).

It seems that in some countries, HIV is seen to be a woman’s or prostitute’s disease, which leads to avoidance of medical intervention, due to the fear of being discriminated against. The preferred care of HIV infected, pregnant women in Thailand is to recommend termination of pregnancy, rather than preventing transmission to the infant (Türmen, 2003:416).

2.6.2 Stigmatisation of HIV positive individuals

Stigma is identified as an important factor at the start of the HIV/AIDS epidemic which impacts on the rapid transmission of the disease (Akpa *et al*., 2010:19).

Adedimeji (2009:16) noted that the main reason for non-disclosure is stigma and being frightened of the outcome. Stigma is defined as the ‘mark of social disgrace and as being shameful’ (Collins Compact Dictionary & Thesaurus, 2006). Gaskins (2006:38) noted that due to the fact that rural communities are more conservative, the stigmatisation of HIV is amplified. The lack of education with regards to HIV and the lower economic status also contribute to the stigma of HIV. This may result in delayed access to treatment and poor adherence to medication. Goudge *et al.* (2009:94) quoted stigma as a major detriment to disclosure.

Specifically Akpa *et al.* (2010:19) reported that in some parts of Nigeria stigmatisation has increased. This results in societies responding in fear, denial and stigma which in turn give rise to prejudices against people with HIV. This factor, among others, is negatively affecting HIV testing. In low prevalence areas, such as Ireland, stigmatisation may be more pronounced (Adedimeji, 2009:16).

HIV/AIDS is a socially devalued attribute which negatively impacts on disclosure rates (Chaudoir *et al.*, 2011:1621). It is also considered a social construction that significantly affects the lives of individuals with HIV, including the partner, family and friends (Norman, Chopra & Kadiyala, 2007:1775).

Stigma is often internalized by people living with HIV, for example, if society is ashamed of the individual, the person feels ashamed of himself. This results in decreased self esteem, feeling dirty, ashamed and depressed. A study completed in Cape Town, South Africa, reported that 30% of people with HIV admitted to being depressed. (Simbayi, *et al.,* 2007:1829).

2.6.3 Due to the fear of blame, rejection and abuse

Simbayi *et al.* (2006:31) reported that individuals often attempt to hide their HIV positive status. This is due to previous negative responses. According to Wong *et al.* (2009:215) the major reasons for non-disclosure are the ‘need for privacy’ and being frightened of losing their partners, as well as violence against them. Furthermore, Visser *et al.* (2007:1138) identified in their study of pregnant females that they are often reluctant to disclose to their partners as they are financially and socially dependent on them.

It did emerge that in most instances, in both developed and developing countries, the action of disclosure resulted in positive outcomes, such as better support, acceptance and reduced anxiety levels. Outcomes which result in violence are reported to be more common in sub-Saharan Africa than in the USA. The results also show that women in sero-discordant couples are the ones who experience the highest rate of violence (WHO, 2004:17). A limitation noted in this study is that there are discrepancies between the intention to disclose and actual disclosure behaviour.

2.7 Interventions

Pinkerton and Galletly (2007:702) suggested that support programmes are required to increase disclosure rates which should advocate the use of condoms.

Furthermore Adedimeji (2009:22), found that more effort should be focused on the service provider to assist clients with managing and counselling techniques in a setting where stigmatisation may be more prevalent due to the lower incidence of HIV. According to the Gaskins (2006:42) it was noted that the majority of individuals who participated in their study warned others to be careful when sharing information about their positive HIV status. It was also noted that education about HIV/AIDS is urgently needed to improve the situation of people living with HIV in rural communities.

Voluntary counselling and testing (VCT) programmes include providing support and advice on the disclosure process. Disclosure provides an awareness of the risk of contracting HIV and leads to increased VCT of the untested sexual partner (Kadowa & Nuwaha, 2009:26). This study also noted that couples can make informed decisions with regard to reproductive health which may reduce the risk of transmission from the mother to the child. A recommendation made by Greig *et al.* (2008:S40) was ‘to promote HIV testing for men and ensure that gender issues are addressed in all VCT programmes, as well as the aspect of disclosing’.

The turnaround of stigmatisation and empowering individuals to deal with this attitude of others were felt to be important by Simbayi *et al.* (2006:33). Medley *et al.* (2004:302) emphasised that the prescribed time allocated for counselling and testing for HIV are five to seven minutes and more time must be allowed for this multifaceted procedure. The WHO (2004:21), emphasises that partners should be encouraged to be counselled and tested together, which will then promote disclosure and encourage support groups. The use of role play is also suggested to allow individuals to broaden their own ability to disclose to their sexual partner.

2.8 Conceptual theoretical framework

Burns and Grove (2009:126), define a conceptual framework as an abstract, logical structure of meaning. It guides the development of the study and enables you to link the findings to the body of knowledge used in nursing. The conceptual framework selected for this study is a bio-psycho-socio-environment model of health, The Mandala of Health as illustrated in figure 2.1.

This model describes the individual as the central focus, whom the family protects, from the community and the culture. The community and society is a holistic eco-system which conceptualizes the contemporary approach to wellbeing. The individual is considered to be the most central focus, surrounded by family.

The individual's health is influenced by four other significant aspects in this model, namely, human biology, personal behaviour, psychosocial environment and the physical environment. The human biology relates to the physical condition of wellbeing or illness, in this instance the HIV positive individual whose immune system is compromised and is therefore ill. The personal behaviour relates to whether an individual adopts safe behaviour practice or is involved in risk taking behaviour, i.e. unprotected sexual contact.

The psychosocial environment relates to the social status of the individual and more importantly for the HIV positive individual, to the social support systems which would need to be accessed to ensure quality care and treatment. The physical environment also affects the individual and family and includes aspects such as adequate housing, satisfactory living conditions and the work environment.

The lifestyle of an individual, the medical system and the community also has a major influence on a person's health. The lifestyle of the individual is not the same as personal behaviour but rather the influences and constraints imposed by society and the culture that an individual lives in, which may result in discrimination and stigmatisation, as seen with HIV. The medical system is concerned with the physical condition of an individual and the behaviour associated with it, which is part of the community. There is a perception that the behaviour of the individual directly resulted in acquiring HIV and therefore there is some accountability for this illness.

These above aspects are found within a community which imposes its values, judgment and support and have an effect on an individual's health.

The human-made environment and finally the culture are an integral part of how health is perceived and the attitude towards health or illness. The human-made environment incorporates the wider sphere such as agriculture, transport, education and others which affect health.

The cultural values and beliefs influence perceptions towards health and illness and how they are perceived. We are all part of the biosphere which is a fundamental part of nature.

All of the above aspects influence an individual whose HIV status is positive and the willingness or not to disclose their status to others (Hancock & Perkins, 1985:8).

2.8.1 Conceptual Map

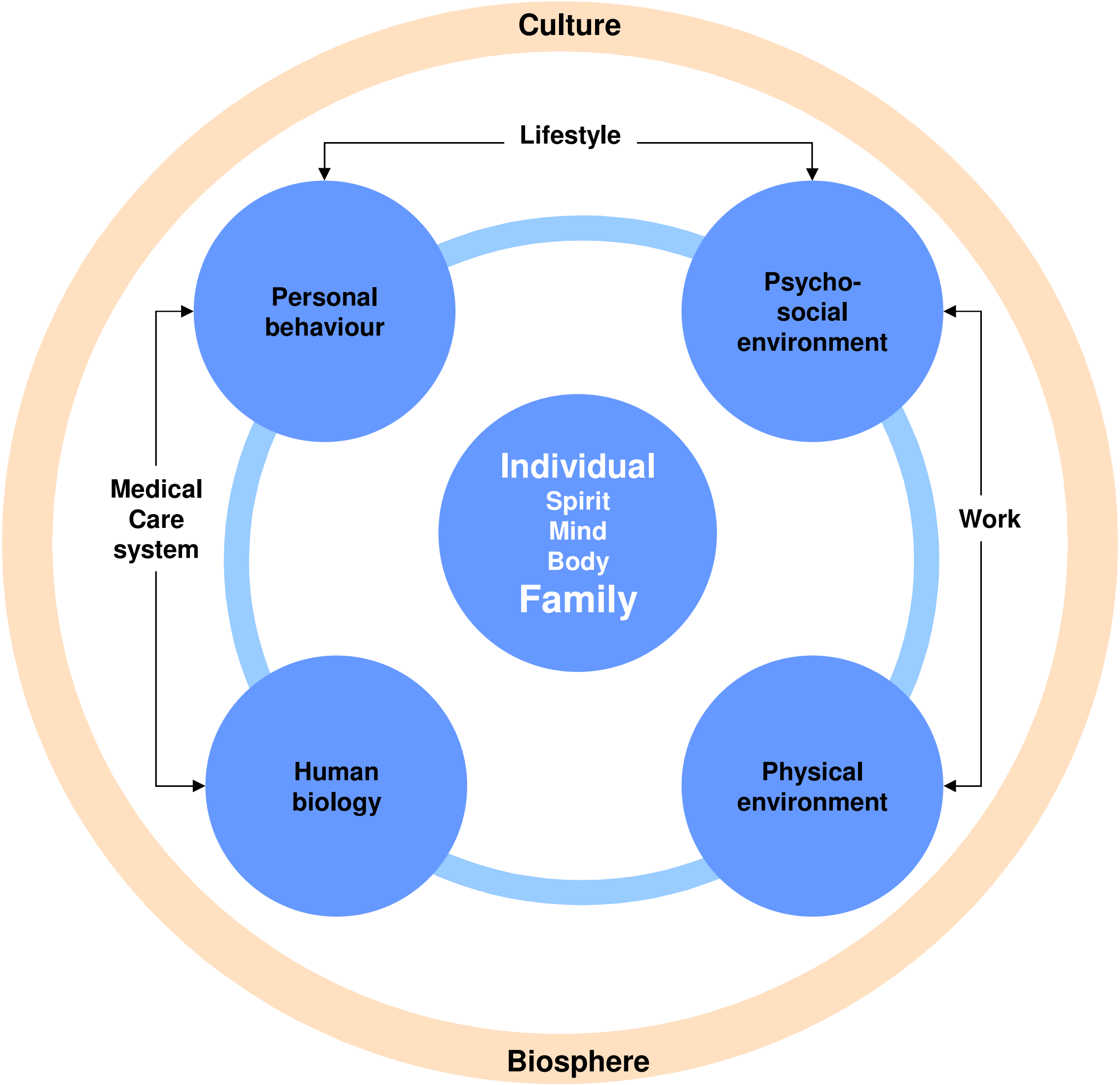


Figure 2.1 - The Mandala of Health – a model of Human Ecosystem

(Hancock T & Perkins F, 1985:9)

2.9 Summary

It was interesting to note that the rate of disclosure has only increased to some extent since 2007. The rates of disclosure also varied widely in a single study and across different studies, from approximately 20% to 80%.
According to WHO GHO (2009:1) 33 million people are living with HIV. The spread of the virus is primarily through sexual transmission or intravenous drug use (Quinn, 2008:7).

The rate of disclosure, particularly casual sexual partners, remains low. It seems that the highest rate of non-disclosure is married men with more than one casual sexual partner. This puts numerous people at risk of contracting the virus and continuing the relentless transmission of the disease.

Interventions are needed to determine whether broader-based initiatives such as community-based stigma reduction interventions have an impact on HIV testing and disclosure rates (WHO, 2004:31).

The time from diagnosis to disclosure has not been reviewed in most studies. In studies where this has been reviewed, it seems to be any length of time from nine months to two years. Programmes implemented to encourage disclosure are only minimally effective and these rates are still low.

2.10 Conclusion

Chapter 2 reveals the results from the review of the current literature and presents a summary of the numerous factors which influence HIV status disclosure. It provides a description of the various factors which persuade an individual whether or not to disclose this HIV positive status to others, either their sexual partner or network partners.

The research has shown that disclosure of HIV positive status, to sexual partners, results in safer sexual practice, such as increased condom use and a reduction in high risk sexual behaviour, which thereby decreases the transmission of the virus. Disclosure to network partners, such as family, friends, work colleagues and religious leaders, has an indirect but definite impact on the transmission of the virus too. The reason for this is that, in most instances, the individual is then able to access treatment without the fear of being discovered attending the clinic and there is increased emotional support.

An improved understanding may support the evaluation of the current programmes which advocate disclosure and to then adapt these to further improve the disclosure rates of individuals with HIV/AIDS.

Chapter 3 will present the research methodology applied in the study.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

The research methodology refers to the process or plan for conducting the specific steps of the study (Burns & Grove, 2009:719). It is important that the researcher has a specific plan in order to decide which methodology to apply to the particular proposed study. Research designs are the plans and the procedures for the research that span the decisions from broad assumptions to detailed methods of data collection (Creswell, 2009:3). Chapter 3 describes the methodology and the design which was applied in the study.

3.2 Research Question

A research question is a concise, interrogative statement and includes one or more variables (Burns & Grove, 2009:167).

The question explored in this study was: What are the factors that influence disclosure of a person's HIV positive status?

3.3 Goal of the study

The overall purpose of the study was to investigate the factors which influence the disclosure of a person's HIV positive status.

3.4 Research objectives

The specific objectives set for this study were to determine whether the following factors influence HIV status disclosure:

- Socio-demographic factors
- Stigma and discrimination of HIV positive individuals
- Religion
- Culture

- Fear of abandonment and rejection
- Knowledge and understanding of the disease.

3.5 Research methodology

3.5.1 Research design

The research design is the blueprint for conducting a study that maximizes control and factors that could interfere with the validity of the findings (Burns & Grove, 2009:236).

A descriptive correlational design with a quantitative approach was applied to determine the factors influencing disclosure of HIV. Descriptive research ‘provides an accurate portrayal or account of the characteristics of an individual, event or group in real-life situations for the purpose of discovering new meaning, describing what exists, determining the frequency with which something occurs and categorizing information’ (Burns & Grove, 2009: 696). The use of the descriptive design assisted the researcher to determine which factors influence HIV positive disclosure.

The conceptual theoretical framework of this study was supported by the design, as discussed in paragraph 2.9, in determining the various factors which influence an individual whose HIV status is positive and the ability to disclose it to others.

3.5.2 Population and sampling

A study population includes all elements (individuals, objects, events or substances) that meet the sample criteria for inclusion in a study; sometimes referred to as a target population (Burns & Grove, 2009:714).

The target population, for the purpose of this study, was all the HIV infected clients who attended a Community Health Clinic (CHC) for HIV management in the Cape Metropolitan area. A total number of (N=1200) HIV infected clients receive their treatment at this particular clinic at present with approximately 60 clients treated per day.

A sample is a subset of the population that is selected for a particular study (Burns & Grove, 2009: 42). The sample was selected from this clinic. In convenience sampling the subjects are included in the study because they happened to be in the right place at the right time (Burns & Grove, 2009:353). The convenience sampling method was applied. This included the first 150 clients who voluntarily agreed and met the criteria for the study.

De Vos *et al.* (2007:195) noted that different resources stated that in most studies, a 10% sample should be sufficient for controlling sampling errors. A statistician was consulted and he recommended that for scientific purposes, a sample size of 100 clients achieves 9% precision when constructing a 95% confidence interval for the true population proportion. Precision of between 5% and 10% are recommended. Thus, the sample size of (n=150/12.5%) was adequate to survey the disclosure parameters within an acceptable degree of accuracy.

The eligibility criteria for the participants were:

- Diagnosed as HIV positive.
- 18 years and older.

3.5.3 Measurement instrumentation

A questionnaire is a printed self-report form designed to elicit information that can be obtained from a subject's written response (Burns & Grove, 2009:406). Therefore, in this study, a closed-ended questionnaire with a limited number of open-ended questions was used to determine the factors which influence the decision to disclose a HIV positive status. A self-administered questionnaire was developed using dichotomous and categorical questions.

The questionnaire was in line with the objectives of the study. It consisted of mostly closed-ended questions with three open-ended questions, which allowed participants to make comments and suggestions. The questionnaire was only in English, with a field worker available to translate when required. The client information leaflet and consent forms were in English, Afrikaans and Xhosa.

The evaluation instrument was validated and approved by the Ethics Committee at the Faculty of Sciences, University of Stellenbosch, including experts in HIV/AIDS, a nurse expert in research methodology and statistician.

The questionnaire was divided into section A and section B.

Section A: Demographics

Information was collected on gender, age, race, relationship status, monthly income, religion and education level.

Section B: Factors influencing disclosure

- **Approximate date of HIV diagnosis**
  The participants were asked to state or write the month and year that they were diagnosed with HIV.

- **Disclosure of HIV status, to whom and how soon after diagnosis**
  Several questions investigated to whom the participant first disclosed their HIV positive status, whether it was to the sexual partner, which included a spouse/life partner, boyfriend/girlfriend or casual partner or to other network partners. Network partners included friends, family members, work colleagues and religious leaders, and how long it took from the time of diagnosis to disclosure.

- **Awareness of sexual partner’s HIV status**
  Participants were asked to state whether they were aware of their sexual partner’s HIV status.

- **The factors which prevented the individual from disclosing**
  Factors which may prevent disclosure were explored, such as fear of blame, non-acceptance in the person’s culture, fear of rejection, loss of financial support, fear of abuse and the fear of stigmatisation. These questions related to the sexual partner and other network partners and were asked separately.

- **Open-ended questions**
  Three open-ended questions gathered information on what may have helped the individual to disclose their HIV positive status to their sexual partners or to other network partners, what is their understanding of a positive HIV diagnosis and if there were any suggestions for helping and supporting people to disclose their HIV positive status.

3.5.4 Pilot study

A pilot study is conducted on a lesser version of the proposed study to develop and refine the methodology or the data collection process. It is also used to refine the steps in the research process (Burns & Grove, 2009:44). This allowed the researcher to determine the strengths and weaknesses of the measurement instrument. A pilot study was conducted on (n=15/10%) of participants at this CHC to test the questionnaire for validity and reliability, including the feasibility of the methodology of the study. This was conducted before the main study.

The results obtained from the pilot study confirmed the ability to understand the questions, the content and the logistic aspects of completing the questionnaire, with the researcher and the assistance of the staff of the CHC. The eligibility criteria were also applied to these participants. In the instance when a participant decided that they would prefer not to participate in the study, they were excused.

It was noted that three questions were not specifically related to the objectives and were therefore eliminated from the questionnaire. These changes were minimal and did not affect the proposed study. The results of this pilot study were analysed by a statistician, who determined whether the construct validity was appropriate for statistical purposes and confirmed that the data collection instrument was valid.

The data obtained from the pilot study was not included in the final analysis and the participants did not form part of the main study.

3.5.5 Reliability and validity

The reliability is determined by the use of a particular instrument and the regularity of the measures obtained and indicates the extent of random error in the measurement method (Burns & Grove, 2009:377). Reliability can be increased by clear definitions for all constructs, higher measurement levels and by using two or more indicators to measure a variable (De Vos *et al.* 2007:163).

The reliability was increased further by conducting a pilot study on (n=15/10%) of the number of participants who attend the HIV division at the CHC, to ensure that the intended data was captured and that the questions were relevant. Minimal changes were made to the questionnaire. Three questions were removed as they were not relevant to the study and in no way affected any other aspect of the intended research. This was reviewed by the statistician, who confirmed the statistical feasibility of the final questionnaire.

Validity of an instrument measures the concept in question and that this concept is accurately measured (De Vos *et al.* 2007160). Face validity verifies that the instrument looked like it was valid and gave the appearance of measuring what it is supposed to measure (Burns & Grove, 2009:381). The measurement instrument was tested for face validity by means of pilot study. The questionnaire was structured to obtain the required information by using a document which appeared professional and uncomplicated to complete.

Content validity examines the extent to which the method of measurement includes all the major elements relevant to the construct being measured (Burns & Grove, 2009: 381). A valid measuring device would provide a representative of the phenomenon being measured (De Vos *et al.* 2007:161). The questionnaire was designed on the results which were established in an extensive review of the literature and was discussed with the study supervisor, Dr. E. Stellenberg, who is an expert in research methodology and nursing. This was also reviewed by the statistician, to make certain that the data obtained would be suitable for analysis. The content validity was checked by five HIV/AIDS experts in the field of nursing.

3.6 Data collection

Data collection is the precise, systematic gathering of information relevant to the research process or the specific objectives, questions, or hypothesis of a study (Burns & Grove, 2009:695). The sister in charge of the HIV division of the CHC agreed to the sample being selected from the waiting area, adjacent to the consultation rooms. The researcher commenced data collection on specific days and times which suited the clinic staff and when there was a consulting room available to ensure the privacy of the participant.

The data was collected personally by the researcher and one field worker. By using convenience sampling the participants were chosen from the waiting area. The first 150 clients who agreed to participate were included. The study was explained to each individual and they were each given a participant information leaflet (Appendix E) to read. The participants were assured that their participation was voluntary and that anonymity and confidentiality would be maintained. The questionnaire was anonymous and coded with only a number on the document. They could then ask any questions with regard to the study.

The consent form was supplied in English, Afrikaans and Xhosa. Once the consent form was read and signed (Appendix D), the participant was guided through all the questions. They were allowed to take as long as they needed to answer the questions. The majority of the participants completed the questionnaire within 10 – 20 minutes and the researcher or field worker was present at all times. The field worker was a nursing aid, employed at the clinic and worked at the HIV division. She was trained by the researcher and familiarized herself with this study and questionnaire. Being fluent in Xhosa she was able to explain this study to the participants whose first language was Xhosa, and assisted them with completing the questionnaire when necessary.

The completed questionnaires are stored safely by the researcher at her residence and she remains the only person who has access to the completed questionnaires. The informed consent forms and the questionnaires are kept separately to ensure anonymity.

Data collection for the empirical study was completed over six weeks, from April to May 2011.

3.7 Data analysis

Data analysis reduces, organizes and gives meaning to the data (Burns & Grove, 2009: 44). The quantitative data was captured on a Microsoft Excel spreadsheet by the researcher and STATISTICA version 9 was used to analyse the data. Distributions of variables were presented with histograms and frequency tables. Statistical associations were determined between the various variables using tests such as Chi-square, Spearmen tests and t-tests. The qualitative data obtained from the open-ended questions were grouped in trends and analysed thematically and then these trends were quantified.
The details of the analysed data will be discussed in chapter 4.

3.8 Ethical considerations

Ethical approval for the study was obtained from the Health Research Ethics Committee at the Faculty of Health Sciences, Stellenbosch University (Appendix B). Permission was obtained from the City of Cape Town: City Health (Appendix C). Informed consent was obtained from the participant (Appendix D) and a participant information leaflet (Appendix E) was distributed to each one.

These clients currently attend an anti-retroviral clinic and therefore the staff of the clinic is aware of their status. This study does not include disclosure to the researcher, because, as a clinical nurse practitioner (CNP), I was considered a member of the health care professional team.

As a clinical facilitator for the Health Assessment, Treatment and Care (HATC) diploma for the previous three years, I facilitated students in the treatment of clients in numerous CHCs, as well as at this particular facility on a continuous basis. The students are qualified nurses who have registered at Stellenbosch University for the HATC programme. The staff supports the placement of these post graduate students and the service which is provided in assisting with the treatment of the clients. I am therefore familiar with the environment and the different divisions within this clinic.

The clients were approached and evaluated whether they met the criteria by myself and I was assisted by a trained field worker employed in the clinic, specifically for the purpose of this study.

The preparation of the clients who attend the ARV clinic was conducted in the form of an information session and a group discussion, while they were waiting to be seen by the CNP or doctor. The research project was explained as gathering information that may improve the management of their situation in relation to the process of disclosure.

The Helsinki principle was applied as non-therapeutic research conducted to generate knowledge for a discipline, and the results may benefit future clients but will probably not benefit those acting as research subjects (Burns & Grove, 2009:185).

Clients were reassured that they do not have to participate and they were encouraged to voice their anxiety and ask questions to clarify any concerns. As the researcher, I was responsible for providing and explaining the participant information leaflet and obtaining informed consent from the clients who were willing to participate.

If they agreed to participate in the study the participant's identity remained anonymous and they had the right to withdraw from the study, without consequences, at any time. A trained field worker who is fluent in English, Afrikaans and Xhosa assisted in translating all the information and helped the participants in completing the questionnaire when required.

Due to the sensitivity of disclosing a person's HIV status, a counselling service was provided for participants who became emotional or who found it difficult to disclose. Support was provided to the client who desired to discuss various aspects of the condition. Contact numbers for counselling were provided and where necessary clients were referred to appropriate services with their permission.

3.9 Summary

A descriptive correlational design with a quantitative approach was used in this study. A pilot study was conducted before the main study. Once signed consent was completed by the participant the questionnaire was completed with the assistance of the researcher or field worker. The data was then captured on a Microsoft Excel spreadsheet and the accuracy of the captured data was assured by the researcher. A statistician analysed the quantitative data with the use of a statistical programme. The qualitative data obtained from the open-ended questions were grouped in trends and analysed thematically.

3.10 Conclusion

In this chapter the research methodology applied in this study is described, emphasising the various steps applied. The ethical considerations, which were adhered to throughout the research process, are also discussed in this chapter.
Chapter 4 will present the results which were obtained from the research.

CHAPTER 4

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.1 Introduction

Chapter 4 presents the analysis, interpretation and discussion of the results in the form of histograms, tables and frequencies. Primarily, this was a quantitative, descriptive study and was analysed with the assistance of a statistician, using a computerised programme, STATISTICA Version 9. A 5% significance level of ($p \leq 0.05$) was used to establish statistically significant associations and these are discussed. The open-ended questions were analysed using a thematic approach (Burns & Grove, 2007: 540).

4.2 Statistical analysis

The results of the study are presented and discussed sequentially according to the demographic data and the variables in the questionnaire. Chi-square tests were used to determine whether there is any significant relationship between the demographic variable and the response variable. The Chi-square test of independence is used to analyse nominal data to determine significant differences between observed frequencies within the data and frequencies that were expected (Burns & Grove, 2009:690).

The Spearman Rank correlation and the T-test were used where applicable. The Spearman rank-order correlation coefficient is the analysis technique for ordinal data used to examine relationships among variables in a study (Burns & Grove, 2009:723). The t-test determines differences between measures of two samples (Burns & Grove, 2009:726). The t-test was used to determine whether there is a significant difference, firstly in age and the disclosure rate to the sexual partner, and secondly, age and the reasons for non-disclosure.

The mean and the median age of the participants were determined. The mean is calculated by adding all the ages and then dividing by the number of variables. The median is the age at the centre of the frequency distribution (Burns & Grove, 2009:708).

4.3 Section A - Demographic data

4.3.1 Variable 1: Gender

There were a disproportionate number of females compared to males, considering the population was a generalised one. The number of females were (n=106/71%) and the number of males were (n=44/29%). (Table 4.1).

The global statistics state that 50% of adults with a HIV positive status are female, but that 14 females for every 10 males in sub-Saharan Africa are infected (Greig *et al.*, 2008:S35). Another important factor is that because more women get tested for HIV the burden of disclosing is on them, which increases their risk of discrimination and rejection (Greig *et al.,* 2008:S36).

The HIV prevalence among South Africans, by age and sex, show that females between the ages of 25-29 years have the highest prevalence, but the male group peak at 30-34 years. The latest statistics available indicate that the total percentage of HIV among females in South Africa is 13.6% and males are 7.9% (South Africa HIV & AIDS Statistics, 2009:3).

Table 4.1 - Gender

Gender	**n**	**%**
Female	106	71
Male	44	29
Total	**150**	**100**

4.3.2 Variable 2: Age

The response rate to this question was (n=150/100%). The mean age was 36.02 years and the median was 35 years. The minimum age was 19 years and the maximum was 61 years. The majority of the participants were between ages 26 – 35 years.

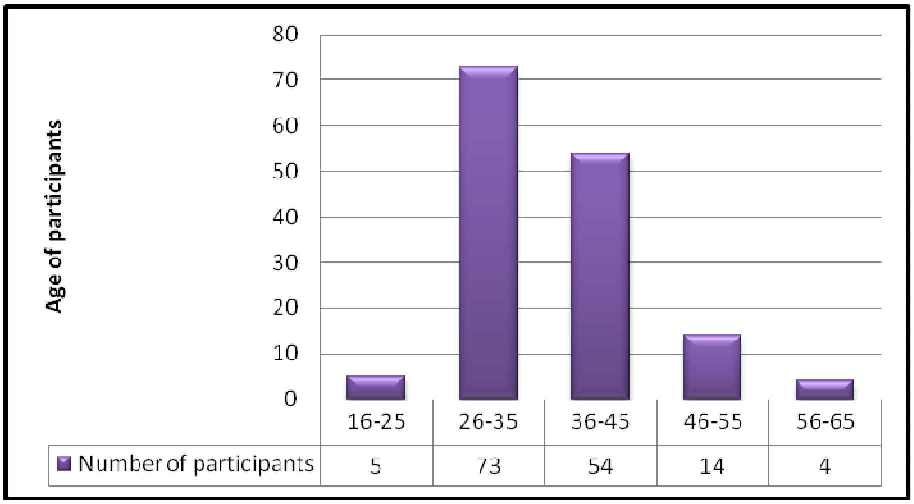


Figure 4.1 – Age

4.3.3 Variable 3: Race

The majority of the participants (n=141/94%) were black, even though this was a cosmopolitan area in the Cape Metropole and one would have expected a more diverse racial sample. In relation with the above findings the reference below indicated that the black population exceeded the other racial groups.

The population estimates for the Western Cape is just over five million. The HIV prevalence in this province is 3.8 % of the national average of 10.9%. The HIV prevalence by population groups for blacks is 13.6 %, whites 0.3%, coloured 1.7% and Indians 0.3% (Statistics South Africa, 2010:4).

Table 4.2 - Race

Race	n	%
African	141	94
Coloured	8	5
Indian/Asian	1	1
White	0	0
Total	**150**	**100**

4.3.4 Variable 4: Relationship status

The majority of the participants (n=67/45%) were never married, followed by those who were married (n=47/31%) as shown in table 4.2. The disclosure rates associated with the relationship status of the participants will be discussed in paragraph 4.4.2.

Table 4.3 - Relationship status

Relationship status	n	%
Never married	67	45
Married	47	31
Divorced	14	9
Widow/Widower	13	9
Life partner	1	1
Traditional	8	5
Total	**150**	**100**

4.3.5 Variable 5: Monthly income

Most of the participants, (n=64/43%) were unemployed and did not receive any monthly income, with only (n=8/5%) who received more than R4001 per month. The total number of participants who received some income, but less than R2000 per month were (n=34/23%) and between R2001 and R4000 were (n=30/20%).

Table 4.4 - Monthly income

Monthly income	n	%
Nil	64	43
Social grant	14	9
Less than R2000	34	23
Between R2001 and R4000	30	20
More than R4001	8	5
Total	**150**	**100**

4.3.6 Variable 6: Religion

Most of the participants were Christian (n=132/88%) and (n=15/10%) stating that they were non-Christian. Judaism and Islam consisted of (n=3/1%).

Table 4.5 - Religion

Religion	n	%
Christian	132	88
Islam	2	1
Judaism	1	1
Other	15	10
Total	**150**	**100**

4.3.7 Variable 7: Educational level

The secondary school level was the highest level of education achieved by most participants (n=109/73%) Grade 8 – 12. There were (n=11/7%) who had a tertiary education as shown in table 4.5.

Table 4.6 - Educational level

Education level	n	%
No education	3	2
Grade 1 - 7	27	18
Grade 8 - 12	109	73
Tertiary education	11	7
Total	**150**	**100**

4.4 Section B – Factors influencing disclosure

The results of the outcomes of the variables contained in the questionnaire will be outlined.

4.4.1 Variable 9: Have you disclosed your HIV status to anyone, excluding health care professionals?

There was only one female participant who reported that she had never disclosed her HIV positive status to anyone. This excluded disclosure to health care professionals, who most often do the HIV test and know the result. There was no significance noted and disclosure rates were (n=149/99%) as shown in figure 4.2.

The rates of non-disclosure are higher in a study conducted by Wong *et al.* (2009:217) which showed that 13% had not disclosed to anyone and a study by Deribe *et al.* (2007:85) showed that 5% of individuals had never disclosed.

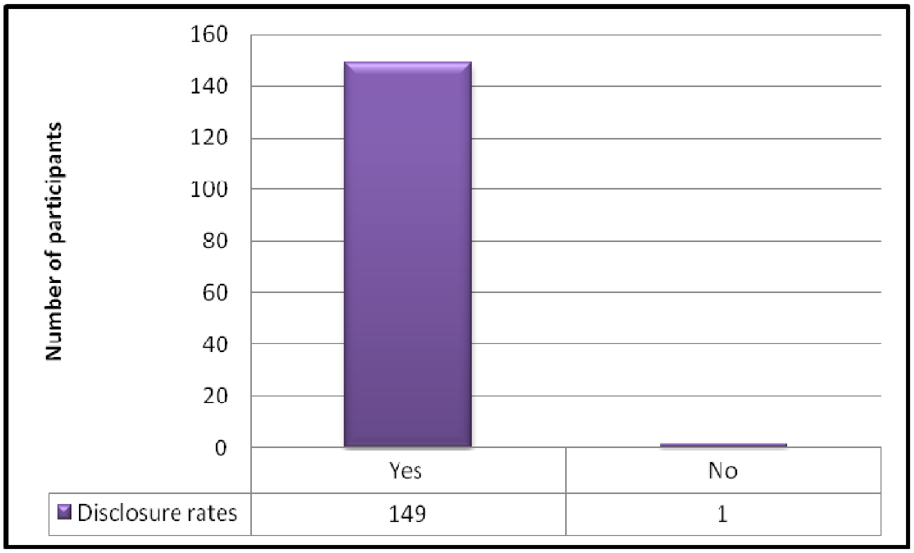


Figure 4.2 - Disclosure rates

4.4.2 Variable 10: Who did you first disclose your HIV status too?

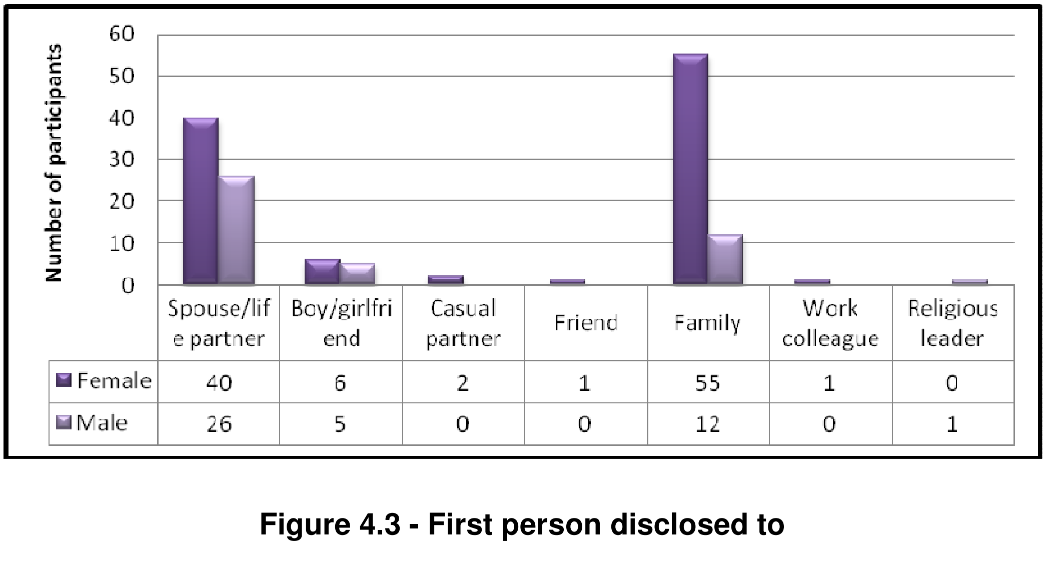
As shown in figure 4.3, there is a significant association (Pearson Chi-square, df=6, p=0.04) among the disclosure of HIV positive status between females and males. Females were more likely to disclose to family members (n=55/37%) first, and secondly to their spouse/life partner (n=40/27%) whereas the males were more likely to disclose to their spouse/life partner first (n=26/17%) and then to family members (n=12/8%). Only 1% disclosed to work colleagues or religious leaders, respectively. There was no relationship with regards to race, income or religion.

The findings in the analysis show a statistically significant association (Pearson Chi-square, df=30, p=0.01), with disclosure of HIV positive status and relationship status. Married individuals most often disclosed to their spouse/life partner (n=30/63%) and those who had never married most often first disclosed to family (n=36/55%). Disclosure to casual sexual partners was the same for married and unmarried participants (n=2/4%).

A divorced participant first disclosed to a work colleague (n=1/7%) and the widow/widower disclosure was to a friend and a religious leader (n=2/15%). The one individual who had not disclosed was a non-Christian. According to Zou *et al.* (2008:81), the fear of being stigmatized is closely related to religion. Religious beliefs affect HIV positive status disclosure as it may be associated with the conviction held, in some religions, as punishment from God.

According to Deribe *et al.* (2007:81) 90% of individuals disclosed to the current partner, though at times this was delayed. This process was influenced by factors such as knowing the partner was HIV positive and a more permanent relationship. Individuals who had not disclosed to the main partner were more likely to engage in high risk sexual behaviour and would be likely to have more sex partners (Simbayi *et al.,* 2007:31).

A study conducted by Wong *et al*. (2009:218) noted that individuals in rural areas mostly just disclosed to their sexual partner and not to the other categories due to the perceived discrimination in these communities. The rates of disclosure in urban areas were often to more than one category, such as partner and family, which is consistent with the findings in this study.



	Spouse/life partner	Boy/girlfriend	Casual partner	Friend	Family	Work colleague	Religious leader
■ Female	40	6	2	1	55	1	0
■ Male	26	5	0	0	12	0	1

Figure 4.3 - First person disclosed to

4.4.3 Variable 11: From the time of diagnosis, how long did it take to disclose to the first person you disclosed too?

The majority of participants disclosed their HIV positive status on the same day of the diagnosis (n=100/67%), of which (n=67/45%) were female and (n=33/22%) were male. There were (n=29/19%) who disclosed months and years later, as shown in figure 4.4.

This was consistent with a study conducted by Deribe *et al.* (2007:85) where disclosure rates varied from the same day to two years, though specifically to whom was not stated. In a study completed on pregnant women, 22% had disclosed within two months and 41% by the fourth year (Medley *et al.* 2004:300). According to Wong *et al.* (2009:217) the average time was 16 months.

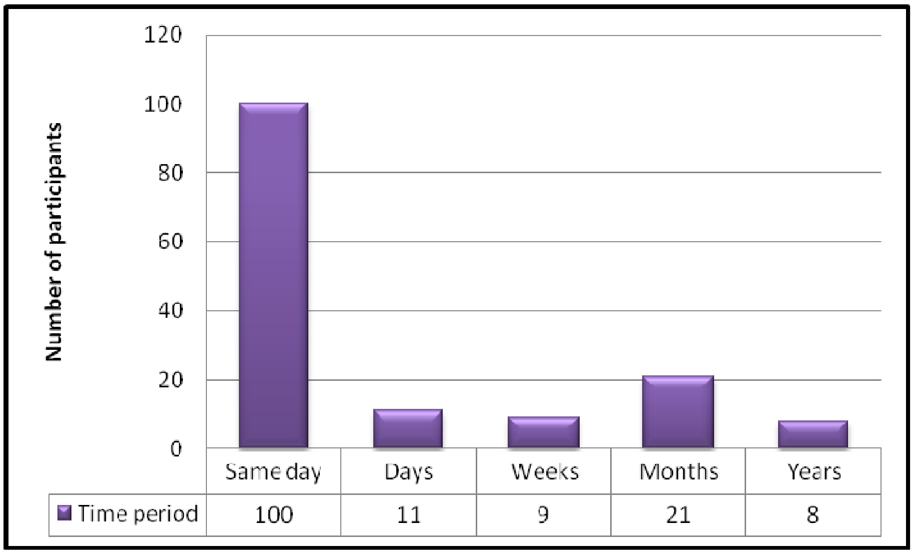


Figure 4.4 - Time from diagnosis to first disclosure

4.4.4 Variable 12: Have you disclosed to your sexual partner?

Of the respondents who indicated disclosure to their sexual partners (n=36/49%), the disclosure of a HIV positive status to the sexual partner showed a statistically significant difference between males and females (McNemar Chi-square (A/D), df=1, p=0.01). The results were the same for female disclosure to their sexual partners (n=30/41%) and those who had not disclosed to their partners (n=30/41%), whereas with the males the disclosure to sexual partners was (n=6/8%) and those who had not disclosed to their partners was (n=7/10%). Of the respondents (n=19/13%) who gave a reason for not disclosing to their partner (n=11/7%) stated that they were no longer in contact with the partner and (n=5/3%) stated that the partner was deceased.

The disclosure rates to sexual partners vary in the literature from 46.2% to 90% (Deribe *et al.,* 2007:81; Brou *et al.,* 2007:1915).

Studies have consistently shown that disclosure rates are higher among permanent partners than casual partners (Chaudoir *et al.*, 2011:1622; Deribe *et al.,* 2007:81; Gari *et al.*, 2010:11).

Table 4.7 - Disclosure of HIV positive status to sexual partner

			Female		**Male**	
Disclosure to sexual partner	**n**	**%**	**n**	**%**	**n**	**%**
Disclosure	36	49	30	41	6	8
Non-disclosure	37	51	30	41	7	10
Total	**73**	**100**	**60**	**82**	**13**	**18**

4.4.5 Variable 13: From the time of diagnosis, how long did it take to disclose your HIV status to your sexual partner?

In this study there was no statistical association between the disclosure rates to sexual partners and time from diagnosis to disclosure with regards to age, race, relationship status, income, religion or educational level. The association between the participant's age and the disclosure rates were investigated and proved statistically significant (T-test, p=0.03), with the mean age for disclosure at 36.02 years and non-disclosure is 19 years. The younger the person was at the time of diagnosis, the lower the disclosure rate and conversely the older the person was at the time of diagnosis the higher the disclosure rates were.

The age of the individual who is HIV positive and the capacity to disclose varies in the literature and this is also affected by other aspects. Similar results are shown by Kadowa and Nuwaha (2009:28) with regard to age and disclosure. This sample consisted of 70% females with minimal education and the higher rates of disclosure were among older women. Those who were unmarried had less than two sexual partners in the previous year and over the age of 25 were more likely to disclose their HIV status.

A study conducted by Medley *et al*. (2004:300) on disclosure among women noted that women under the age of 24 were more likely to disclose than older women. This was supported by O'Brien *et al*. (2003:732) which showed that individuals over the age of 22 were more likely to disclose to sexual partners and individuals over the age of 35 were more likely to disclose to a friend.

4.4.6 Variable 14: Awareness of sexual partner's HIV status

A statistically significant association was found between the female's and male's awareness of the sexual partner's HIV status (McNemar Chi-square (A/D), df=1, p=0.03). The number of females who were not aware of the sexual partner's status (n=49/33%) was 5% lower than those who were aware (n=57/38%). The number of males who were not aware of the sexual partner's status was much lower (n=15/10%) than those who were aware (n=29/19%) as shown in table 4.8.

There was also a significant statistical association between awareness of the sexual partner's HIV status and the relationship status (Pearson Chi-square, df=5, p=0.01). The participants who were never married (n=33/22%) had the highest rate of not being aware of their partner's status. Participants who were married had the highest rates of awareness of their partner's status (n=36/24%).

Similarly, a study conducted on women attending an ART clinic found that women were less likely to disclose to their partner if they did not know the partner's status (Gari *et al*., 2010:9). Individuals are more likely to disclose to an HIV positive partner than to a partner who they thought was negative or unaware of their status (Deribe *et* *al.*, 2007:82). According to Simbayi *et al.* (2007:33) there is often increased high risk sexual behaviour in people who had not disclosed and that there was a mutual unawareness of the partner's HIV status, 'the practice of not asking and not telling'.

Table 4.8 - Awareness of partner's HIV status

			Female		Male	
Awareness	**n**	**%**	**n**	**%**	**n**	**%**
Not aware of status	64	43	49	33	15	10
Awareness of status	86	57	57	38	29	19
Total	**150**	**100**	**106**	**71**	**44**	**29**

4.4.7 Variables 15 to 20: Reasons cited for delayed or non-disclosure of HIV status to sexual partners

The findings in the analysis show a statistically significant association (Pearson Chi-square, df=2, p=0.02), with regards to fear of being blamed and the relationship status. Those who had never married (n=29/19%) cited blame as a reason for fear of disclosure, which was 13% higher than any other category of the relationship status. There was no other significant association with the sex, race, income, religion and educational level.

Fear of rejection was also cited most often by participants who were never married (n=27/18%) which is statistically significant (Pearson Chi-square, df=5, p=0.03). The income level showed a statistically significant association (Pearson Chi-square, df=5, p=0.03) with individuals who have no income and those who fear rejection.

The fear of blame and rejection is therefore most often given as reasons for delayed disclosure or non-disclosure by individuals who have never married and have no income.

According to King *et al.* (2007:233) the rates of disclosure to sexual partners is lower in the developing world, especially among pregnant women, who cite the main reasons for non-disclosure as fear of blame, abandonment and rejection. The implication of not disclosing negatively affects the mother-to-child transmission and women's adherence to treatment and care.

The rates of disclosure are also higher with women who volunteer to be tested for HIV than those who attend antenatal clinics and are routinely tested. (Medley *et al.,* 2004:298).

Other reasons cited for not disclosing to the sexual partner, which were not specified in the questionnaire, were mostly because the individual was no longer with the partner at the time of diagnosis (n=11/7%). The remaining participants who answered this question (n=8/5%) stated that the partner was deceased or it was a once off encounter and the identity of the other person was unknown.

4.4.8 Variable 21 to 27: Reasons cited for delayed or non-disclosure to others

The findings in this study was that females feared stigmatisation (n=46/30%) less often than not (n=60/40%), which was statistically significant (McNemar Chi-square (A/D), df=1, p=0.01). Males (n=25/17%) feared stigmatisation more often than not (n=19/13%).

The level of education with regards to stigma also showed a statistically significant association (Pearson Chi-square, df=3, p=0.01). The participants with an education level of grade 8 – 12 feared this the most (n=44/29%).

In summary, the majority of participants who feared stigmatisation had no income (n=34/23%), (Pearson Chi-square, df=5, p=0.03) and were Christian (n=59/39%), with a grade 8 – 12 level of education.

There was no statistical association with regards to fear of blame when disclosing to others, which indicates a difference with disclosing to a sexual partner, where fear of blame was an influencing factor.

Very few respondents (n=12/8%) gave other reasons, which were not specified in the questionnaire, for not disclosing to family. Of those who did, the most frequent reason given was upsetting the family and being ashamed or not having friends and family in Cape Town.

This was supported by a systematic review which concluded that the majority of individuals, who had not disclosed to family and friends, were due to the fear of shaming the family and disappointing them. There was also an unwillingness to burden the family (WHO: 2004:14).

Table 4.9 - Fear of stigmatisation

			Female		Male	
Fear of stigmatisation	**n**	**%**	**n**	**%**	**n**	**%**
Yes	71	47	46	30	25	17
No	79	53	60	40	19	13
Total	**150**	**100**	**106**	**70**	**44**	**30**

4.4.9 Variable 28: Open-ended question: What do you think may have helped you to disclose?

Of the number of respondents who completed this question (n=31/21%), the predominant theme that emerged was that the counsellor helped them to disclose and that they could ask the counsellor to support them. This was closely followed by the health care professional.

Only one participant felt that a doctor had provided support with regards to this aspect and only one participant had been for HIV testing with their partner and described the process as positive. Of these participants most (n=22/14%) stated that they would ‘ask the counsellors or health workers to help and support’.

Table 4.10 - What do you think may have helped you to disclose?

Response	n	%
Counsellor	14	9
Health worker	8	5
Other	9	7
Total	**31**	**21**

4.4.10 Variable 29: Do you think HIV is curable?

A vast number of the respondents indicated that HIV was not curable (n=146/97%). The majority of participants (n=106/71%), who indicated that HIV was not curable had a grade 8 – 12 level of education which was statistically significant (Pearson Chi-square, df=3, p=0.01). There were very few who indicated that they thought HIV was curable (n=4/3%).

Table 4.11 - HIV is curable

HIV is curable	n	%
Yes	146	97
No	4	3
Total	**150**	**100**

4.4.11 Variable 30: Open-ended question: What do you understand about your diagnosis?

The majority of participants (n=60/40%) indicated that they understood that HIV was incurable but that medication can control the virus. The overall theme that emerged was that individuals should practice safe sex by using condoms and having one partner, lead healthy life styles such as exercise, no smoking or alcohol and to exercise regularly. One participant said ‘If you are HIV positive, use condoms each time, eat healthy food and take medication at the right time’. Similar comments were made by many others.

A limited number of participants (n=21/14%) reported some knowledge about the pathophysiology of HIV/AIDS. The most frequent explanation given for the disease was that it was manageable if you take your tablets. One participant stated “It is OK, everybody has it”, while another said: “As long as I am taking my medication everytime, it is fine”.

The knowledge of HIV/AIDS was investigated by Türmen (2003:414) and the results are that though 90% had heard about AIDS, only 16% knew enough to be able to safeguard against the disease.

4.4.12 Variable 31: Open-ended question: Do you have any suggestions or recommendations for helping and supporting people to disclose their HIV positive status?

Most of the participants (n=84/56%) revealed the importance of attending support groups and to talk about the disease, which increases support and provides encouragement to disclose. Another reason cited for the advantages of joining a support group was that other people in the group give valuable advice and that one should listen to what they say. It also helped many of the participants to accept their HIV status and reduce anxiety and stress levels. A similar view was shared by the majority of participants (n=84/61%), with comments such as “to join a support group and socialize with other people, they must not blame themselves and talk about it to relieve the stress”, “join a support group and share with others, accept status”.

Another theme which emerged is the importance of disclosure. The positive outcomes that most participants received enabled them to encourage others to disclose.

There was emphasis placed on the increased support that they received after disclosure of their HIV status and the ability to attend the clinic openly to receive the appropriate treatment and management of the disease. As one participant revealed, “When you disclose your status people give you support and it becomes easy to take your tablets”.

Gaskins (2006:42), found in her study conducted in a rural area that the majority of the participants wanted to warn others to be careful about disclosing. The advice was to choose cautiously who they disclose to and be careful about sharing this information.

4.5 Summary

In summary, (n=107/71%) of the participants are female, with a mean age of 36 years. The majority is black, have never married and do not receive any income. The participants are predominantly of a Christian religion with a grade 8 – 12 level of education. The researcher assessed which factors influenced HIV status disclosure and these were identified throughout the study.

4.6 Conclusion

In this chapter, the data collected in this study was presented, analysed and interpreted. The researcher successfully investigated the research question, i.e.: What are the factors that influence disclosure of a person’s HIV positive status?

The factors that influence HIV status disclosure were scientifically investigated and identified.

The following objectives were thus achieved:

To determine whether the following factors influence HIV status disclosure:

- Socio-demographic factors
- Stigma and discrimination of HIV positive individuals
- Religion
- Culture

- Fear of abandonment and rejection
- Knowledge and understanding of the disease.

Chapter 5 will present an overview of the objectives achieved and recommendations made based on the findings of this study. The limitations will also be discussed.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

Chapter 5 presents the conclusions regarding the factors which influence disclosure of a positive HIV status. The conclusions are discussed according to the purpose, research question and objectives set for the study, based on the findings. Areas for further research and the limitations of the study are also discussed. Recommendations to facilitate the disclosure rates of HIV status are presented.

5.2 Conclusions

The specific objectives set for this study were to determine whether the following factors influence HIV status disclosure:

- Socio-demographic factors
- Stigma and discrimination of HIV positive individuals
- Religion
- Culture
- Fear of abandonment and rejection
- Knowledge and understanding of the disease.

These objectives were met through a research study that aimed at identifying the factors influencing HIV status disclosure.

5.2.1 Objective 1: to determine whether socio-demographic factors influence HIV status disclosure

The findings in this study suggest that there were several socio-demographic factors that influence HIV status disclosure and these will each be discussed in turn.

The results discussed in paragraph 4.4.1 showed that the majority of participants were female (n=106/71%), even though this was a generalised population. Females disclosed to family members first (n=55/37%) and then to their spouse/life partner (n=40/27%). This delayed disclosure to the sexual partner of the females may increase the transmission of HIV due to continued unsafe sexual practice and the incapacity to make informed decisions with regards to sexual behaviour due to ignorance of the partner's HIV status. Males disclosed most often to their spouse/life partner (n=26/17%). These results are substantiated in a study conducted in South Africa which shows that males disclose to the partners more often than females (Deribe *et al.,* 2007:83).

Furthermore, women are more likely to acquire HIV infections, due to biological characteristics. Male to female transmission of HIV is between two to four times higher than female to male. Women with sexually transmitted diseases are often asymptomatic which results in delayed treatment and increases the transmission of HIV tenfold. They also lack the power and financial independence to negotiate safe sex and insist on condom use (Greig *et al.*, 2008: S35).

A statistically significant association was found between age and disclosure (p=0.03), with the mean age for disclosure at 36.02 years and non-disclosure is 19 years, as indicated in paragraph 4.4.5. The younger the person was at time of diagnosis, the lower the disclosure rate and conversely the older the person was at the time of diagnosis the higher the disclosure rates.

However, the results are different in a study conducted by Medley *et al.* (2004:300), who found that younger women are more likely to disclose than older women. According to O'Brien *et al.* (2003:732), younger women are more likely to disclose to their partner and older women are more likely to disclose to a friend.

The relational status of the participants and to whom they disclosed was found to be statistically significant (p=0.01). Married individuals most often disclosed to their spouse/life partner (n=30/63%) and those who had never married most often first disclosed to family (n=36/55%). Disclosure to casual sexual partners was the same for married and unmarried participants (n=2/4%) as shown in paragraph 4.4.2.

Numerous factors influence disclosure rates of which one is relational status as shown by Deribe *et al.* (2007:81). This study shows that most of the participants disclose to their main partner, though 14% delay the disclosure and have sexual relations with the individual before admitting to being HIV positive. Less than half tell their casual partner. Disclosure is also related to awareness of the partner's status.

There is no significant association with disclosure rates and income level as participants with no income and those who earned some income, less than R4000, showed the same disclosure pattern.

However, it has been noted in numerous studies that income does affect disclosure and that individuals who have no income or financial security, disclose their HIV status less often. Gaskins (2006:38) and Deribe *et al. (*2007:82), in their studies show that unemployment is related to no income and being dependant on others, which results in reluctance to disclose. This is substantiated further by people from low socio-economic environments who delayed disclosure to sexual partners by an average of nine (9) months (Wong *et al.* 2009:218).

According to Türmen (2003:412), in many societies women have a lower social and economic status simply because they are women and are seldom in a position to talk about safe sexual behaviour. Similar results were found by Greig *et al.* (2008:S38), in South Africa which reveals that "poorer women were more likely to have an early sexual debut, a non-consensual first sexual encounter and higher rates of physically forced sex or having exchanged sex for money, goods or favours – all significant risk factors for HIV". It also indicates that women who have some financial security are better able to avoid these relationships and their empowerment shows to reduce the risk of HIV.

The more empowered individuals are, the better equipped they are to make informed decisions, which influence the ability to disclose their HIV positive status.

5.2.2 Objective 2: To determine whether stigma and discrimination influence HIV status disclosure

The results indicated that the reasons for delayed or non-disclosure differed between the sexual partner and others, namely, friend, family, work colleagues and religious leaders.

The fear of stigmatisation was identified as a factor which influences HIV disclosure to others, especially among the male participants. The results revealed that this was the major reason for delayed or non-disclosure. The male participants feared this aspect more than the female participants, which was statistically significant (p=0.01).

An analysis also showed that the level of education influenced the fear of stigmatisation, with the grade 8 – 12 level fearing this the most.

There was a statistically significant association (p=0.02), between fear of blame or discrimination and disclosure to the sexual partner. This fear was most often cited by the participants who had never married. Another factor which influenced disclosure rates was that of income. The participants, who feared blame or discrimination the most, reported having no income, as indicated in paragraph 4.4.7.

HIV/AIDS is a socially unacceptable disease and results in the community discriminating against an individual's lifestyle and personal behaviour (Chaudoir *et al.,* 2011:1621). This often delays access to the medical care system. MSM are often the target of stigmatisation and the cultural constructions of masculinity discourage the use of health services by men, otherwise they are considered to be weak. Men often attend the health services only when they are very ill and, in the case of HIV, in the advanced stage of the disease (Greig *et al.,* 2008:S35).

Stigma affects the psycho-social environment and the physical environment of an individual with HIV, as well as the partner, family and friends. This makes the process of disclosure extremely difficult because it makes one vulnerable to being devalued as a human in a particular social context (Norman *et al.,* 2007:1775).
Therefore, stigmatisation has a major negative influence on disclosing a socially devalued illness or condition, such as HIV.

5.2.3 Objective 3: To determine whether religion influences HIV status disclosure

There were no significant findings in this study with regard to religion as the majority of participants (n=132/88%) were Christian. All the participants reported having disclosed to at least one person, excluding health care professionals, except one, who stated that she was a non-Christian.

Religious beliefs, such as not following the word of God, can powerfully influence shame-related stigma. This aspect could be addressed by religious leaders to reduce stigma and encourage the community to support individuals and the families who are affected and infected by HIV (Zou *et al.* 2008:81).

The fear of being stigmatized is closely related to religion. Religious beliefs affect HIV positive status disclosure as it may be associated with the conviction held, in some religions, that it is a punishment from God (Zou *et al.* 2008:81).

Religious leaders have an additional supportive role, as one can normally share confidential information without fear of reproach. However, in this study it appeared that individuals preferred not to discuss their HIV positive status with their religious leader. This aspect should not be a determent in disclosing one's illness and should be addressed with education and compassion.

5.2.4 Objective 4: To determine whether culture influences HIV status disclosure

All the participants (n=150/100%) revealed that they believed that HIV was mostly accepted in their culture and that it did not in any way affect their ability to disclose their HIV positive status. The results in this study therefore indicate that there was no statistical significance with regards to the culture of the participants and disclosure rates.

This is a simplistic and one dimensional view. The finding that people fear blame and stigmatisation as discussed above, as well as the fear of rejection and the lack of disclosure would in of itself support this notion.

5.2.5 Objective 5: To determine whether the fear of abandonment and rejection influence HIV status disclosure

The results indicated, as described in paragraph 5.2.2, that the reasons for delayed or non-disclosure differed between the sexual partner and others, namely, friend, family, work colleagues and religious leaders.

The participants who feared rejection the most were those who had never married (n=27/18%). These participants cited fear of rejection with regards to disclosure to the sexual partners only and not to the other categories of relationships. Another factor which was identified is that participants with no income also feared rejection more than the participants with some level of income. Again this was specifically disclosed to the sexual partner. There was no other significant association with the gender, race, religion and educational level. The fear of abandonment and rejection therefore were not the major reasons for delayed disclosure to other categories of relationships. It was revealed in the open-ended questions that support groups were helpful in accepting one's status and the importance of disclosure, as in most instances resulted in positive outcomes.

However, an important factor is that because more women get tested for HIV the burden of disclosing is on them, which increases their risk of discrimination and rejection (Greig *et al.* 2008:S36).

According to WHO (2004:12), the fear of abandonment among women is most often cited in developing countries. This is directly correlated to the loss of financial support from the partner. Consequently this reluctance to disclose their HIV positive status may be the result.

In conclusion, the results in this study therefore include that the fear of abandonment and rejection influenced disclosure rates to sexual partners.

5.2.6 Objective 6: To assess the knowledge and understanding of the HIV/AIDS

The results in this study showed that the majority of the participants (n=97/65%) did reveal that there was some level of understanding about HIV/AIDS and realise that it is incurable. The importance of remaining compliant on medication, ARV's, was reiterated and most accepted that once you started medication, unless you were instructed by a doctor, that it was for life.

The awareness of the sexual partner's status is a concern as almost half of the participants were not aware of their partner's status (n=64/43%). This was most often found among the participants who were not married. These were also the individuals who feared abandonment and rejection, especially from the sexual partner.

The highest level of education achieved by most participants (n=109/73%) was grade 8 – 12. The health education level of the participants seemed incongruent as their knowledge of the disease and the physical effects were limited, with only (n=21/14%) aware of the fact that it destroys one's immune system and can be a life threatening disease. An open-ended question revealed that there was a basic understanding that HIV is incurable, but manageable with medication. Furthermore, a fundamental understanding existed among participants that it is important to maintain a healthy life style by not smoking or not indulging in alcohol and to exercise regularly.

Only a limited number of participants (n=37/25%) stated that it was necessary to practice safe sex by using condoms regularly and remaining faithful. Similarly this practice could be as a result of the apparent sense of blame and stigmatisation, as well as the fear of abandonment that the infected and affected party carries as described in paragraph 4.4.10.

The knowledge of HIV/AIDS was investigated by Türmen (2003:414), and the results are that though 90% had heard about AIDS, only 16% knew enough to be able to safeguard themselves against the disease.

In conclusion the process of disclosing is complex and individuals need to understand the importance and implication of disclosing or not disclosing, especially to the sexual partner, to reduce the transmission of HIV/AIDS.

5.3 Recommendations

The recommendations are presented according to the results that emerged from the study.

5.3.1 Voluntary counselling and testing

The results in this study, which were reiterated in the open-ended questions, revealed that though the participant benefited from the initial counselling session, there were certainly ongoing unresolved issues such as continued unawareness of the partner's status, underlying anger and resentment. It is recommended that there should be multiple counselling sessions after the client has disclosed to provide ongoing support and encouragement.

Multiple counselling sessions are needed to improve disclosure rates as this is an ongoing process and requires ongoing support and encouragement. The local authorities and the CPN in the clinic should take a more active and specific role in creating opportunities for this to be able to happen.

According to Medley *et al.* (2004:302), counselling sessions are between five and seven minutes. More time and more sessions need to be allocated to this complex process. Women who attend voluntary counselling and testing clinics are motivated and have mostly internalised the process of testing for HIV. Women who attend ante-natal clinics are given an option to be tested for HIV and have often not thought about this. In addition, they have not had the chance to discuss being tested with their partners. Consequently, this makes the disclosure process more difficult (WHO, 2004:12).

5.3.2 Support groups

The findings from the open-ended questions also emphasised the importance of assuring that individuals have access to support groups as these were enormously advocated by the participants of this study. Support groups seem to provide the much needed support and coping skills needed to accept their HIV positive status and live normal lives. These support groups also encourage and advise others on aspects such as disclosure, and the positive reaction that they received, as well as information about the medication. Many participants stated that attending these groups reduced their anxiety and stress levels.

The provision and encouragement of couple counselling may reduce the barriers to disclosure and increase the awareness of the partner’s status, which remains unacceptably low. Couple counselling could be considered in order to reduce the negative outcome of HIV positive status disclosure and promote safe sexual practice among couples.

It is therefore recommended that support groups are established in the communities and churches. Stakeholders in the communities such as professional health workers, social workers, church ministers and non-governmental organizations are some of the leading individuals to establish such groups. In addition, it is recommended that couple counselling also be introduced for the benefits as described in the previous paragraph.

5.3.3 Community based programmes

Programmes need to be community based in an attempt to reduce the stigmatisation of individuals with HIV and increase their access to social support systems and health care facilities. These include programmes that are based on information about the disease, coping skills and support groups.

Programmes aimed at empowerment of women to change gender norms and access some form of income and financial security, which would allow increased independence and reduce the fear of abandonment when disclosing should be introduced.

Additional exploration of why females disclose to their family and specifically to whom in their family will provide light as this may illicit an alternative opportunity to request that this person possibly becomes more involved in the level of care for the affected individual from receiving the diagnosis to being able to manage the impact in all spheres of his/her life going forward.

The burden on disclosure is most often with women, who have a higher incidence of HIV and are tested more frequently. Involving men in the testing and counselling process would reduce the barriers that women are faced with, and result in higher awareness of the partner's status.

Culturally appropriate counselling must be offered to the intended populations. Involving men in VCT will reduce the burden of disclosing on women and promote safer sexual behaviour practices as this is often the male's decision. The lifestyle and personal behaviour of individuals need to be taken into account, as well as the physical and psycho-social environment.

Fear of abandonment and fear of discrimination and isolation from the family and community is cited as an important barrier to disclosure of HIV status, both in developed and developing worlds. Community-based programmes are needed to reduce the stigma of HIV.

Knowledge based programmes on HIV/AIDS should be offered to the community, in churches, work environment and at the health care facility. The environment and culture of the individual can have an effect on an individual's health. The community may also act as a determinant to an individual's health, as seen with HIV and the high rates of discrimination. Health promotion must be advocated as it creates awareness in the community of the necessity to change attitudes and misconceptions (Hancock & Perkins, 1985:9).

5.4 Further research

More research is needed to determine the effectiveness of couple counselling, which may reduce blame and rejection of the person who is tested first and accused of being the primary source of the infection. More females are tested for HIV first, often at ante-natal clinics, which place them at an increased risk of discrimination and rejection.

The discovery in this study is that most individuals receive only one counselling session at the time of diagnosis, unless there is a specific request to see the counsellor again. Further research is needed to determine whether multiple counselling sessions would improve disclosure rates and reduce the time from diagnosis to disclosure, especially to the sexual partner. Ongoing counselling may help individuals to overcome the barriers to disclosure. The negative outcomes to disclosure are much less than expected, with most individuals responding with acceptance and kindness (WHO, 2004:12).

The rates of disclosure to a religious leader were extremely low and research is needed to determine why individuals do not feel comfortable disclosing their status to this category of persons.

5.5 Limitations of the study

This study was limited to one CHC in the Cape Metropole area and it was difficult to make generalizations based on the small sample size. Convenience sampling was used and this may not represent the entire clinic population.

Unfortunately the race distribution was limited, with 94% blacks, so there could be no correlations analysed between the different races, this is could be attributed to the high incidence of HIV/AIDS positive Africans in comparison to other groups in the Western Cape Province (Statistics South Africa, 2010:6).

5.6 Conclusion

The study identified that there are numerous factors which influence HIV status disclosure. Disclosure is a multifaceted process and one particular factor does not necessarily influence disclosure but most often it is a combination of factors.

An individual is at the centre of an ecosystem, surrounded by family. The physical well-being, personal behaviour, psycho-social environment and the physical environment all influence the health and illness of an individual. The community and society affect the ability of an individual to remain healthy or cope with an illness such as HIV. Individuals are also affected by their culture and environment. In addressing the management of a person with HIV, all the above-mentioned need to be considered and initiatives must be implemented at the highest level, as described in the conceptual framework, which shows the importance of a holistic approach.

The findings from the research supported the research question that was explored, i.e. what are the factors which influence the disclosure of HIV positive status?

This chapter showed that the aim and objectives were achieved. There were numerous statistically significant associations with regards to the demographics and the responses and these findings were analysed and interpreted.

The scientific evidence which was obtained from the participants who completed the questionnaire was used to make recommendations. The recommendations were made to further facilitate and increase the disclosure rates of HIV positive individuals.

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Appendix A – Questionnaire

Number ☐

Questionnaire

This questionnaire consists of 4 pages and will take approximately 10 minutes to complete.
Please return the completed questionnaire to the researcher.

Instructions:

Please answer the questions by marking your choice with a tick (√).

Example: Do you live in Cape Town?

Yes	√
No	

Section A: Demographics

Q. No.	Profile
1	Gender: Please mark with a tick Male ☐ Female ☐
2	Age: (Write in the number) Years: ☐
3	Race: Please mark with a tick Black ☐ Coloured ☐ Indian/Asian ☐ White ☐ Other: please elaborate: ………
4	What is your relationship status? Please mark with a tick Never married ☐ Married ☐ Divorced ☐ Widow/Widower ☐ Life partner ☐ Traditional ☐
5	What is your monthly income? Please mark with a tick Nil ☐ Social grant ☐ Less than R2000 ☐ Between R2001 and R4000 ☐ More than R4001 ☐
6	Religion: Please mark with a tick Christian ☐ Islam ☐ Judaism ☐ Hindu ☐ Other: please elaborate: ……......

7 Education level: Please mark with a tick

No education	
Grade 1 – 7	
Grade 8 – 12	
Tertiary education	

Section B: Factors influencing disclosure

No.

8 What was the approximate date you learned of your HIV diagnosis? Please write in the month and year.

____

9 Have you disclosed your HIV status to anyone, excluding health care professionals? Please mark with a tick.

Yes	
No	

10 If yes to question 9, who did you **first** disclose your HIV status too? Please mark with a tick.

Spouse/life partner	
Boyfriend/girlfriend	
Casual partner	
Friend	
Family member	
Work colleagues	
Health practitioner	
Religious leader	

11 From the time of diagnosis, how long did it take to disclose your HIV status to the **first** person you disclosed too? Please mark with a tick.

The same day	
Days	
Weeks	
Months	
Years	
Never	

12 Have you disclosed your HIV status to your sexual partner? Please mark with a tick.

Yes	
No	

13 If yes to question 12, from the time of diagnosis, how long did it take for you to disclose your HIV status to your sexual partner? Please mark with a tick.

The same day	
Days	
Weeks	
Months	
Years	
Never	

14 Are you aware of your sexual partner’s HIV status? Please mark with a tick.

Yes	
No	

If you have not disclosed to your **sexual partner**, what do you think prevents you from disclosing? Please mark with a tick.

15 Fear of blame:

Yes	
No	

16 Because it is not accepted in your culture:

Yes	
No	

17 Due to fear of rejection:

Yes	
No	

18 Loss of financial support:

Yes	
No	

19 Due to fear of abuse:

Yes	
No	

20 Other reasons. Please comment.

……

……

If you have not disclosed to anyone, excluding the health care professionals, what do you think prevents you from disclosing? Please mark with a tick.

21 Fear of stigmatisation:

Yes	
No	

22 Fear of blame:

Yes	
No	

23 Because it is not accepted in your culture:

Yes	
No	

24 Due to fear of rejection:

Yes	
No	

25 Loss of financial support:

Yes	
No	

26 Due to fear of abuse:

Yes	
No	

27 Other reasons. Please comment.

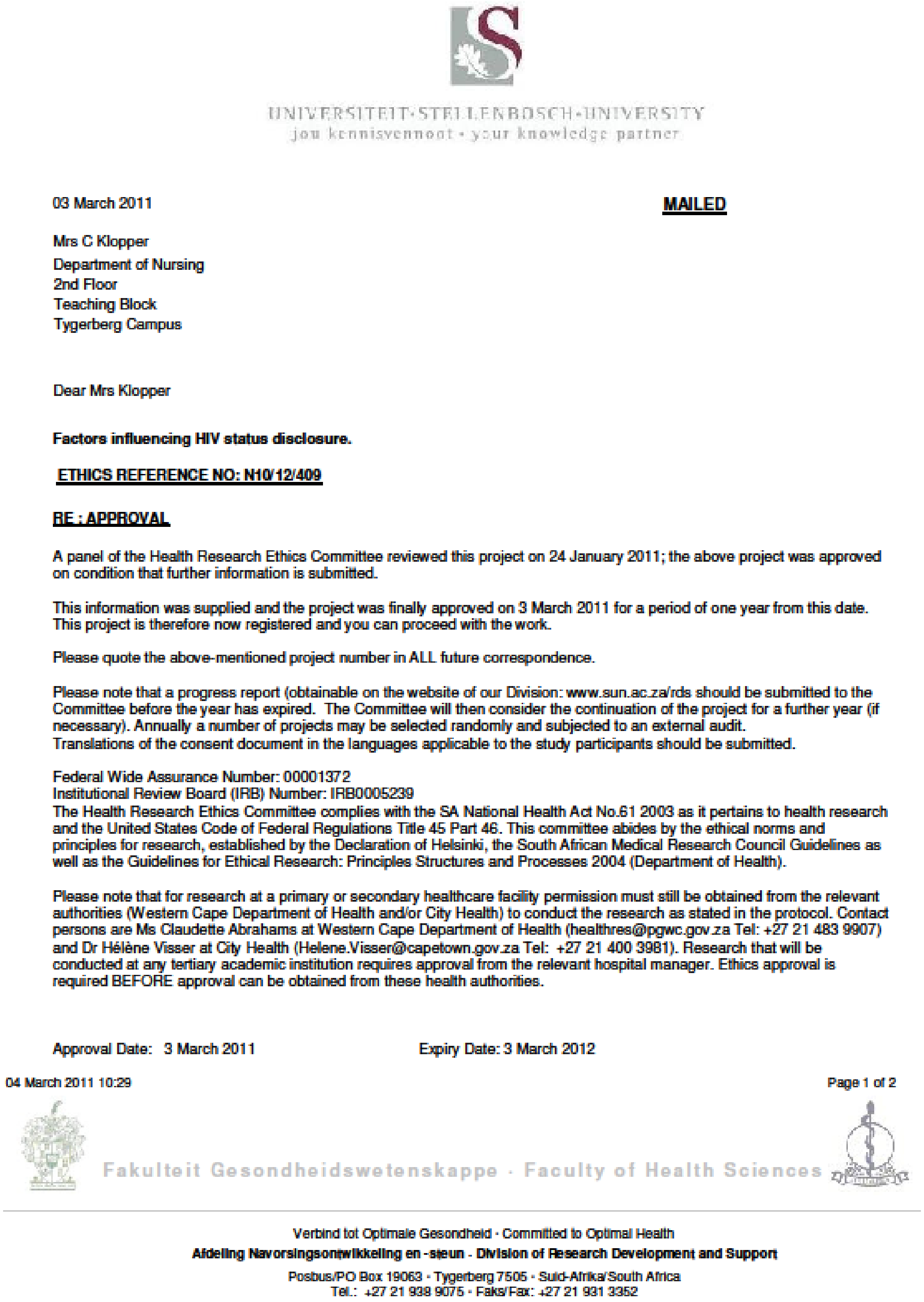
……

……

<table>
<tr><td>28</td><td>What do you think may have helped you to disclose? Please comment.
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………</td></tr>
<tr><td>29</td><td>Do you think that HIV is curable? Please mark with a tick?<table><tr><td>Yes</td><td></td></tr><tr><td>No</td><td></td></tr></table></td></tr>
<tr><td>30</td><td>What do you understand about your diagnosis? Please comment.
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………</td></tr>
<tr><td>31</td><td>Do you have any suggestions or recommendations for helping and supporting people to disclose their HIV positive status? Please comment.
……………………………………………………………………………………………
……………………………………………………………………………………………
……………………………………………………………………………………………</td></tr>
</table>

Thank you for participating in the study.

Appendix B - Ethical approval: University of Stellenbosch



UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

03 March 2011

MAILED

Mrs C Klopper
Department of Nursing
2nd Floor
Teaching Block
Tygerberg Campus

Dear Mrs Klopper

Factors influencing HIV status disclosure.

ETHICS REFERENCE NO: N10/12/409

RE : APPROVAL

A panel of the Health Research Ethics Committee reviewed this project on 24 January 2011; the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 3 March 2011 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.
Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239
The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

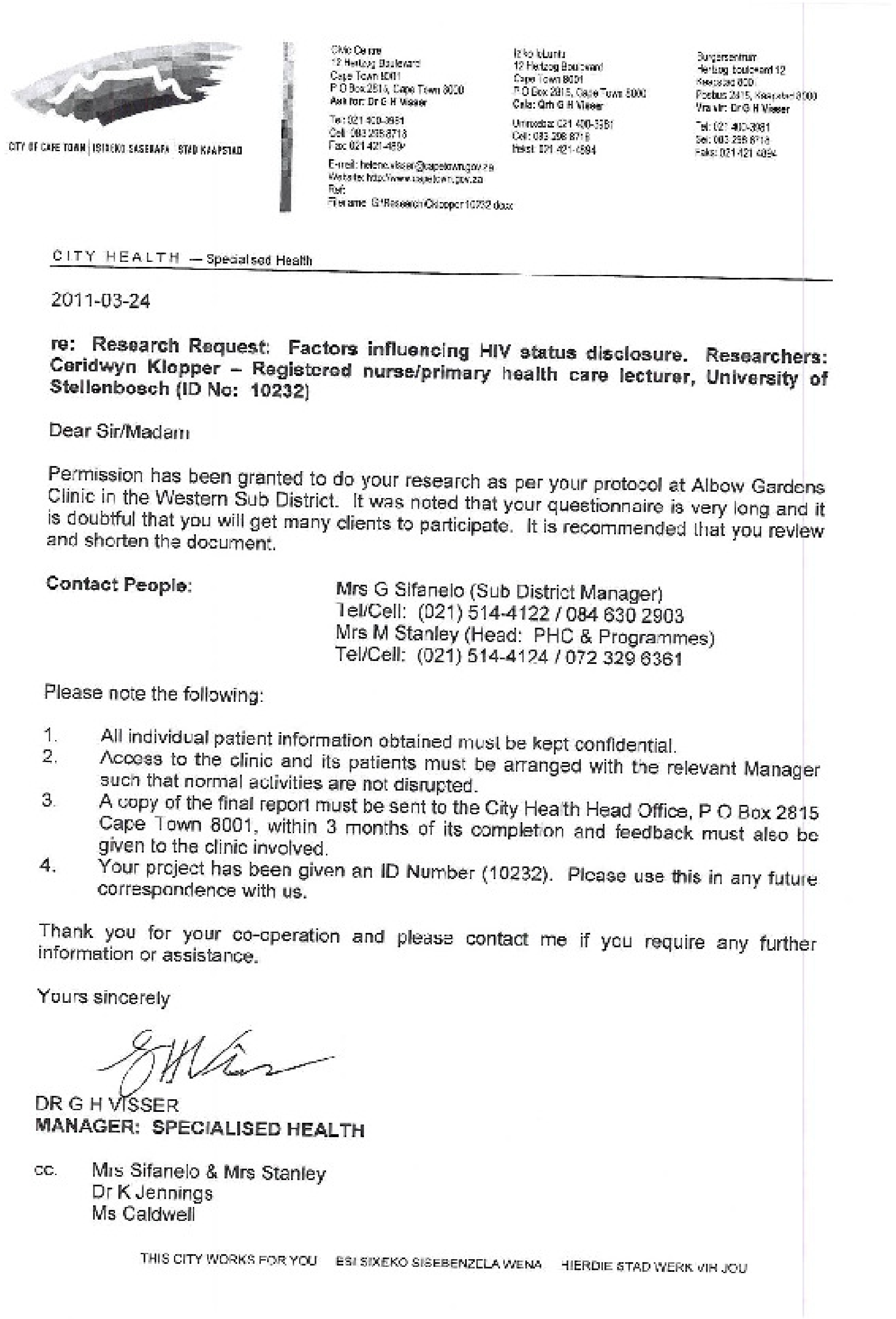
Approval Date: 3 March 2011 Expiry Date: 3 March 2012

04 March 2011 10:29 Page 1 of 2

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun - Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

Appendix C - Letter of permission – City of Cape Town: City Health



CITY OF CAPE TOWN | ISIXEKO SASEKAPA | STAD KAAPSTAD

Civic Centre
12 Hertzog Boulevard
Cape Town 8001
P O Box 2815, Cape Town 8000
Ask for: Dr G H Visser

Tel: 021 400-3981
Cell: 083 298 8718
Fax: 021 421-4894

E-mail: helene.visser@capetown.gov.za
Website: http://www.capetown.gov.za
Ref:
Filename: G:\Research\Klopper 10232.docx

Iziko loLuntu
12 Hertzog Boulevard
Cape Town 8001
P O Box 2815, Cape Town 8000
Cela: Gqirha G H Visser

Umnxeba: 021 400-3981
Cell: 083 298 8718
Ifeksi: 021 421-4894

Burgersentrum
Hertzog-boulevard 12
Kaapstad 8001
Posbus 2815, Kaapstad 8000
Vra vir: Dr G H Visser

Tel: 021 400-3981
Sel: 083 298 8718
Faks: 021 421 4894

CITY HEALTH — Specialised Health

2011-03-24

re: Research Request: Factors influencing HIV status disclosure. Researchers: Ceridwyn Klopper – Registered nurse/primary health care lecturer, University of Stellenbosch (ID No: 10232)

Dear Sir/Madam

Permission has been granted to do your research as per your protocol at Albow Gardens Clinic in the Western Sub District. It was noted that your questionnaire is very long and it is doubtful that you will get many clients to participate. It is recommended that you review and shorten the document.

Contact People:

Mrs G Sifanelo (Sub District Manager)
Tel/Cell: (021) 514-4122 / 084 630 2903
Mrs M Stanley (Head: PHC & Programmes)
Tel/Cell: (021) 514-4124 / 072 329 6361

Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinic and its patients must be arranged with the relevant Manager such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 3 months of its completion and feedback must also be given to the clinic involved.
4. Your project has been given an ID Number (10232). Please use this in any future correspondence with us.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR G H VISSER
MANAGER: SPECIALISED HEALTH

cc. Mrs Sifanelo & Mrs Stanley
Dr K Jennings
Ms Caldwell

THIS CITY WORKS FOR YOU   ESI SIXEKO SISEBENZELA WENA   HIERDIE STAD WERK VIR JOU

Appendix D - Participant informed consent form

Declaration by participant

By signing below, I …………………………………..………… agree to take part in a research study entitled *Factors influencing HIV status disclosure*.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…....……….. on (*date*) …………....……….. 2011.

....	....
Signature of participant	**Signature of witness**

Declaration by investigator

I Ceridwyn Klopper declares that:

- I explained the information in this document to the participants.
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (*place*) ....…....………….. on (*date*) …………....……….. 2011.

....	....
Signature of investigator	**Signature of witness**

Supervisor: Dr. E Stellenberg

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek, ……......................………....……...……….., om deel te neem aan 'n navorsingsprojek getiteld *Factors influencing HIV status disclosure*.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in 'n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te *(plek)* ....……….. op *(datum)* ………...……….. 2011.

....	....
Handtekening van deelnemer	**Handtekening van getuie**

Verklaring deur navorser

Ek, Ceridwyn Klopper, verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan ………………..………..
- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.)*

Geteken te *(plek)* ....……….. op *(datum)* ………...……….. 2011.

....	....
Handtekening van navorder	**Handtekening van getuie**
Supervisor: Dr. E Stellenberg	

Isifungo somthathi-nxaxheba
Ngokuytyikitya ngezantsi, Mna ………………………………..…………. ndiyavuma ukuthatha inxaxheba kwisifundo sophando semfuzo esibizwa ngokuba *Factors influencing HIV disclosure*.

Ndazisa ukuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo
- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube **kukuzithandela kwam** kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye uqal' ugwetywe nangayiphi indlela.
- Usenokucelwa ukuba usishiye isifundo phambi kokuba siphele, ukuba ugqirha wesifundo okanye umphandi ukubona kuyinzuzo kuwe, okanye ukuba andisilandeli isicwangciso sesifundo, ekuvunyelenwe ngaso.

Kutyikitywe e-(indawo) ....…......………….. ngo-(usuku) ……….....……….. 2011.

....
Umtyikityo womthathi-nxaxheba **Umtyikityo wengqina**

Isifungo somphandi
Mna Ceridwyn Klopper ndiyafunga ukuba:

- Ndilucacisile ulwazi olu kweli xwebhu ku-…………………..……………...
- Ndimkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndiyaneliseka kukuba uyakuqonda ngokwanelisayo konke okumalunga nophando okuxoxwe ngasentla.
- Ndisebenzise/andisebenzisanga toliki. (*Ukuba itoliki isetyenzisiwe kumele ityikitye isaziso ngezantsi.*

Kutyikitywe e-(indawo) ....…......……….. ngo-(usuku) ……….....……….. 2011.

....
Umtyikityo womphandi **Umtyikityo wengqina**
Supervisor: Dr. E Stellenberg

Appendix E - Participant information leaflet

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Factors influencing HIV status disclosure.

REFERENCE NUMBER: N10/12/409

PRINCIPAL INVESTIGATOR: Ceridwyn Klopper

ADDRESS: 21 Gleneagle Crescent
Sunningdale
7441

CONTACT NUMBER: (w) 021 938 9038 (c) 084 557 7080
SUPERVISOR: Dr. E Stellenberg (w) 021 938 9244

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- *The study will be conducted at Albow Gardens Community Health Clinic. There will be 150 participants recruited for the study.*
- *The aim of the study is to determine why people decide to tell or not to tell others their HIV positive status.*
- *You are being asked to complete a questionnaire for the purpose of this study.*

Why have you been invited to participate?

- *You have been invited to provide health care professionals with information that would improve their understanding and support with regards to HIV disclosure.*

What will your responsibilities be?

- *You will need to complete the attached questionnaire and return it to myself or the sister working in the clinic.*

Will you benefit from taking part in this research?

- By providing us with the knowledge it will empower health care professionals to better understanding of the clients and the difficulties they experience with regards to telling people if they are HIV positive.

Are there any risks involved in your taking part in this research?

- You will be asked to complete a questionnaire. This is a sensitive matter and if you become emotional contact numbers will be provided for counselling and support. Your privacy and confidentiality are guaranteed. Your identity will remain anonymous.

If you do not agree to take part, what alternatives do you have?

- *You may refuse to participate in the study or withdraw at any time. Under no circumstances will you be discriminated upon.*

Who will have access to your medical records?

- *Your medical records will not be accessed.*

Will you be paid to take part in this study and are there any costs involved?

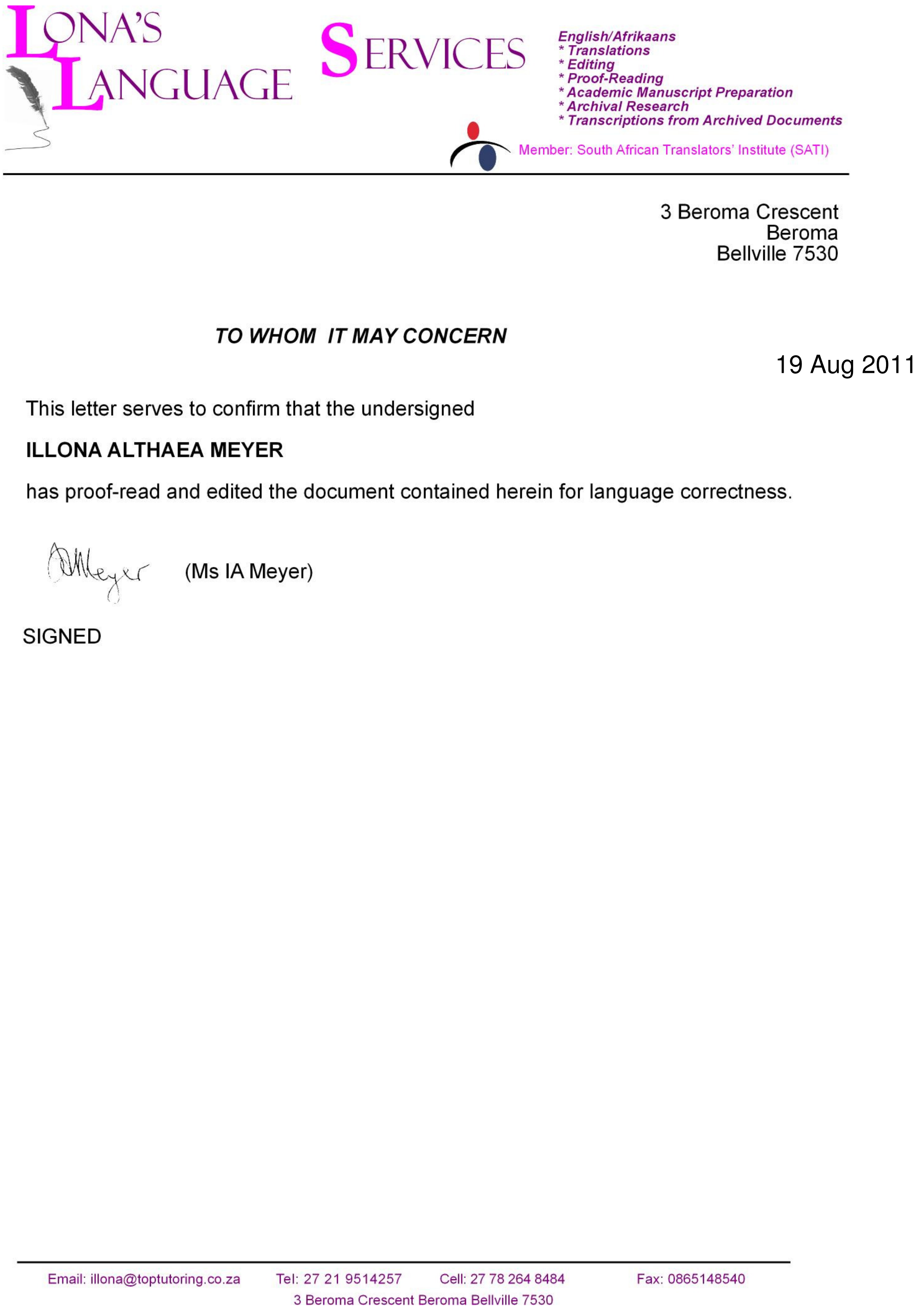
- *No, you will not be paid to take part in the study. There will be no costs involved for you, if you do take part.*

Is there anything else that you should know or do?

- *The study involves completing a questionnaire.*
- *These questions will consist of information such as:*
    - *Gender, age, race, marital status, income, religion and level of education.*
    - *When were you diagnosed with HIV?*
    - *When did you disclose your HIV status to another person?*

- *You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study person.*
- *You will receive a copy of this information and consent form for your own records.*

Appendix F – Confirmation of language correctness



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Member: South African Translators' Institute (SATI)

3 Beroma Crescent
Beroma
Bellville 7530

TO WHOM IT MAY CONCERN

19 Aug 2011

This letter serves to confirm that the undersigned

ILLONA ALTHAEA MEYER

has proof-read and edited the document contained herein for language correctness.

AMeyer (Ms IA Meyer)

SIGNED

Email: illona@toptutoring.co.za Tel: 27 21 9514257 Cell: 27 78 264 8484 Fax: 0865148540
3 Beroma Crescent Beroma Bellville 7530