

**COUPLES' EXPERIENCES ON DISCLOSURE OF HIV-
POSITIVE STATUS AT THULAMELA B CLINIC, VHEMBE
DISTRICT, LIMPOPO PROVINCE**

by

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DECLARATION

I, **Tsakani Millicent Maluleke**, declare that **“Couples’ Experiences on Disclosure of HIV-Positive Status at Thulamela B Clinic, Vhembe District, Limpopo Province”** hereby submitted for the degree of Master in Nursing Science and Arts (MCur) at the University of Limpopo has not been submitted previously by me at this or any other university, and that all materials contained herein have been duly acknowledged.

Tsakani Millicent Maluleke :

Date Signed :

DEDICATION

This dissertation is dedicated to:

All HIV-positive patients in Mhinga Clinic, my late father—Hlengani Shadrack Maluleke, my mother—Mamayila Dorris Maluleke, my two daughters—Bongani and Tshembho Mbhanye, my fiancée—Risenga Ernest Mbhanye, my brothers—Rindelani and Vongani Maluleke, my sisters—Vulani, Miyelani and Tlangelani Maluleke, my grandparents and Mhinga clinic staff

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ABSTRACT

Purpose of the study

The purpose of this study was to investigate the experiences of couples on disclosure of their HIV-positive status to each other.

Research methodology

Qualitative, Phenomenology, exploratory descriptive and contextual research was conducted to identify the experiences and to determine the strategies that address non-disclosure of couples on their HIV-positive status. The population comprised 12 participants (six (6) couples). Purposive sampling was used to select eight (8) participants (four (4) couples) who participated in the study. Semi-structured interviews were used to collect data until data saturation was reached.

Study findings

Data were analysed using Tesch's open-coding method. Five themes emerged, namely, fear of being HIV-positive, disclosure of HIV-positive status is a difficult process, acceptance of HIV-positive status, relations between partners post knowledge of HIV-positive results and encouragement pertaining to disclosure of HIV-positive status. Strategies were developed to address the experiences identified. Recommendations were made for the Department of Health, clinic staff, future researchers, patients and community members.

Conclusion

Although couples disclosed their status to one another disclosure was found to be a difficult process. Acceptance of HIV status was also found to be one of the challenges that led to delayed disclosure of the status. Support system from both family and community is a very important factor which might increase HIV status acceptance and disclosure from couples.

Keywords: Couples, experiences, disclosure, HIV-positive status.

ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Treatment
BONELA	Botswana on Ethics Law and HIV/AIDS
CPC	Centre for Positive Care
DoH	Department of Health
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
HST	Health Systems Trust
MDG	Millennium Development Goal
OACHA	Ontario Advisory Committee on HIV/AIDS
OSFSA	Open Society Foundation for South Africa
PICT	Provider Initiated Counselling and Testing
PLWH	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
SHARP	Strengthening HIV/AIDS Response Partnership
TASO	The Aids Support Organisation
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

DEFINITIONS OF CONCEPTS

Couple	Couple refers to two persons in an ongoing sexual relationship (World Health Organisation, 2012: 10). In this study, it referred to any two persons who are male and female involved in a sexual relationship, even if they are not married.
Couple HIV discordance	Couple HIV discordance refers to a stable sexual relationship where one partner is infected with HIV while the other one is not infected (Ateka, 2006: 495). In this study, it referred to any two people, male and female, where one of them is HIV-positive and the other one is HIV-negative.
Disclosure	Disclosure is a process whereby a client shares the results of his/her HIV status with a family member, trusted friend or sexual partner (Pillay, 2010: 86). In this study, it referred to a process where people in a sexual relationship share their HIV status results to one another.
HIV-positive	HIV-positive refers to an HIV antigen/antibody test that shows a reaction to indicate the presence of HIV antigen/antibody in blood (Department of Health, 2011: 64). In this study, it referred to a person who is infected with the human immunodeficiency virus (HIV).
Non-disclosure	Non-disclosure refers to not exposing, or making something not known (Ateka, 2006: 495). In this study, it meant inability of HIV-infected persons to share their HIV-positive results with their sexual partners.

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 Introduction and Background

Disclosure of human immunodeficiency virus (HIV) positive status is a complex, difficult and personal matter (Remien & Bradley, 2007: 1). Disclosing one's HIV status entails communication about potentially life-threatening, stigmatised and transmissible illness. Non-disclosure may have lifelong implications since people are living longer and often asymptomatic therefore spreading the infection (Remien & Bradley, 2007: 1).

Public health messages have traditionally urged HIV-positive clients to disclose their HIV status to their sexual partners, including drug-using partners (Remien & Bradley, 2007: 1). Some HIV positive people may chose not to disclose their status due to fear of being rejected. Another reason for non-disclosure includes fear of being harmed, feeling ashamed and the desire to keep the secret. Lastly people can conceal their status if they are using condoms in their relationship because they don't see the need of disclosure when they practice safe sex (Remien & Bradley, 2007: 1).

According to Seid, Wasie and Admassu (2012: 97) HIV status disclosure is vital for HIV prevention efforts. Furthermore Seid et al. (2012: 98) indicated that studying the factors affecting disclosure of HIV status to sexual partner in an area where no assessment was done previously is very important for the better care of people living with HIV and AIDS.

HIV status disclosure is complicated further by the phenomena of couple HIV status discordance which makes it more difficult to tell other sexual partners of one's results (Ateka, 2006: 494). Deribe, Woldemichael, Wondafrash, Haile and Amberbir (2008: On-line) supported this by stating that HIV-infected individuals are more likely to disclose to a partner whom they know is also

HIV-positive than to an HIV-negative or unknown HIV status partner. Furthermore, a study conducted by Mamogobo, Lekhuleni and Matlala (2013: 36) on HIV-positive status disclosure reported that it is difficult for some people to disclose their HIV-positive status to their partners. They also revealed that this occurs if the positive client is not aware of the partner's status. The way each person experiences and copes with HIV is reflected in the way that the person takes a decision to disclose or not and to whom she/he discloses.

Various countries such as the United States of America (USA) and England have passed laws to treat willful exposures as a criminal offense. Willful exposure happens when someone knows she/he is infected with HIV, but decide not to disclose to their sexual partners and is not mindful of the possible transmission and continue to expose partners to infection (Castelee, 2006: On-line).

According to the Human science research council (2014: 35) the national estimate for HIV prevalence among South Africans in 2012 was 12.2%. This estimate is statistically different from the 2008 national estimates of 10, 6%. In absolute numbers there has been a significant increase of almost 1, 2 million more people living with HIV in South Africa.

Reports by the DoH (2011: 9) confirmed that South Africa, particularly the sub-Saharan Africa, has the largest burden of HIV/AIDS in the world. This country contains approximately 30% of the world's population living with HIV/AIDS, yet it only contains about 2% of the world's population. Women in sub-Saharan Africa are also disproportionately more affected by the HIV epidemic where, for every 10 adult men infected with HIV, 16 women are infected due to sharing of men. The DoH further reports that infection continues to grow because of population growth and also due to lifelong antiretroviral treatment (ART) which keeps infected people symptom free, whereas disclosure of HIV-positive status amongst couples is still low (DoH, 2011:10).

Limpopo province HIV prevalence among antenatal women in 2012 was estimated at 22.3% (National DoH, 2013: 42). The overall HIV prevalence in Limpopo has slightly increased from 21.9% in 2010 to 22.1% in 2011 and 22.3% in 2012. Furthermore they indicated that erratic changes in HIV prevalence rates were seen in Vhembe district, which has consistently recorded the lowest HIV prevalence, from 17.0 % in 2010 to 14,6% in 2011 and 17,7% in 2012.

The Centre for Positive Care (CPC) (2011: On-line) reported that for the period 2010 to 2011 Limpopo had an HIV prevalence of 21.5 % and this suggested that there is still an increase in prevalence of HIV although Limpopo has a fairly low HIV prevalence compared to other South African provinces.

1.2 Research Problem

Despite Millennium Development Goal (MDG) Number six (6) of combating HIV/AIDS, malaria and other diseases by 2015 (halt new infections and reverse the spread of HIV/AIDS, targeting to reduce prevalence among 15 to 24 years old pregnant women) there are new infections reported in the province on a monthly basis (CPC, 2011: On-line). Limpopo is reported to have a fairly low HIV prevalence compared to other provinces, but it still has new infections occurring. Statistics for Thulamela Municipality B indicates that HIV prevalence during the reports for 2007 and 2008 was at 13.7%, and for 2009 and 2010 was at 14.7% whereas Limpopo as a whole had an HIV prevalence of 21.5 % in 2010 (CPC, 2011: On-line).

Interventions are needed in South Africa to reduce AIDS and to assist people with HIV to make effective decisions on disclosure (Simbayi, Kalichman, Cloete, Henda & Mqeketo, 2007: 33). The control of new infections for HIV relies on disclosure of the positive status amongst couples. Thulamela B Municipality still has new infections reported by couples on a monthly basis.

1.3 Aim of the Study

The aim of the study was to investigate the experiences of couples on disclosure of HIV-positive status to one another.

1.4 Research Question

The following research question guided the researcher during the study:

What are the experiences of HIV-positive couples on disclosure of HIV-positive status at Thulamela Municipality B in Limpopo Province?

1.5 Objectives of the Study

The objectives of this study were to:

- Explore the experiences of HIV-positive status disclosure on couples at Thulamela B Clinic of Limpopo Province.
- Determine strategies for addressing the experiences identified, for possible control of non-disclosure of HIV-positive status amongst couples at Thulamela Municipality B of Limpopo Province.

1.6 Overview of Research Methodology

The study was qualitative in nature. Creswell (2014: 32) defines a qualitative research as an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem. A phenomenological, Exploratory, descriptive and contextual design was used in the study as the researcher intended to understand the lived experiences of couples on their HIV-positive status disclosure at Thulamela Municipality B. Phenomenological research is a research design of inquiry coming from philosophy and psychology in which the researcher describes the lived experiences of individuals about a phenomenon as described by participants (Creswell, 2014: 42). The population consisted of 12 HIV-positive couples

who were selected using purposive sampling.

The researcher used an in-depth interview and probing techniques following a central question to gather enough data on the phenomena under study. Data collection took place at Mhinga ARV clinic, and face-to-face interviews were used in order to obtain sufficient information. A voice recorder and field notes were used as sources of collected data used to analyse and collate data into meaningful findings. The voice recorder and field notes were kept for future reference about the interview which took place, and the researcher reported findings as they were described by the participants. Details of the research methodology will be discussed in Chapter 3 of this mini-dissertation.

1.7 Significance of the Study

The study could help in increasingly identifying experiences that cause couples not to disclose their HIV-positive status at Thulamela Municipality B. The study could also assist in reducing the prevalence of HIV at Thulamela Municipality B by intensifying risk reduction through disclosure of HIV-positive status amongst couples, and it might also assist couples who were previously unable to disclose to one another to do so.

1.8 Conclusion

Chapter 1 provided an overall impression of the study, including the research problem, aim and objectives as well as the research question which motivated the researcher to undertake the study. This chapter also presented an overview of the research methodology as well as the significance of the study. Chapter 2 will discuss the literature review of issues pertinent to the study area.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This chapter encompasses a review of relevant literature on the phenomena under study. The purpose of the literature review is to identify gaps from previously conducted research. In order to understand the research topic in a way that clearly formulates the research problem, some background information was necessary. The researcher reviewed literature on experiences of couples on HIV status disclosure from various journals, textbooks and databases.

2.2 Challenges Facing Couples on HIV Status Disclosure

People living with HIV/AIDS (PLWH) are challenged to make decisions about whether or not to disclose their sero-positive status to their partners (Sullivan, 2005: On-line). Self-disclosure of an HIV-positive status informs couples of their potential risk and may facilitate negotiation of safer behaviours (Sullivan, 2005: On line). Hong, Goldstein, Rotheram-Borus, Wong and Gore-Felton (2006: 153) maintained that due to inconsistent disclosure of HIV-positive status PLWH continue to engage in unprotected sexual intercourse with their steady sexual partners, but not their casual sexual partners. When HIV-positive status is not disclosed couples may underestimate their own risk of infection and subsequently engage in less protective measures (Sullivan, 2005: On-line). Disclosure is further reduced by experiences that HIV-positive people face when sharing their HIV-positive status with their partners (Mabuza, 2010: 25).

Sowell, Seals, Phillips and Julious (2006: 42) indicated that in order to provide quality health care and support services to HIV-infected women, greater understanding needs to be gained. It should include how women

make decisions related to disclosure, and what interventions by health providers and educators will be most helpful to women in making the decision to disclose.

Disclosure of HIV-positive status is a most personal and more sensitive issue because of the stigma attached to HIV/AIDS (Mabuza, 2010: 32). Couples are faced with difficulty when they have to disclose their HIV-positive status to each other. Due to the stigma attached to HIV/AIDS, sero-positive spouses can be rejected by their partners (Mabuza, 2010: 33). In some countries, such as Nigeria, the HIV-negative partners in sero-discordant couples are advised to divorce their partners (Mabuza, 2010: 33). This is one of the experiences that some couples face when disclosing their positive status to each other and it further complicates and makes it difficult for couples to share their status with each other. The Open Society Foundation for South Africa (OSFSA, 2009: On-line) reported that ending HIV and fighting human rights violations is the best formula to promote openness.

Rejection amongst couples is largely based on moral judgments because HIV is often linked to at-risk sexual behaviour resulting in couples judging one another (Mabuza, 2010: 33). Some HIV-positive individuals delay to disclose their HIV-positive status to their partners and have at least one sexual contact before disclosing and this raises possibility of transmission if a condom was not used (Deribe et al., 2008: On-line). Furthermore, Deribe et al. (2008: On-line) stated that disclosure in main partners is 90.8% and 38.5% in casual partners.

Fear of partner reaction, not wanting partners to worry about health and fear of physical and emotional abuse are some of the factors reported to be the reasons for non-disclosure in most couples (Deribe et al., 2008: On-line). HIV status disclosure is central to debates about HIV because of its potential for HIV prevention and its links to privacy and confidentiality as a human rights issue (Obermeyer, Baijil & Pegurri, 2011: 1011). Niccolai, King, D' Entremont and Pritchett (2006: 103) indicated that the overall rates of disclosure vary

between studies, but many studies indicate that disclosure does not occur in a substantial minority of sex partnerships.

Simbayi et al. (2007: 29) conducted an anonymous survey on 413 HIV-positive men and 641 HIV-positive women sampled from HIV services around Cape Town. The study revealed that 42% had sex with a person whom they did not disclose to in the previous three 3 months. Participants who had not disclosed their HIV status to their sex partners did so because they have lost their job or place to stay as a result of being HIV-positive, and feeling less able to disclose to partners.

2.3 Disclosure of HIV-Positive Status and Reactions Amongst Couples

Greene (2011: 747) indicated that as the HIV epidemic enters its third decade it remains one of the most pressing health issues of our time. Furthermore, she stated that disclosing an HIV diagnosis remains a decision process fraught with difficulty and despite encouraging medical advances, an HIV diagnosis creates significant anxiety and distress about one's health, self-identifying and close relationships (Greene, 2011: 750).

A study was conducted in Houston, Texas (USA) on a sample of 80 HIV-positive pregnant women to assess HIV-positive status disclosure patterns amongst couples and patterns of social support breakdown following HIV status disclosure (Egger, 2006: On-line). The results indicated that partners who were HIV-positive already at the time of disclosure remained in the relationship for support of partners, but those who were HIV-negative or whose status was unknown left their partners and started new relationships with new partners whose HIV status they did not know about (Egger, 2006: On-line). In South Africa (SA), a similar study was conducted to the one in Houston, Texas, but on a sample of 169 HIV-infected male miners and their female sexual partners on disclosure and social support (Ateka, 2006: 494). The results on partner HIV status disclosure and breakdown in social support were counter intuitive, 70% (19 out of 27) of partners of unknown HIV status continued to offer support to their HIV-positive partners, whereas 83% (15 out

of 18) of HIV-positive partners broke their relationships (Ateka, 2006: 495). The study further indicated that encouraging disclosure may prevent infection amongst discordant couples, but at the expense of social support (Ateka, 2006: 495).

The Desmond Tutu HIV Foundation (2007) investigated the influence of non-disclosure amongst couples. Results showed that stigma was a common cause of non-disclosure and it remains a most difficult obstacle in tackling the HIV epidemic. Due to the stigma and discrimination people are often avoided, assaulted or killed when they disclose their HIV-positive status to their sexual partners. The HIV-related stigma and discrimination were associated with not disclosing HIV status to sexual partners and non-disclosure was closely associated with transmission of HIV (Simbayi et al., 2007: 33).

Another study focused on HIV-positive status disclosure based on gender in Mali, Burkina Faso and in the USA on couples living with HIV, women and men in material relationship (those who are in a relationship because they are in need of money, food or clothes), and those in cohabitating relationship (Simbayi et al., 2007: 34). Report of disclosure was 72.1% in men and 79.9% in women which indicated that women tended to disclose more than men (Simbayi et al., 2007: 34).

One study by Deribe et al. (2008: On-line) revealed that women with higher education (those with tertiary qualifications) are more likely to disclose their status than illiterate women because illiterate women fear rejection due to self-submission (Deribe et al., 2008: On-line). Many couples delay disclosure until the disease has progressed because individuals require emotional or material assistance from their spouses and it is difficult to conceal illness from partners at a later stage (Deribe et al., 2008: On-line). Deribe et al. (2008: On-line) further reported on a cross-sectional study from 2007 to 2009 in Jimma University Specialised Hospital on disclosure of HIV-positive status amongst couples: 71.6% of participants were taking ARVs; up to 94.5% disclosed their status to at least one person and 90.8% disclosed to their

current main partner, not one-night partners or partners from previous relationships. Furthermore, the study found that 14.2% of disclosure was delayed and 20.6% did not know their partner's HIV status; this was the reason for delayed disclosure. Amongst those who did not disclose, 54% stated that their reasons included fear of negative reaction from their partners. After disclosure of HIV status amongst couples only 5% reported negative reactions and 80.3% reported that they received support from their partners after disclosing.

Similar to the study reported by Deribe et al. (2008: On-line), a study conducted by Mabuza (2010: 30) revealed that HIV-positive women who are economically disadvantaged or illiterate can experience additional strain when it comes to deciding whether to disclose their status or keep it confidential, because disclosure of their status may jeopardize their relationships with their partners (Mabuza: 2010: 30).

Achilla (2010: 65) also conducted a study on disclosure of status to sexual partners amongst people who receive ante-retroviral treatment in Kampala (Uganda). The study revealed that while some PLWH wish to disclose their status to their partners. There are compound factors that make it difficult to disclose and this calls for the government, TASO and other agencies to come up with measures to reduce non-disclosure in sexual partners, especially those in cohabitating and steady relationships in order to reduce the vulnerability of HIV infection.

2.4 Impact of Not Disclosing HIV-Positive Status in Couples

The Human Sciences Research Council (HSRC) reported on a study conducted during the period 2002 to 2005 on disclosure of HIV-positive status in couples and prevalence of HIV in SA (HSRC, 2007: On-line). The results were that SA has the highest number of people with HIV in the world. Although some infections were thought to be through nosocomial transmission, it was argued that there was a degree of consensus that the main route of infection was through heterosexual and homosexual sex, the

more leading route being non-disclosure of HIV-positive status amongst couple (HSRC, 2007: On-line).

Research conducted by Strengthening HIV/AIDS Response Partnership (SHARP, 2005: On-line) revealed that most HIV-positive individuals had not disclosed their HIV status to their spouses or regular partners with fear of divorce or rejection as the main reason indicated by respondents. As a result of not disclosing HIV-positive status in couples, there are profound negative consequences for safer sex negotiation, prevention of new infection and a healthy positive lifestyle (SHARP, 2005: On-line). SHARP (2005: On-line) further revealed that there should be a comprehensive approach to HIV prevention and it requires that HIV-positive people must take protective and preventive measures since they may be at risk of infecting their sexual partners and re-infecting themselves with different strains of the virus.

Remien and Bradley (2007:1) indicated that disclosure to sexual partners is more likely to occur in a long-time relationship than in casual relationships, anonymous and group sex. Disclosure also varies depending on perceived HIV status of partner, level of risk of sex activities, sense of responsibility to protect partners and alcohol or drug use. Public health messages have traditionally urged HIV-positive clients to disclose their HIV status to their sexual partners and drug using partners (Remien & Bradley, 2007: 1).

2.5 Benefits of Disclosure of HIV-Positive Status in Couples

Self-disclosure of sensitive information is generally thought to have beneficial effects on an individual's health, lower stress, and leads to better psychological health (Sullivan, 2009: 29). Furthermore disclosure of HIV-positive results in couples requires a stepwise process of sensitisation and agreement by the infected partner (Kairania, Gray, Kiwanuka, Makumbi, Sewankombo, Serwadda, Nalugoda, Kigozi, Semanda & Wawer, 2010: 1041).

Disclosure of HIV-positive status in couples is useful based on the following:

2.5.1 Prevention of HIV/AIDS

Disclosure of HIV-positive status facilitates couples not to underestimate their own risk of HIV and to seek testing (Mabuza, 2010: 26). When one partner discloses their HIV-positive status, the other partner may think of their own risk. This will enable them to practice safer sex to prevent re-infections because the other partner will be aware of the risk of contracting the infection (Sullivan, 2005: On-line).

In support of this view, Mabuza (2010: 25) reported that one of the reasons of disclosure of HIV-positive status in couples, is to serve as a forewarning or notifying the other partner about the risk of contracting infection. This also encourages the partner to prevent re-infections. Kgwete (2008: 28) indicated that fear of being blamed or rejected by partners lead women to deny HIV status and treatment, they prioritise their immediate needs such as food for the family, over risks to their health and survival.

The World Health Organisation (WHO), (2012: 15) indicated that disclosure benefits couples with prevention of infection. Further advising that when an HIV-positive partner has a CD4 cell count of more than 350cells / μ L in sero-discordant (where one partner is HIV-positive and the other one is HIV-negative), couples should be offered ART to reduce chances of HIV transmission to the uninfected partners. This is a strong recommendation based on high quality evidence.

2.5.2 Sexual and Reproductive Health Choices

Non-disclosure of HIV status to partners has implications not only for sexual transmissions, but also for the individuals' ability to attend clinics regularly for treatment, HIV related services and family planning services. WHO (2012: 20) reported that there are many potential benefits to supporting couples to test together for HIV infection and to mutually disclose their HIV status to each other, most importantly that together they can make informed decisions about prevention and reproductive health choices.

The National Department of Health (National DoH, 2010: 22) supports this by stating that disclosure enables couples to make informed reproductive health choices. This may lower the number of unintended pregnancies among HIV-positive women who are pregnant to comply with prevention of the mother-to-child transmission (PMTCT) of HIV programmes. This could assist them to bear healthy babies.

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2015: On-line) reported that male behaviour is a key determinant of the pandemic of HIV. Men have a significant role to play in ending this behaviour. Furthermore, they reported that strategies have to be developed to work with men to change risky behaviours. A top priority of many other health benefits accrue, such as reduction in sexual coercion and violence, or unwanted pregnancies.

Mabuza (2010: 26) reported that disclosure of HIV may assist people to protect themselves from re-infections by negotiating the use of condoms with their partners. In support of the positive HIV status disclosure in couples, National DoH (2010: 27) reported that for keeping women and children healthy and improving their quality of life and reducing mortality, all pregnant women should be encouraged to involve partners or spouses for testing. Spouses should be counselled on persistent use of condoms to prevent HIV infection.

They also reported that if a partner is not aware of the other partner's HIV status it is not easy to negotiate the use of condoms in couples. Disclosure of HIV-positive status in couples, may also promote the effectiveness of programmes on PMTCT of HIV because HIV-positive women tend to comply with all the requirements when their status is known to the partner (National DoH, 2010: 28). The Terrence Higgins Trust (2015: On-line) reported that one benefit of disclosure of HIV status to partners is that if they are exposed to HIV infection, such as during sex when a condom breaks then the un-infected partner can receive post-exposure prophylaxis for the duration of 28 days to prevent infection.

Lougue (2010) stated that HIV infection continues to spread each year, and further indicated that new infections may suggest that infected people have sex with those who were not previously infected and they become infected. He further reported that ignorance of the sexual partner's status has been shown as the main reason for the spread of HIV, while disclosure can be an important strategy for controlling the spread of infection.

2.5.3 Psychological, Emotional, Physical and Other Forms of Support

HIV status disclosure, counselling and early initiation of ART may be effective in improving HIV status disclosure (Ongoina, Ikuabe, Ebuenyi, Harry, Inatimi & Chukweke, 2015: 11). However, disclosure of HIV-positive status in couples is often successful only if there is support (Van Dyk, 2008: 241). No HIV prevention programme can be successful without support to partners. Mabuza (2010: 25) also revealed that reasons for disclosure of HIV-positive status in couples, include a desire for emotional closeness with support from the other partner. Sullivan (2005: On-line) reported that other potential benefits or advantages of disclosing HIV status include stress reduction, because keeping secrets may be psychologically and physically burdensome. Furthermore, Sullivan (2005: On-line) revealed that self-disclosure has the potential to improve mental and physical health and possibly increase lifespan by decreasing distress of concealing something because withholding thoughts and feelings may lead to chronic stress and weakening of immune system functioning (Sullivan, 2005: On-line). Mabuza (2010: 38) reported that disclosure of an HIV-positive status may also help people to accept their positive status and reduce the stress of coping on their own. Similar to this view, the Wellness Project (2014: On-line) indicated that some people decide to become more public and use their stories to advocate for others in the government or in the media and this increases their self-esteem by telling their stories.

2.6 Risks of HIV-Positive Status Disclosure in Couples

Some people do not want to disclose their HIV-positive status because they do not know how their partners will react (Nabilek, 2009: On-line). In support of this perception, Chen, Starks, Shiu, Fredricksen-Golden, Simons and Zhang (2007) revealed that many women chose not to disclose to anyone, including husbands. This study was conducted among Chinese HIV-positive patients. One of the reasons for non-disclosure, was that disclosure often involved risks, particularly when information revealed is potentially embarrassing.

A study was conducted in two medical facilities in Enugu (Nigeria) from September to November 2007 on HIV-positive pregnant women accessing PMTCT services at two centres. Ninety two women were interviewed: 89 (96.7%) had disclosed while three (3) (3.3%) had not. Fifty two (58.4%) gave emotional support as the reason for disclosure and 46 (51.7%) gave economic and financial support as a reason for disclosure. Fifty six (62.9%) reported understanding from partners as a positive outcome and 44 (49.4%) reported financial support.

Forty six (51.7%) reported no negative outcome. Sero-positive status disclosure was high without any negative experiences (Ezegwui, Nwogu-Ikojo, Enwereji & Dim, 2009: 789).

Due to the stigma attached to HIV/AIDS, sero-positive spouses can be rejected by their partners because of their status (Mabuza, 2010: 32). In some countries such as Nigeria, HIV-negative partners in non-discordant couples are advised to divorce their partners (Mabuza, 2010: 33). This is another experience that couples face when disclosing their HIV-positive status. The SA Positive Magazine (2014: On-line) reports that due to the issue of stigma, many people avoid disclosing their HIV status because they fear that this information will spread in their community and affect their lives negatively.

Another study was conducted by the HSRC during the period 2002 to 2005 on disclosure and prevalence of HIV. The results were that SA has the highest number of PLWH in the world. Although some infections were thought to be through nosocomial transmission, research revealed that there is a degree of consensus that the main route of infection was through heterosexual and homosexual sex. The more leading causes were non-disclosure of positive status among sexual partners (HSRC, 2007: On-line).

Rejection is often based on moral judgement because HIV is often linked to at-risk sexual behavior, resulting in couples judging each other (Mabuza, 2010: 33). Some HIV-positive individuals choose not to disclose their status to their partners because of fear that the partner might get angry with them, separate from them, accuse them of cheating or being labelled as a bad partner (Mabuza, 2010: 33). Similarly, Nabilek (2009: On-line) reported that HIV-positive status disclosure always has some risks attached to it. People might be rejected by friends or partners or might even suspect discomfort from them when they find out about their status. Deribe et al. (2008: on-line) also conducted a study which revealed that fear of reaction which include physical and emotional abuse are the most reasons reported to be the leading cause of non-disclosure of positive status in couples. Another study, conducted by Simbayi et al. (2007: 30) revealed that stigma and discrimination were associated with not disclosing HIV-positive status in couples and also with transmission of the HIV infection. According to Simbayi et al. (2007: 29), although many people know about safer sex and how to prevent HIV infection, fear of stigma still is a reality and disclosing one's positive status will put off people from associating with the infected person.

Egger (2006: On-line) indicated that it is difficult to identify a more charged issue in HIV/AIDS prevention, than that of non-disclosure of HIV-positive status to sexual partners. HIV/AIDS control relies on disclosure of HIV-positive status among sexual partners and failure to disclose, interferes with

risk reduction and increases re-infections. Gari, Habte and Markos (2010: 87) indicated that even though the magnitude of HIV-positive status disclosure to sexual partners in the study conducted on women attending ART clinic at Hawasa was encouraging, risk behaviour and negative partner reactions following disclosure were high. Therefore, efforts should be made for follow-up couple counselling and testing use of behaviour rehearsal techniques to overcome barriers to disclosure.

Other studies were conducted in SA (Johannesburg and Cape Town), Tanzania (Dares Salaam) and Ukraine (Kiev, Rivne & Ivano-Frankovsk) on sero-discordant couples who have been living together for at least one year. Couples 18 years and older and in a heterosexual and homosexual relationships revealed varying degrees of tension as a result of sero-discordance after disclosure. The study conducted on HIV-positive status disclosure among sero-discordant couples in SA revealed that the majority of couples (71%) did not report tension after disclosure, but 24% reported tension in their relationship after disclosure. The study revealed this tension was related to four issues, namely, fear of infection for the negative partner; lack of trust due to perceived infidelity, multiple sexual partners or cheating; persistent use of condom with low sex drive, and strained relations at the time of first disclosure of the HIV-positive status. In the same study, 71% of couples reported a decrease in the frequency of sexual activity due to fear of infection of the negative partner. The study further reported that most partners did not disclose to the other partner immediately due to fear of loss of a partner. The interviews also revealed selective disclosure where a person disclosed to only one regular partner and not to casual partners, resulting in exposing other partners to the risk of infection (Mabuza, 2010: 27).

Some of the risks of disclosure of HIV-positive status in couples include isolation and rejection which are thought to be associated with non-disclosure of HIV-positive status (Van Dyk, 2008: 280). In support of this view, Maseko (2012: 94) reported about a client who was deserted by her boyfriend after

she disclosed her HIV-positive status to him. She was concerned that in future, when she meets another boyfriend she would not disclose her status due to fear of being unhappy when she is in the relationship (Maseko, 2012: 94).

Another issue on risks following disclosure of HIV-positive status was found in a case study. In this case study a client was tested for HIV and she shared her positive results with her husband hoping to get support. Instead the husband accused her of cheating and after a short while, he started abandoning her (Van Dyk, 2013: 48). As a result of this abandonment, the client reported she kept quiet about her status and never shared it with anyone, even her family. This led to her deterioration, because she was stressed and very negative about further disclosure of her HIV status.

Disclosure can also be accompanied by negative consequences such as sexual problems in couples (Van Dyk, 2008: 281). In some communities where women are less empowered, disclosure might lead to eviction, violence and, in extreme cases even murder can occur (Van Dyk, 2013: 45). Modeste and Majeke (2014: 7) conducted a study to find out sources and types of information on self-care symptom management strategies for HIV/AIDS patients. The study included the use of multiple sources to get information on management of symptoms experienced related to HIV disclosure. Sources used included health care providers, family and friends, as well as themselves.

2.7 Impact of Not Disclosing HIV-Positive Status in Couples

The Botswana Network on Ethics Law and HIV /AIDS (BONELA, 2008: 71) reported that the most common barriers to disclosure based on a study conducted in Eastern and Southern African countries like Tanzania and Ethiopia include fear of abandonment, rejection, discrimination, violence, upsetting family members and accusations of infidelity. In a case study titled price of not disclosing HIV-positive status by Van Dyk (2008: 282) the following negative effects were discussed:

2.7.1 Emotional Stress

Anxiety, guilt feeling, stress, low self-esteem, deterioration of mental health, isolation, general sense of loss of everything (feeling alone and worthless), severe depression and suicidal thinking, may result from not disclosing one's own positive results. When the other partner becomes sick of any other illness, it makes the one who is concealing the status to feel guilty and think maybe they have infected them by not telling to negotiate for safer sexual practices.

In-line with the findings of the above case study, Kalichman, Dimarco, Austin, Luke and Difonzo (2013: 318) reported that disclosure and its association to social support and depression varied from different relationships and these differences have implications for mental health and coping interventions. However, a study conducted by Clayton (2011: On-line) indicated that disclosure of HIV-positive status is not associated with psychological problems or any emotional symptoms as reported by HIV-positive children who were assessed for possibility of future disclosure to their sexual partners.

2.7.2 Relationship Problems

Van Dyk (2008: 283) reveals that relationship problems include: withdrawal from friends, break-ups with partners, making excuses as to why they don't want to have sex with permanent partner, fear of starting new relationships. In support of the above findings, HIV and AIDS-Sharing Knowledge, Changing Lives (2015: On-line), HIV prevention is a shared responsibility from a person living with HIV and the sexual partner where both partners in a sexual relationship should take measures to reduce the risk of transmission/acquisition. Withdrawal from friends, break-ups with partners, making excuses as to why they do not want to have sex with permanent partners, fear of starting a new relationship may also result from not disclosing one's HIV status. The Ontario Advisory Committee on HIV/AIDS)

(OACHA,2012: On-line) indicated that disclosure is a personal and intimate process which engages the soul, the mind and the body, and might affect self-image, self-efficiency, self-perception and confidence, therefore, making PLWHA to be more vulnerable.

2.7.3 The Toll of Living a Lie

Fear that one will have to think before speaking to avoid to prevent accidental slip out of an HIV-positive status. A person becomes more stressed by concealing lies. Secret also makes a person not to live freely which increases stress which is not good for the body, at times HIV positive clients live in a permanent fear that someone will find out their status (Van dyk, 2008: 283). On the other hand, Golberg (2011: On-line) is of view that sero-status disclosure is widely regarded as a central component of post diagnosis adjustment and coping.

2.8 HIV Disclosure Patterns Among Sero-Discordant Partners

Mlambo and Peltzer (2011: 32) conducted a study on HIV sero-status disclosure and sexual behaviour among HIV-positive patients who are on ART in Mpumalaga. Their study revealed disclosure patterns to be as follows:

- Partners with unknown HIV are linked to non-disclosure of HIV increasing HIV infection rate.
- Partners with discordant results were motivated for HIV disclosure due to poor health, pregnancy, and death. In a case where couple loses a child though death as a result of illness, the couples were encouraged to test for HIV. Furthermore, in sorting occurred where clients got involved in a relationship with a partner who is of same HIV status as them.
- Action taken by discordant partners included condom usage, which

challenges disclosing. Partner testing and abstinence also challenges disclosing.

- After disclosure, sero-concordant that refers to changes in sexual desire; partners' reaction included separation, partner togetherness and sero-sorting.

Olagbuji, Ezeanochie, Agholor, Olagbuji, Ande and Okonofu (2011: 486) conducted a study on spousal disclosure of HIV in urban Nigeria. The study recommended that for strategies to reduce the stigma associated with HIV infection, appropriate management of the information following disclosure of sero-positive status by HIV-infected persons, are necessary. This will encourage disclosure to sexual partners and ultimately prevent new infections. Tshisuyi (2014: 20) also conducted a study on HIV-positive status disclosure among pregnant women in Botswana, which revealed that disclosure can be important, as far as prevention and subsequent treatment and care amongst discordant couples. This also leads for PMTCT, and to ensure family or partner support.

2.9 Percentage of Deaths Due to HIV-Related Infections in Vhembe District

The Health Systems Trust (HST, 2015: On line) reported that statistics for AIDS related deaths were 25.6 % in 2013 mid-year, 26.4 % in 2014-2015, 27.5% by March 2015, which indicates clearly that deaths due to HIV-related infections are increasing rather than decreasing. Birnbaum, Murray and Lozano (2011: On-line) reported that in SA issuers of death certificates seldom know or have no access to an individual's status. Rural community leaders often omit it when they fill out abbreviated certificates. Furthermore, they reported that many people are unwilling to be tested for HIV for fear of stigma or losing health insurance benefits. This fears leads to underreporting of deaths from HIV/AIDS. They concluded that despite these issues SA's vital registration system remains a key source of data. It comprises the largest continuous data set for causes of death in Southern Africa.

2.10 HIV Disclosure Laws

AIDS Government (2012: On-line) indicated that if a person tests positive for HIV, the clinic or other testing site will report the results to the state or Health Department. They do so to enable the health officials to monitor what is happening with the epidemic in the city and state. Reporting will be in form of statistics only to protect the privacy of the person. Various states have passed laws to treat willful exposures as a criminal offense. Willful exposure happens when someone knows he/she is infected with HIV, but decides not to disclose to their sexual partners and is not mindful of the possible transmission and continue to expose partner to infection (Castele, 2006: On-line).

According to Lambda Legal (2014: On-line), criminalization harm PLWH in a way that it may actually reduce disclosure. A person might be jailed for telling his/her status and may be disinclined to share that information, especially on the second or later encounter. They may even create disincentives to HIV testing because if you do not know your status, you cannot be prosecuted for infecting someone. The USA has also passed a law that states that if a person tests HIV-positive he/she must inform his/her sexual partners of the results because they are a couple. The health care worker may legally be obliged to tell the client's sex partner of the results to protect them from infection and if the status is not disclosed, the person can be charged of crime (United States Department of Health and Human Services, 2012: On-line). However, Legal Action Centre (2012: On-line) raised a view that providers do not have a legal duty to disclose the results to the tested person or partner.

The SA Constitution affords everyone the right to privacy. No one may disclose a person's HIV status without the persons' permission (SA Positive Magazine, 2014: On-line). In support of the report by SA Positive Magazine (2014: On-line), the AIDS Confidentiality Act (2012: Online) indicated that no person can be compelled to disclose HIV-related information, except under

certain specific indications such as request by the law or the disclosure benefits the individual in any other way. Similarly, The Centre for HIV Law and Policy (2014: On line) reported that disclosing ones' HIV status is still widely perceived as socially dangerous. Another great risk for PLWH face the inadvertent or improper disclosure of their status which can result in denial of employment, violence and many other collateral consequences.

National implementation guidelines on Provider Initiated Counselling and Testing (PICT) (2010: 46) indicated that lack of disclosure can lead to transmission of HIV to sexual partners. Therefore, disclosure should be encouraged strongly with the express permission of the patient. Furthermore, National implementation guidelines on PICT (2010: 28) stated that health care providers should be cautioned against disclosing the patient's HIV status to sexual partners without written consent from the patients. Health care workers can only tell a patient's sexual partner(s) about his/her status in the following exceptional cases: The sexual partner is a clearly known and identifiable person, the sexual partner is at risk of being infected with HIV, and the patient has refused to inform him/her of his/her HIV status or has refused to have safer sex, and the patient has been informed of the intended action. Before the health care worker informs a person's known sexual partner of the persons HIV status, it is recommended that the patient is carefully counselled on why it is important to tell a sexual partner. Disclosure should always be done following discussions with senior colleagues in the most appropriate way of doing this.

In South Africa, the only law that gives permission to disclose the HIV status of the individual, is when the results are demanded by the court of law or in case of prisoners under the Occupational Safety and Health Administration Act (OSHA). This Act states that the results must be disclosed to public health authorities, parole officers or sexual partners (National DoH, 2010: 27). The law does not protect any health worker who discloses the HIV-positive status of a non-prisoner to his/her sexual partner.

The New York City Department of Health and Mental Hygiene (2015: On-line) passed a law. It states that if a person tests positive for HIV and wants to disclose to the partner but is afraid to do so, the person must discuss their personal situation with their doctor or with the counsellor who conducted the HIV test. They can help in informing the partner(s) through the use of a contact notification programme which is available in the area, because non-disclosure of HIV status is a criminal offence. In support of this law, Klitzman, Marhefka, Mellins and Wiener (2015: 53) reported that many states and some cities have partner notification laws. This means that if a person tests positive for HIV, that person or the health care provider, may be legally obliged to tell the sex or needle sharing partner. If they fail to disclose the HIV status of the infected individual, they may be charged with a crime.

Furthermore, on partner notification law, WHO (2012: 8) reported that partner notification is challenging and is rarely implemented in many countries. The decision of partner notification should only be made if the HIV-positive person in question has been thoroughly counselled, counselling of the infected person has failed to achieve appropriate behavioural changes, or the HIV-positive person has refused to notify or consent to the notification of the partner(s), a real risk of HIV transmission to the partner(s) exists and the HIV-positive person is given a reasonable notice.

The Health Professional Council of South Africa (HPCSA, 2008, section 9.2.5) indicated that follow-up for the patient and partner to check whether disclosure has caused adverse consequences or violence must be done after partner notification and, if so, appropriate intervention must be carried out for the patient. The Offence against the Person Act (2008: section 20) has passed out a law which indicates that a person may only be charged in case of reckless transmission or deliberate transmission of HIV. Reckless transmission occurs when the person shows no regard for danger or consequences of unprotected sex while the person knows that s/he has HIV infection. The Act further indicates that intentionally or deliberately infecting refers to intentionally or purposefully exposing another person to HIV in order

for the person to be infected.

2.11 Conclusion

Chapter 2 entailed the literature review which included its purpose and how it was undertaken. The literature review included challenges facing couples on HIV status disclosure. Disclosure of HIV-positive status and reactions amongst couples and the impact of not disclosing HIV-positive status together with benefits of disclosure of HIV-positive status in couples, were outlined in this chapter. This chapter also discussed risks of HIV-positive status disclosure in couples and the impact of not disclosing HIV-positive status in couples, HIV disclosure patterns amongst couples, percentage of deaths due to HIV-related infections and HIV disclosure laws. The next chapter will discuss research methodology adopted for the study.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

This chapter discusses the research methodology used in the study. It covers the nature of the study undertaken, describes the study site where the research took place, provides details of the population included in the study and how sampling was done. Furthermore, it explains the data collection procedure and how data were analysed to give meaningful findings. In addition, the chapter discusses how trustworthiness was ensured, including confirmability, transferability, dependability and credibility. Ethical considerations are also discussed in detail in this chapter, including the process of obtaining permission to conduct the study and protecting the rights of participants. Another aspect discussed is bias in the study and how it was prevented from occurring.

3.2 Study Site: Health Structure of Thulamela

The Malamulele Hospital Report (2008: On-line) indicates that Malamulele comprises of one hospital which is Malamulele. The hospital consists of 17 feeder clinics, namely: Malamulele, Xingwedzi, Mavambe, Mphambo, Mtititi, Mukhomi, Nghezimani, Matiyani, Mhinga, Makuleke, Ntlhaveni (block C, D, E and H), Peninghotsa, Tshikonelo, and Xigalo. Out of these clinics there is only 1 health centre which is Mphambo Health Centre. There are three (3) mobile stations, namely: Mhinga, Xingwedzi and Mphambo. The study was conducted at Mhinga ARV clinic of Thulamela Municipality B, Vhembe District, Limpopo Province, South Africa. Thulamela is approximately 190 km east of Polokwane. It covers an area of about 2966.411970 km². It is divided into A and B. Thulamela A covers Louis Trichardt until Thohoyandou and its surrounding villages. Thulamela B covers Malamulele and its surrounding villages. Thulamela B ARV clinics offer HIV counselling and testing as well as

initiation of antiretroviral treatment. Mhinga clinic consists of one (1) operational manager, six (6) clinical nurse practitioners, three (3) professional nurses, one (1) enrolled nurse, three (3) enrolled nurse auxiliaries, three (3) lay counsellors, one (1) data capturer and one (1) mother mentor.

All clinical nurse practitioners, one professional nurse and all lay counsellors in the clinic have been trained in offering HIV counselling and testing (HCT). The mentor mother (a woman who is part of home-based carer, living with HIV and has undergone PMTCT programme) offers health education concerning HIV to the community and the HIV-positive pregnant women and breastfeeding women who are HIV-positive. Mhinga clinic has 1246 patients receiving ART; out of this number, 12 clients are couples (making six (6) pairs), only 10 clients (five (5) pairs) of the 12 use the clinic regularly. Utilisation of services in the clinic was rated to be 97% (Vhembe District Data Indicators, 2013: On-line).

3.3 Research Method

A qualitative research method was used in this study to obtain narrative information from the participants. According to Creswell (2014: 31) a qualitative research is an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem. The researcher chose the qualitative research approach with the intention of identifying the experiences of couples on disclosure of HIV-positive status. Qualitative research methods commonly generate words rather than numbers. In line with this, the researcher reported collected data in the form of themes other than percentages or numbers (de Vos et al., 2011: 400).

Samples in qualitative research are small and not necessarily representative of the broader population. So it is difficult to know how far the researcher can generalise the results. The researcher, therefore, wants to indicate that the study findings will not be generalised to other couples from other clinics as it was focused at Mhinga clinic only.

3.4 Study Design

A study design is a plan or strategy which moves from the underlying philosophical assumptions, the data gathering techniques to be used and the data analysis to be done (Maree, 2008: 70). Phenomenological, exploratory, descriptive and contextual designs were used to identify the experiences of couples on disclosure of HIV-positive status at Thulamela B Clinic, Vhembe District of Limpopo Province.

3.4.1 Phenomenological Research Design

Phenomenology was used to obtain the experiences of couples on disclosure of their HIV-positive status at Thulamela B Clinic Vhembe District, Limpopo Province. de Vos et al. (2011: 316) indicated that phenomenology is the intent to understand the phenomena under study and to provide description of human experiences as it is lived through by subjects for the study. It describes the experiences of participants using in-depth interviews to obtain information. Du Plooy (2009: 88) maintained that the objectives of the qualitative design are to explore areas where limited or no prior information exists and to describe behaviours, themes, trends, attitudes, needs or relations that are applicable to the units analysed. Due to focusing on the lived experiences in this research design, some participants may have forgotten how the phenomenon under study actually happened and findings may not be exactly how the phenomenon was experienced. The researcher prolonged interviews to 15 minutes in order to allow participants sufficient time to recall exactly what they experienced.

3.4.2 Exploratory research design

Explorative research is defined as an attempt to connect ideas to understand cause and effect. This is where a researcher has an idea or has observed something and seeks to understand more about it (Devin, 2015: On-line). The researcher asked a central question in order to be able to explore in depth the experiences of couples on HIV disclosure of their HIV positive status.

Listening and probing skills were used to gather more information and explore the experiences of couples in order to explain it in details. The researcher paraphrased what participants said to ensure that what the researcher heard was actually correct.

3.4.3 Descriptive Research design

Descriptive research is an attempt to explore and explain while providing additional information about a topic (Devin, 2015: On-line). Descriptive research is the act of exploring something, creating a fuller picture on what you are looking at. The researcher gave participants the chance to describe what they experienced in regard to disclosure of HIV positive status. The detailed description by the participants enabled the researcher to describe the experiences in a fuller picture, in a form of themes and sub-themes.

3.4.4 Contextual Research Design

A contextual research design was used to explore in-depth and in a loose and unstructured way as the purpose of arriving at a description of experiences of participants. During this study, the researcher applied this by developing semi-structured questions, which enabled the researcher to gather information in a way that allowed probing for freely collecting detailed information about the experiences of the study participants. Qualitative studies are always contextual as collected data are only valid in a specific context and not meant for generalisation of findings (Botman, Greef, Mulaudzi & Wright, 2010: 195). The study was contextual as the findings are only focused on Mhinga ART clinic as the area of data collection and cannot be generalised to other ART clinics.

3.5 Pilot Study

A pilot study refers to a procedure for testing and validating an instrument by

administering it to a small group of participants from the intended population (de Vos et al., 2011: 237). Similarly, Stachowiak (2014: On-line) defines a pilot study as a feasibility study to ensure that the ideas or methods behind the research focus are sound, as well as to work out the kinks in a study protocol before launching a larger study. One couple was selected at Mhinga ARV clinic to test the data interview schedule in order to detect any unforeseen and possible flaws of the interview schedule. The researcher allocated identification numbers to participants which were A and B, in order to differentiate them from the numbers which were allocated in the main study which were 1, 2, 3,...The selected couple did not form part of the main study in an attempt to minimize bias in the study. There were no challenges observed with regard to the pilot study results, except that the probing time which was estimated to be 20 minutes had decreased to 15 minutes as participants had no new information to communicate. The researcher did not change anything regarding the developed interview schedule, it was also used in the main study.

3.6 Population and Sampling

3.6.1 Population

A population is the totality of persons events, organisational units case records or other sampling units with which the research problem is concerned (de Vos et al., 2011: 223).

The population in this study was 12 HIV-positive participants (six (6) couples) receiving service at Mhinga ARV Clinic of Thulamela Municipality B in Limpopo Province. The population included 12 heterosexual participants who were sexually related. There were no homosexuals in the clinic. Out of the 12 participants (six (6) couples), 10 participants (five (5) couples) were regular users of the clinic on a monthly basis, regardless of their marital status. The number of couples who were included in the study was four (4) (eight (8) participants), because only regular users were needed. Two participants (one (1) couple) out of the 12 participants were included in the pilot study and the

remaining 8 participants were included on the main study.

3.6.2 Sampling

Sampling is a process of selecting units of analysis from a target or accessible population (du Plooy, 2009: 108). Purposive sampling was used to select eight (8) participants (four (4) couples) who participated in the study until data saturation was reached. According to Polit and Beck (2008: 71), saturation of data occurs when the sample provides no new information. The couples were selected as they could provide the researcher with the relevant information about the experiences that HIV-positive couples encounter when they share their status with one another (Babbie & Mouton, 2009). The researcher went to the clinic prior to sampling and asked the data capturer to check all HIV-positive couples on the register, who were utilising the clinic on a monthly basis and noted them for inclusion in the study if they are willing to participate. Only couples who have disclosed their status were included in the study. Mhinga ART Clinic (Ntshembho) was selected because it was one the first clinics under Mhinga local area to render HIV services and most couples from Vutomi (Malamulele Hospital ART Clinic) residing around Mhinga were down-referred to this clinic. The codes were generated for each couple and the actual list of names was kept safe to prevent the access and link of responses to the couples.

3.7 Data Collection

3.7.1 Preparation of Data Collection

An ethical clearance certificate was obtained from the University of Limpopo's Medunsa Research and Ethics Committee (MREC) prior to data collection. Permission for data collection was obtained from the Limpopo Province Department of Health, the area manager of Mhinga Clinic and the clinic manager. The researcher went to Mhinga ART Clinic and asked the data capturer to check all the files of HIV-positive couples on the register in order to obtain their contact numbers and arrange suitable appointments. Only

couples utilising the clinic on a monthly basis were noted for inclusion in the study if they were willing to participate. A private room which was freely available for support services was used to conduct the interviews at Mhinga ARV Clinic. All equipment, including consent forms, audio recorder and a book with a pen was gathered before the interview started. Data were collected at ARV clinics using a room which was not used for consultation. Participants went into the room individually for face-to-face interviews after being informed about the study and after the researcher had obtained their permission to voluntarily participate and be recorded for proof of their participation. The researcher interviewed participants using developed open-ended questions on the experiences contributing to non-disclosure of HIV-positive status amongst couples. The duration of the interview sessions was 15 to 20 minutes for each couple. The interviews were conducted on eight (8) participants (four (4) couples) until data saturation was reached.

3.7.2 Data Collection Procedure

Data were collected using semi-structured interviews with the selected participants. Semi-structured interviews seldom span a long time period and usually requires the participant to answer a set of predetermined questions and also allows probing and clarification answers (Maree, 2008: 87).

During the interviews, the researcher avoided leading questions, but asked a central question and probing questions. The central question was:

“What were your experiences when you disclosed your HIV-positive status to your partner?”

The researcher then ensured good data by using listening and probing skills after each participant’s response to obtain in-depth information and also by paraphrasing to ensure that what the researcher heard was actually what the participant meant. The researcher kept using words such as “okay” and “ooh” after a participant’s response to demonstrate interest in what was actually said.

A voice recorder was used to record responses where clients gave consent for the interview to be recorded. The researcher also took field notes to document any non-verbal cues from participants which gave an indication of their feelings following certain questions. One-to-one type of interview was conducted to collect data. Probing methods were used to collect detailed information as guided by Maree (2008: 88) and it included detailed questioning to understand words such as who, where and what answers. Elaboration probes were used to get a full picture where a participant talked about a certain example or answer and it was unclear. Clarification probes were asked where the researcher asked follow-up questions to confirm what the participant meant.

3.7.3 Measures to Ensure Trustworthiness

The following were used as ways to ensure trustworthiness:

3.7.3.1 Confirmability

Confirmability refers to objectivity or neutrality of the data in such a way that there would be agreement between two or more independent people about the data's relevance or meaning (Streubert & Carpenter, 2011: 47). During the study, confirmability was ensured by using additional field notes and the voice recorder. These data sources were kept in a safe place where the supervisor could access information. An audit trail was also done by submitting the voice recorder to the supervisor to verify the data.

3.7.3.2 Credibility

Credibility refers to the confidence in the truth of the data and the researcher asks if there is a match between research participant's view and the researcher's reconstruction and representation of those views (de Vos et al., 2011: 419). In this study, credibility was ensured by prolonging the time of the interview to at least 20 minutes, to enable the researcher to collect detailed

information from each participant. The researcher also collected data from different participants on the same questions until data saturation was reached. In addition, the researcher used a voice recorder and took field notes to gather sufficient data. The researcher also provided feedback to study participants regarding data and the researcher's findings and interpretations immediately after data collection to identify if what was interpreted was actually what the participants were saying (member checking). Raw data and transcripts were sent to an independent coder who is a qualitative research specialist.

3.7.3.3 Transferability

Transferability refers essentially to the generalisability of the data, or whether the findings of the research can be transferred from a specific situation to the other (de Vos et al., 2011: 420). In this study, this was ensured by giving a full description of the research design. It was also ensured by describing how data were collected, and using more participants to collect data until saturation. The researcher also ensured that more plausible information could be collected and could be applied to other possible participants as no new or undiscovered information surfaced. The researcher also conducted a literature control where data of similar findings were reported to compare the observed responses.

3.7.3.4 Dependability

Dependability refers to stability of data over time and the researcher asks whether the process is logically well documented and audited (de Vos et al., 2011: 420). In this study, dependability was ensured by conducting a pilot study on couples to identify areas that needed to be edited after analysing the pilot study results. It was further ensured by using a voice recorder and field notes. The researcher took data and the other documents used in the research for scrutinising by the supervisor to confirm that data reported were actually from participants, and the researcher explained the research method and design in detail to enable verification of results.

3.8 Data Analysis

Data analysis is the process of bringing order, structure and meaning to the mass of collected data (de Vos et al., 397). Data were analysed using the following steps as guided by de Vos et al. (2011: 410) and Techs' eight steps open-coding method (Creswell, 2014: 247). The method was used in the following way:

- The researcher transcribed data by copying information from the voice recorder, and linking it to field notes to add information such as non-verbal cues and gave it more meaningful words.
- Then the researcher read the texts over and over and wrote down any impressions identified. The researcher read through all transcripts carefully and wrote down pertinent ideas as they came to mind.
- The researcher coded data using the open-coding method where transcribed data were read line by line, and grouped together concepts with the same meanings, and allocated a unique identifying name or descriptive word for each group.
- When the researcher finished grouping the concepts, the researcher clustered together similar topics and formed columns that were arranged as major topics, unique topics and left-over topics.
- The researcher then kept a master list of all codes that were generated and used in the study, took the master list and went back to the data, and abbreviated the topics
- Related codes were then combined into categories and assigned an identifying name for the new category using the researcher's own descriptive words from recorded text to establish a category.
- The researcher continued categorising until collected data had been

identified and labelled or coded into relevant categories and no new themes or sub-categories were identified.

- The researcher listed the identified themes and sub-themes on paper and spread them across a table.
- Finally the researcher then reported findings in the form of themes and sub-themes.

3.9 Ethical Considerations

Researchers need to protect their research participants, develop a trust with them, promote the integrity of research, and guard against misconduct. (Creswell, 2014: 31). In this study, the researcher adhered to the following ethical considerations:

3.9.1 Ethical Clearance and Permission to Conduct the Study

Before the researcher conducted this study, a clearance certificate was obtained from the University of Limpopo Medunsa Research and Ethics Committee. Permission was then obtained from the Limpopo Department of Health area manager and sub-district manager of Thulamela Municipality B clinics (the researcher attached a proof of registration with the South African Nursing Council (SANC) in order to be allowed to access patients' records). A consent form for participant was written in Xitsonga, requesting them to put in writing that they agreed to participate in the study for investigating experiences of disclosure of HIV-positive status to their partners and that no payment would be received by participants, but the study was for their own interest and relied on their willingness to participate.

3.9.2 Privacy, Confidentiality and Anonymity

In this study, anonymity was ensured through not using names during interviews, or anything that could enable the participants to be linked to the information. Confidentiality was maintained by keeping the voice recorder and

field notes safely in a locked place and no other person could access the data, except the researcher, and the supervisors. Study findings were reported through anonymous quotations.

3.9.3 Right to Self-Determination

Every person has human rights as a human being (Bless, Smith & Kagee, 2007: 142). In this study, the human right to self-determination was protected by making participants to decide for themselves on whether they wanted to participate in the study or not after receiving information about the intention of the study in the language which they understood best to ensure participation with full information about the study. They were informed that if a person was selected for the study and was not willing to be involved, she could withdraw as participation was voluntary. Due to the sensitivity involved in the issues about HIV/AIDS, the researcher included the receipt of registration with the SANC to access the information in the clinic as part of improvement plan by conducting research on the issues pertaining to HIV/AIDS.

3.10 Bias in the Study

Bias in a study occurs when there is an influence and prejudice that improperly affect the study such as information, loss of data due to interview schedule decay or interview schedule which is not well designed (de Vos et al., 2011). This study was protected from bias by testing the instrument to check if it was properly designed to gather needed information through a pilot study, and by the use of more than one form of data collection instrument which was a tape record together with field notes and analysing data immediately after collection to prevent information loss that could lead to information bias. The researchers had also set aside any preconceived ideas about the experiences during the interview session as another means to avoid bias.

3.11 Conclusion

Chapter 3 discussed the study site, research method, study design, pilot study, population and sampling procedure. The chapter also outlined the data collection process, trustworthiness, data analysis and ethical considerations. The next chapter will discuss the results and interpretation of the study.

CHAPTER 4

DISCUSSION OF RESULTS AND STRATEGIES FOR ADDRESSING EXPERIENCES OF HIV-POSITIVE STATUS DISCLOSURE

4.1 Introduction

This chapter discusses the results and the strategies for addressing the identified experiences. Four themes and eleven sub-themes emerged from the interviews.

4.2 Demographic Data

Table 4.1 shows the demographic characteristics of participants.

Table 4.1: Characteristics of participants

Characteristics	Number
GENDER	
Female	4
Male	4
AGE	
18-29	2
30-49	6
MARITAL STATUS	
Married	4
Cohabiting	4
OCCUPATION	
Employed	5
Unemployed	3
HIGHEST EDUCATIONAL QUALIFICATION	
Primary only	2
High school	1

Matriculated	4
Tertiary	1

4.2.1 Gender

Gender was represented equally by both males and females, 4 females and 4 males, because only HIV-positive couples were selected and consented to participate in the study and there were no participants from homosexual relationships.

4.2.2 Age

Participants of age 18 years and older were considered for participation in the study. The main reason was because of the need to give consent to participate in the study, as any client under 18yrs needs parent/ guardian signature. Any client above 18yrs old can sign in respect of the issue of informed consent which is one of the ethical considerations of research.

4.2.3 Marital Status

Marital status was important in the study to identify what type of couples the researcher was dealing with. Participants who were found to be married were 4; other 4 participants were in cohabitating relationships.

4.2.4 Occupation

The occupational status was included in the demographic data in order to identify the occupational and socio-economic status of the participants. In this study, there were 5 participants who were employed and 3 who were unemployed.

4.2.5 Educational Qualification

The study revealed that 2 participants attended school until primary level only, 4 participants achieved matric certificates, 1 participant dropped out of grade 10, and 1 obtained tertiary qualification. These characteristics assisted

the researcher to identify the participants' level of understanding as some people who never attended school, have difficulty in understanding the interview questions.

4.3 Discussion of Themes and Sub-Themes

The themes and sub-themes on the experiences of couples on disclosure of HIV-positive status are summarized in Table 4.2.

Table 4.2: Themes and sub-themes on the experiences of couples on disclosure of HIV-positive status

Themes	Sub-Themes
1. Fear of being HIV-positive	1.1 Denial of being HIV-positive
	1.2 Accusing each other
	1.3 Self-blame by guilty partner
	1.4 Decreased trust experienced
2. Disclosure of HIV-positive status is a difficult process	2.1 Not easy to disclose
3. Acceptance of HIV-positive status	3.1 Acceptance of HIV-positive test results
	3.2 Acceptance of the condition
	3.3 Acceptance of ARV treatment
4. Relations between partners post knowledge of HIV-positive results	4.1 Experienced support from the other partner
	4.2 Experienced negative couple relationship
5. Encouragement pertaining to disclosure of HIV-positive status	5.1 Sharing information about HIV/AIDS
	5.2 Support for partners living with HIV/AIDS

4.3.1 Theme 1: Fear of Being HIV-Positive

Participants expressed fear of being HIV-positive, one common, but obviously risky response to receiving a diagnosis of HIV is persistent denial of one's results. Four sub-themes emerged from this theme, namely: denial of being HIV-positive, accusing each other, self-blame by guilty partner and decreased trust experienced.

4.3.1.1 Sub-Theme 1.1: Denial of Being HIV-Positive

Denial is one of the challenges that make partners not to disclose their status easily. Some participants were in denial of their HIV-positive status at first, which made them not to disclose immediately to their partners. Worth, Patton and Goldstein (2008: On-line) indicated that for some people non-disclosure is a result of denial of HIV status. The implication of denial and lack of disclosure might mean the individual is not practicing safe sex. The study findings revealed denial of HIV infection from the other partner.

This was evident from what the following participants said:

“I was surprised and didn't want to believe the results were actually correct at first, but after two days I changed my mind and believed them.”

“After I went home and shared the results with my husband, things were not easy as he denied the results saying that you know where you got the infection it's not from me, but as time went on he went to test and found that he is positive and started to use ARVs just like me.”

Denial of HIV-positive status is a protective mechanism against shock that is valuable in the short-term. However, people need to move on and face it, into action which is usually accomplished by getting more information from support groups or counselling (Latino Commission on AIDS, 2014: On-line).

4.3.1.2 Sub-Theme 1.2: Accusing Each Other

One of the experiences with regard to HIV status disclosure by couples included accusations where participants are accused of being unfaithful. Experiences of this kind need to be addressed because people may conceal their status due to fear of being accused. The study findings revealed that participants experienced a challenge of accusation during disclosure of HIV status and this was evident from the following participant responses:

“When I disclosed my status he accused me that you know where this infection is from and as I knew myself that I was not cheating, I didn’t mind.”

“At first I was the one who had a problem. I was always pulling aside as I knew how I lived my life I was faithful so I blamed him, and at the end I realised that I cannot change the situation, because as you know when the water has spilled you can’t collect back, except to live well together as we move forward.”

Anglewicz and Chintsanya (2011: 914) asserted that since the future course of the HIV epidemic will be partly determined by the extent to which HIV-positive individuals infect others, efforts should be made to create an environment that encourages HIV status disclosure without negative consequences such as accusations. On the other hand, Okoboi, Igulot, Tayebwakushaba and van der Kwaak (2010: 8) indicated that reasons for non-disclosure included being accused of infidelity.

4.3.1.3 Sub-Theme 1.3: Self-Blame by Guilty Partner

Some participants experienced self-blame after being told of their partner’s HIV status because they knew that they might be the ones responsible for the infection. The study revealed that participants experienced self-blame, this is evident from the following response by one participant:

“After my wife told me of her results I didn’t want to believe at first, but after two days I realised it might have happened that we are infected because where I am working at mines I was cheating and that made me to accept the situation.”

Individuals who have extra marital affairs are more likely to inflict blame on themselves when the other partner becomes infected with HIV (Thupayagole-Tshweneagae, 2010: 12).

4.3.1.4 Sub-Theme 1.4: Decreased Trust Experienced

HIV-positive status always suggests that the other partner is not trustworthy and is cheating. The study revealed that the participants had decreased trust in their partners after finding out about their status. This was evident from the following participant responses:

“When she disclosed the status to me she indicated that she will no longer trust me.”

“After discovering the results I started to behave differently and was always pulling aside as my trust for him had decreased.”

Norval (2012: On-line) reported that disclosure of HIV-positive status may lead to decreased trust.

4.3.2 Theme 2: Disclosure of HIV-Positive Status is a Difficult Process

Non-disclosure of HIV status to partners has implications not only for sexual transmissions, but also for the individual’s ability to attend clinic regularly for care, treatment initiation and the use of HIV-related services (Gari et al., 2010: 87). One sub-theme emerged from this theme.

4.3.2.1 Sub-Theme 2.1: Not Easy to Disclose

Disclosure of HIV-positive status was reported as a difficult obligation as participants were unable to disclose at some stage even though they ended up disclosing. The study findings revealed that it was not easy to disclose after being diagnosed as HIV-positive and this is evident from what the following participants said:

“Hey, there! It was tough, I did not know where to start.”

“I did not tell her on my own she found out while she was pregnant and had to be tested.”

Mamogobo et al. (2013: 36) reported that it is difficult for some people to disclose their HIV-positive status to their partners. In support of this statement, Remien and Bradley (2007:1) indicated that disclosure of HIV-positive status entails communicating about a life-threatening, stigmatised and transmissible illness—hence it is not an easy task. Couple HIV testing has been recognised as a critical course of action to increase uptake of HIV testing and to facilitate disclosure of HIV status to a marital partner (Musheke, Bond & Merten, 2013: 97).

4.3.3 Theme 3: Acceptance of HIV-Positive Status

Three sub-themes emerged from this theme as discussed below.

4.3.3.1 Sub-Theme 3.1: Acceptance of HIV-Positive Test Results

Acceptance of HIV status after diagnosis is vital for the person to be able to share the condition with his/her sexual partner (Hatcher, Kwena & Turan, 2013: 1128). The study revealed that partners assisted each other to accept the results and this was evident from the following responses:

“My husband used to have a tendency of having fear to go to the clinic to get tested.”

“I did not want to accept it; well I felt like I could change myself and found that I am not myself again.”

“I was not accepting the situation well until my husband talked to me and counselled me to accept.”

Genet, Sebsibie and Gultie (2015: 112) indicated that discussion of HIV test results with friends and relatives also facilitated disclosure of HIV-positive status to sexual partners, as the individual is motivated to accept the results.

4.3.3.2 Sub-Theme 3.2: Acceptance of the Condition

For couples to effectively utilise HIV services, it is important to accept the condition which will in turn facilitate disclosure. Nam, Fielding, Avalos, Dickinson, Gaolathe, and Geissler (2008: 301) asserted that acceptance of one's HIV status leads to a possibility of self-disclosure and, in turn, adherence to treatment. The study findings revealed that even though participants had difficulty, they assisted each other to accept the condition. This was evident from the following responses:

“I experienced a problem in accepting the condition.”

“At first I was the one who was always pulling aside until my partner counselled me and assisted me to accept and now I am doing well.”

Ncama (2007: 391) agreed with the findings that acceptance of an HIV-positive condition is more likely to yield disclosure of HIV-positive status to family and sexual partners. On the other hand, Baratedi, Thupayagole-Tshweneagae and Ganga-Limando (2014: 961) indicated that there are some people who seem to have an opposition to HIV infection even though exposed to it.

4.3.3.3 Sub-Theme 3.3: Acceptance of ARV Treatment

Acceptance and utilisation of treatment is the most crucial thing in the control

of HIV disease progression. The study findings revealed that participants assisted each other with regard to the use of ARV treatment as is evident from the following responses:

“You know how it happened was on my first disclosure he refused to go for the test and said ‘you are the one who has it I am fine,’ yaaahhhh! ... after a little while when I was taking my treatment he started to ask for my treatment and say ‘can you share your treatment with me Haaaa?’ I told him that the treatment can never be shared, each one of us must have their own treatment. I told him to go where I got the treatment in order to get treatment. I didn’t give him, iyoh how can he not go there, he went there to get his own treatment now we are using treatment both of us.”

“My wife comes here at Mhinga Clinic now she is able to collect treatment on my behalf as it is packed so that when I come back month end I find it ready and take it for me to use when I am at work.”

Genet, Sebsibie and Gultie (2015: 114) indicated that individuals find it easy to start ART when they disclosed their status to their sexual partners. Alemayehu, Aregay, Kalayu and Yebyo (2014: 747) also reported that early disclosure of an HIV-positive status and treatment acceptance are crucial and helpful for treatment adherence.

4.3.4 Theme 4: Relations Between Partners Post Knowledge of HIV-Positive Results

Two sub-themes emerged from this theme namely: Experienced support from the other partner, and experienced negative couple relationship. Masupe, Van Rensburg and Human (2012: 18) reported that disclosure is a multistage process. People infected with HIV experienced mainly positive reaction, but also experienced some negative consequences following disclosure of HIV

positive status. Such experiences were associated with the individual's ability to disclose in the current relationship.

4.3.4.1 Sub-Theme 4.1: Experienced Support from the Other Partner

People living with an HIV-positive status are more likely to disclose where the outcome of disclosure is positive and they feel happy about having their status disclosed. Expectations of women post-disclosure of their HIV-positive status, include acceptance without complaints, emotional support or strengthened relationship (Malaju & Alene, 2013: 113).

The study findings revealed that disclosure of HIV-positive status yielded a positive outcome. There was a generally good atmosphere between the couples. They were happy most of the time and were doing most of their activities together. They planned their future families well in terms of having children whilst they are HIV-positive and decided to be faithful to the partner as evidenced from the following participant responses:

“Our relationship is good because we now live as twins and it also increased trust as we are always together and I told myself not to repeat the same mistake of cheating anymore.”

“Our relationship is very good now as we are all taking treatment well.”

“We live well when we are at home, we are happy.”

Genet, Sebsibie and Gultie (2015: 112) and Kelley, Karita, Sullivan et al. (2011: On-line) reported that disclosure may motivate partners for voluntary counselling and testing (VCT), reduce risk behaviours and increase acquisition of support.

4.3.4.2 Sub-Theme 4.2: Experienced Negative Couple Relationship

Although disclosure of HIV-positive status is associated with certain benefits, it may also yield some negative reactions from the partners. A study by Gari

et al. (2010: 88) on HIV-positive status disclosure indicated that even though the magnitude of HIV-positive status disclosure to sexual partners in the study conducted on women attending ART clinic at Hawasa was encouraging, risk behaviour and negative partner reactions following disclosure were alarmingly high.

The study findings revealed that participants experienced some negative couple relationship following HIV-positive status disclosure to their partners, which included: divorce, accusation of bringing infection to the house, feeling that the other partner was cheating and decreased trust—this was evident from the following responses:

“When I disclosed how the results were, he started by being quiet and did not answer me. I don’t know if he knew how this happened, but he then accused me of knowing where I got this whereas he brought this thing to me. Do you understand? He was angry.”

“I had a partner and lived with her and one day I disclosed to her about my HIV status, after sharing my status with her she did not want to understand she packed her bags and left.”

Bott and Obbermeyer (2013: 6) demonstrated that level of disclosure among studies ranges from about 46% to 94% in HIV-positive cases and disclosure could result in negative outcomes, including anger, yelling, and rejection.

4.3.5 Theme 5: Encouragement Pertaining to Disclosure of HIV-Positive Status

Two sub-themes emerged from this theme, namely: sharing information about HIV/AIDS and support for partners living with HIV. Olagbuji et al. (2011: 486) reported that disclosure of HIV is associated with appropriate management of the information following disclosure of sero-positive status by HIV-infected persons, and it is necessary for encouraging disclosure to

sexual partners for prevention of new infections.

4.3.5.1 Sub-Theme 5.1: Sharing Information About HIV/AIDS

For possible control of HIV spread, it is important for PLWH to talk to others about how to overcome the stigma that is attached to HIV, which is making it difficult for sexual partners to share their HIV status. Education and Training Unit (ETU), by Olof Palme International Center , Sida and the JS mott foundation (2015: On-line) indicated that for PLWH to live longer and comply well with HIV programmes, it is important to organise meetings where they come together and discuss their feelings, common problems and ways of coping. The study findings revealed that participants deemed it beneficial to share ideas about HIV status disclosure, as supported by the following statements:

“One thing that is bothering us people is that we are afraid to disclose because we feel our status will be known and people will laugh at us, so people must learn not to be afraid of others because you will die and those people that you are afraid of will be left alive.”

“It is very much important, because when we are alive we are not living for ourselves only. There are people whom we are living for and not only relatives or our kids there can be people in the community who come and learn good behaviour from you, so it is most important that when you are with others you talk about it and teach each other in order for us to be fair to our partners.”

Hardon, Gomez, Vernooij, Desclaux and Wanyenze (2013: 563) indicated that support groups can provide HIV-positive individuals with information about HIV, including disclosure of status. Maman, van Rooyen and Grooves

(2014: 227) supported this notion by signifying that information sharing on the importance of HIV disclosure and support system for people living with HIV/AIDS, is vital.

4.3.5.2 Sub-Theme 5.2: Support for Partners Living with HIV/AIDS

Support for PLWH is of great importance because individuals feel a sense of belonging to others and they can freely disclose their status. Crankshaw et al. (2014: 2) indicated that providers require support in dealing with HIV disclosure issues and in becoming more confident in dealing with couples and sero-discordance concerning information giving.

The study findings revealed that participants support each other as borne out by the following responses:

“Even when I want to go somewhere and forget to take my treatment along, she reminds me that you have forgotten your treatment, and we help each other to take treatment when it’s time.”

“She is able to collect treatment on my behalf as it is packed so that when I come back month end I find it ready and take it for me to use when I am at work.”

Mabuza (2010: 25) also revealed that reasons for disclosure of HIV-positive status in couples include a desire for emotional closeness with support from the other partner. On the other hand, Meyer (2011: On-line) reported that potential benefits or advantages of disclosing HIV status include stress reduction, because keeping secrets may be psychologically and physically burdensome.

4.4 Strategies for Addressing Experiences of Couples on Disclosure of HIV-Positive Status

HIV-positive couples face negative experiences while disclosing their status to the other partner which may have an impact on others' decision to disclose their status. Non-disclosure is, in turn, associated with increased rates of HIV infection amongst couples. Figure 4.1 shows the strategies to address the experiences of HIV-positive disclosure on couples.

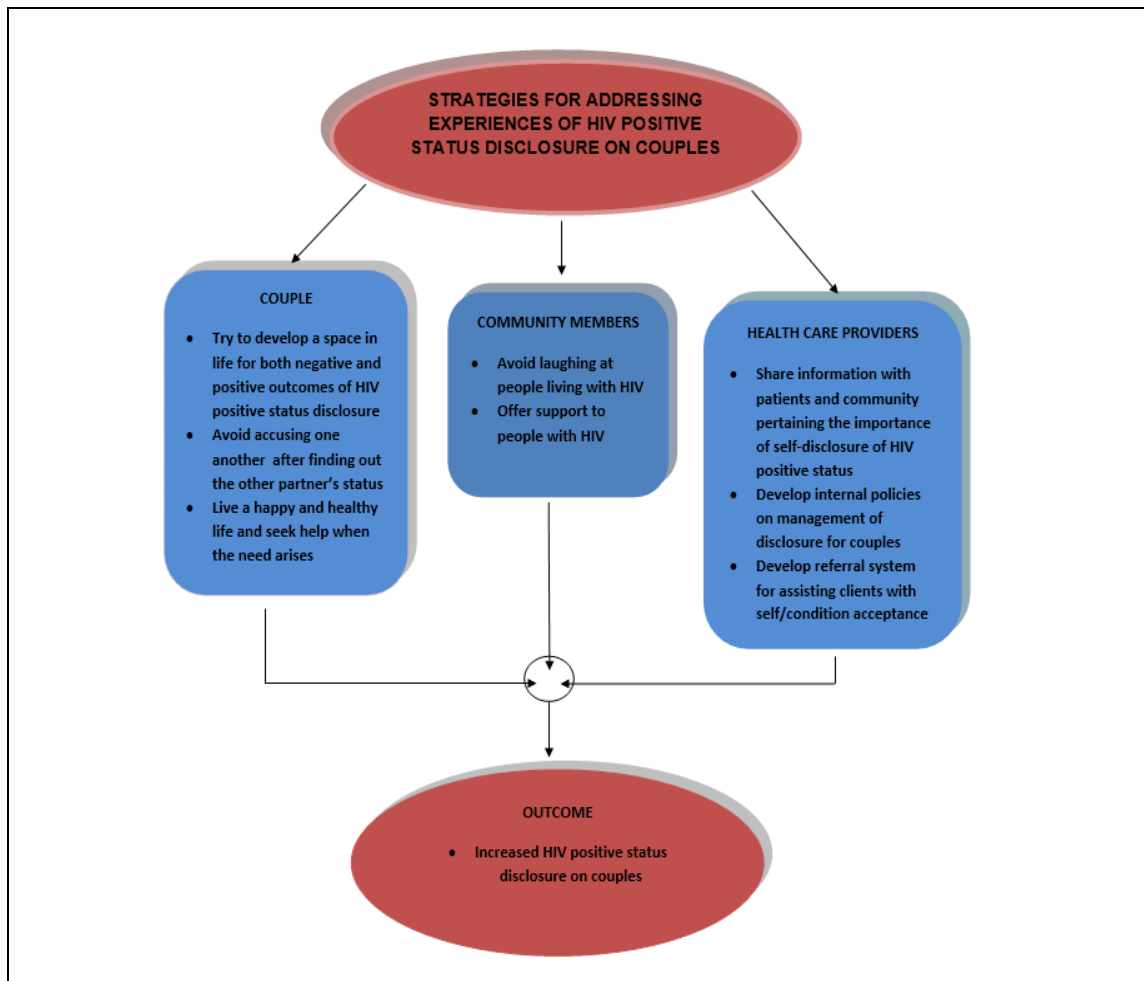


Figure 4.1: Strategies for addressing experiences of HIV-positive status disclosure

4.5 Discussion of Strategies to Address Couples' Experiences of HIV-Positive Status Disclosure

Figure 4.1 shows that the strategies for addressing experiences of couples on disclosure of HIV-positive status can be possibly dealt with by the patient, healthcare provider and community to facilitate disclosure of HIV-positive status in couples. The arrows indicate that the strategies are dependent on couple, health care provider and community members' efforts. Finally, the arrows also indicate that joined efforts from couple, health care provider and community members lead to an outcome which is increased HIV-positive status disclosure on couples.

4.5.1 Couples

- All couples must minimize fear of HIV-positive test results in order to gain acceptance of their results or partners results, they have to create a room to deal with either both negative and positive reactions from the other partner
- Avoid accusing the partner of cheating if the person receives HIV-positive test results
- Partners who test positive for HIV must avoid blaming themselves for the results because it will result in stress which, in turn, will weaken their immune system
- Find a way to build back the trust they had for each other after finding out about their positive test results, because decreased trust will impose strain on the relationship
- Avoid divorcing each other after knowing that the other partner is HIV-positive because it will affect the tendency of disclosure in future from those couples whenever they find new partners; and
- Live a happy and healthy life and always seek advice when the need

arises.

4.5.2 Health Care Providers

- Health care providers must share information with clients who test positive for HIV concerning the importance of self-disclosure of status to their partners and also teach coping mechanisms for experiences that might be encountered during disclosure
- The DoH must provide funds and other resources for conducting campaigns, such as transport, and offering meals for people who attend campaigns
- Emphasise on utilising internal policies on management of disclosure systems for couples, e.g., offer follow-up counselling about disclosure of HIV-positive status to sexual partners for those who find it not easy to disclose, accept the results, accept the condition, and be prepared on how to deal with negative or positive reactions from the partner after disclosure; and
- Develop a referral strategy for couples who fail to cope with experiences encountered after disclosure—for example, refer them to a social worker or clinical psychologist or family counsellor.

4.5.3 Community Members

- Community members must avoid making a laughing stock of HIV-infected couples and must avoid creating conditions which will not encourage disclosure by couples
- There should be a support system in terms of caring for couples who are positive; and
- Community members must be educated through a form of health

education or campaigns for them to know that we are all at risk of contracting HIV because no one is immunised against the virus and it can affect anyone, so community members must treat HIV-positive couples like any other person and stop discrimination.

An outcome after combined efforts from couples, community members and health care providers will be an increase in HIV-positive status disclosure which may reduce new HIV infections.

4.6 Conclusion

Chapter 4 discussed the results and literature control. Strategies for addressing couples' experiences on disclosure of HIV-positive status were discussed. The next chapter will outline the summary of research findings, limitations and recommendations of the study.

CHAPTER 5

SUMMARY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION OF THE STUDY

5.1 Introduction

This chapter provides a summary of the research report. It also includes recommendations based on identified themes, limitations and conclusion about the study.

5.2 Summary of the Findings of the Study

5.2.1 Aim of the Study

The study aimed at investigating the experiences of couples on disclosure of HIV-positive status to one another.

5.2.2 Research Question

The research question generated for the study was:

What are the experiences of HIV-positive couples on disclosure of HIV-positive status at Thulamela Municipality B in Limpopo Province?

5.2.3 Objectives of the Study

The objectives of the study were to:

5.2.3.1 Objective 1

Explore experiences of HIV-positive status disclosure on couples at Thulamela Municipality B of Limpopo Province.

The objective was achieved through conducting interviews after selecting participants using purposive sampling with a view that they would provide the researcher with relevant answers to the research problem. The findings of the study revealed the following 5 themes as outlined and discussed in Chapter 4:

Theme 1: Fear of Being HIV-Positive

Couples' experiences revealed that during disclosure they were in denial of being HIV-positive, accused each other, experienced self-blame by the guilty partner and decreased trust experienced.

Theme 2: Disclosure of HIV-Positive Status is a Difficult Process

Experiences on this theme revealed that couples did not find it easy to disclose their status to their partners.

Theme 3: Acceptance of HIV-Positive Status

Couples' experiences on this theme revealed that couples assisted each other on acceptance of HIV-positive test results, recognition of the condition and also on acceptance of treatment.

Theme 4: Relationship Between Partners Post-Knowledge of HIV-Positive Results

The study revealed that some couples experienced support from the other partners while others experienced negative couple relationships.

Theme 5: Encouragement Pertaining to Disclosure of HIV-Positive Status

The study revealed that participants experienced sharing of information about HIV/AIDS and support for partners living with HIV/AIDS.

5.2.3.2 Objective 2

Determine strategies for addressing the experiences identified, for possible control of non-disclosure of HIV-positive status amongst couples at Thulamela Municipality B of Limpopo Province.

This objective was achieved through development of strategies based on the research findings. The strategies which were developed were based on couples' data obtained during interview sessions. These strategies included accepting the condition, avoiding accusations of one another, avoiding self-blame, and finding a way to build trust for the partner after finding out about his/her HIV status, and finally for the couples to avoid divorcing those partners who tested positive for HIV.

For the health care provider the strategies included sharing of information with the community and patients pertaining the importance of self-disclosure of HIV-positive status, developing internal policies on management of disclosure of status for couples and developing referral system for assisting clients with self/condition acceptance.

The final strategy was based on the community and it included that the community must avoid mocking couples who are HIV-positive and they must offer support to couples who tested positive for HIV.

The developed strategies provided further suggestions regarding the research problem for the Department of Health, patients, nursing staff, future researchers and community at large based on the findings of the study.

Strategies for Couples' Experiences to Increase Disclosure

The study revealed that couples feel that accepting the condition can increase disclosure in couples. If couples support each other after finding out one partner HIV positive status, it can also increase disclosure. It can also

increase peoples' choices to utilise health services on HIV care without fear of their partner. Finally, the study revealed that when people get sick, it can also give them an idea of the type of treatment to take and minimize deaths related to HIV.

5.3 Limitations of the Study

The study was conducted only at Mhinga Clinic in Vhembe District of Limpopo Province, therefore, the results cannot be generalised to other clinics from other districts and provinces.

5.4 Recommendations

The recommendations are based on themes to help other patients, the DoH and future researchers. These are considered in turn in the sub-sections.

5.4.1 Challenges Regarding HIV-Positive Status and Disclosure

Disclosure of HIV status turns out to be a difficult process due to challenges such as denial of HIV-positive status, accusing each other, self-blame and decreased trust in a relationship. Patients must learn to increase acceptance of their condition and support each other throughout all stages of dealing with exposure of the virus in order to increase disclosure in couples. HIV disclosure is a form of personal disclosure, as it involves revealing personal information about oneself. Individuals may disclose their status as a way of expressing trust and seeking a way forward in their personal relationship. However, it can also be a source of interpersonal stress and individuals weigh the cost/consequences prior to disclosing.

5.4.2 Current laws with regard to HIV status disclosure

Laws need to be reviewed on disclosure in couples, to control HIV and

promote disclosure in couples. Based on the fact that most women are the ones who take HIV tests and disclose to their male partners, partner notification policies and support programmes must be responsive to the potential negative consequences associated with others learning that a woman is HIV-positive. The high rates of historical violence in the lives of women living with HIV underscore the need for routine screening and intervention of domestic violence in all settings that provide health care to HIV-positive women.

5.4.3 The Department of Health

The government must emphasise the use of the developed policies on HIV disclosure. They need to further develop policies which bind people to disclose their status to their partners immediately after diagnosis in order to increase disclosure amongst couples and avoid delaying disclosure till they get very sick. Various states for example: United state and India, have passed laws to treat willful exposure as a criminal offense. Willful exposure happens when someone knows she/he is infected with HIV, but decides not to disclose to his/her sexual partners and is not mindful of the possible transmission and continue to expose the partner to infection. The National government must copy from the other states eg, the United state and India, and develop its own policy on handling the disclosure of the HIV status. It should not only rely on the current policy which allows disclosure only as requested by a court of law during certain criminal trials or after repeated follow-up counselling of infected persons. It has to be made compulsory to disclose within hours of knowing about ones status to prevent deliberate transmission whilst the person is still deciding on how to disclose.

5.4.4 Patients

Patients must always make it a routine to be tested for HIV on a quarterly basis and not to wait until getting they get sick. They must continuously apply preventative strategies to keep themselves free from HIV. Whenever a

patient tests positive for HIV, she/he must accept and disclose to their partners early and at least on the same day or a day after the results, to share with their partners about what is happening in their lives regarding this infection and in order to utilise HIV services freely without fear.

5.4.5 Clinic Staff

The clinic staff must develop internal policies on how to handle HIV-positive individuals to assist in their disclosure to their partners at least within hours of finding out about their status. The staff must also include a timeframe of not more than seven days to confirm that the patient has really disclosed to the partner. This should ensure minimising relying only on follow-up counselling on disclosure as it may pose a risk of transmission, if disclosure is delayed, further sexual contacts are being made. Staff members must also develop a policy which indicates that if the patient has not disclosed after seven days, they request a mandate to do so on behalf of the client in order to reduce new HIV infections.

5.4.6 Future Researchers

Disclosure of HIV status is not easy because of the experiences of couples. Therefore, it is recommended that future researchers must find out about how long it takes partners to share information about their infection after diagnosis. Prolonging disclosure also places other patients at risk of contracting infection. The researchers must also investigate ways that can make it easy for partners to share status, without experiencing negative couple relationship.

5.5 Conclusion

Chapter 5 presented a summary of the study wherein the aim of the study was indicated. It also outlined the two objectives of the study and how these objectives were met. This chapter also detailed and discussed the study findings that were revealed during the interviews with participants in the

study. Lastly, Chapter 5 discussed the recommendations based on identified themes to help other patients, current laws on HIV disclosure, the Department of Health, clinic staff and future researchers.

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APPENDIX 1

MEDUNSA RESEARCH AND ETHICS COMMITTEE CLEARANCE CERTIFICATE

UNIVERSITY OF LIMPOPO
Medunsa Campus



MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 09/2014
PROJECT NUMBER: MREC/HS/354/2014: PG

PROJECT:

Title: Couples' experiences on disclosure of HIV positive status at Thulamela B Clinics, Vhembe District, Limpopo Province

Researcher: Miss TM Maluleke
Supervisor: Prof ME Lekhuleni
Co-supervisor: Mrs. MK Thopola
Department: Nursing & Human Nutrition
School: Health Sciences
Degree: MCur

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: 06 November 2014




PROF GA OGUNBANJO
CHAIRPERSON MREC

The Medunsa Research Ethics Committee (MREC) for Health Research is registered with the US Department of Health and Human Services as an International Organisation (IORG0004319), as an Institutional Review Board (IRB00005122), and functions under a Federal Wide Assurance (FWA00009419)
Expiry date: 11 October 2016

Note:


- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

Finding Solutions for Africa



APPENDIX 2

PERMISSION BY LIMPOPO PROVINCE DEPARTMENT OF HEALTH TO CONDUCT THE STUDY



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila Ref:4/2/2

Maluleke TM
University of Limpopo
Turloop Campus

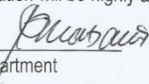
Greetings,

RE: Couples experiences on disclosure of HIV positive status at Thulamela B Clinics, Vhembe District, Limpopo Province

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
 - Research must be loaded on the NHRD site (<http://nhrd.hst.org.za>) by the researcher.
 - Further arrangement should be made with the targeted institutions.
 - In the course of your study there should be no action that disrupts the services.
 - After completion of the study, a copy should be submitted to the Department to serve as a resource.
 - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
 - The above approval is valid for a 3 year period.
 - If the proposal has been amended, a new approval should be sought from the Department of Health.

Your cooperation will be highly appreciated.


Head of Department 25/02/2015
Date

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: <http://www.limpopo.gov.za>

The heartland of Southern Africa – development is about people

APPENDIX 3

APPROVAL LETTER FROM THULAMELA SUB-DISTRICT



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Enq: Hlungwani SR

Tel: 015 851 4790

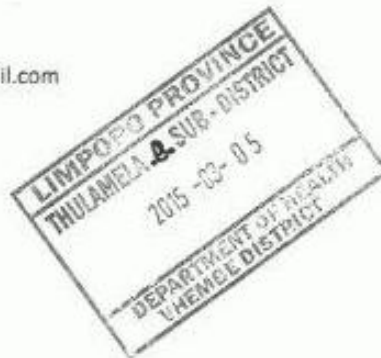
Cell: 084 9520686

Email: sikhetoHLungwani@gmail.com

To: Maluleke TM

Shikundu Village

SASELAMANI



Subject: APPROVAL LETTER TO CONDUCT A STUDY ON "COUPLES' EXPERIENCES ON DISCLOSURE OF HIV STATUS" BY MALULEKE TM, PERSAL NO: 82311501

1. The above matter bears reference.
2. Following your request to conduct a study on couples' experiences on disclosure of HIV status, on behalf of the management of Thulamela 'A' sub-district, permission is hereby granted that you conduct such study in Mhinga clinic from the date you receive this letter as requested.
3. The purpose of the study should be to improve quality of care to HIV clients and for your personal professional development. You are therefore expected to follow all the ethical considerations throughout your research study such as obtaining informed consent from participants, maintain privacy, confidentiality and anonymity as well as protection of harm.
4. We therefore wish you all the success.

Yours in the spirit of "Batho pele"

Hlungwani SR (AAMN MHINGA L/A)

Signed: 

Date: 05/03/2015

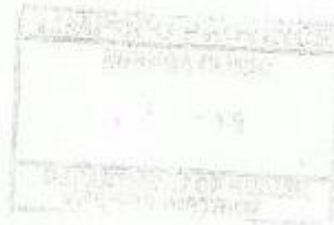
APPENDIX 4

APPROVAL LETTER FROM MHINGA CLINIC



LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

Enq: Hlungwani SR
Tel: 015 851 4790
Cell: 084 9520686
Email: sikhetoHLungwani@gmail.com



To: Maluleke TM
Shikundu Village
SASELAMANI

Subject: APPROVAL LETTER TO CONDUCT A STUDY ON "COUPLES' EXPERIENCES ON DISCLOSURE OF HIV STATUS" BY MALULEKE TM, PERSAL NO: 82311501

1. The above matter bears reference.
2. Following your request to conduct a study on couples' experiences on disclosure of HIV status, on behalf of the management of Thulamela 'B' sub-district, permission is hereby granted that you conduct such study in Mhinga clinic from the date you receive this letter as requested.
3. The purpose of the study should be to improve quality of care to HIV clients and for your personal professional development. You are therefore expected to follow all the ethical considerations throughout your research study such as obtaining informed consent from participants, maintain privacy, confidentiality and anonymity as well as protection of harm.
4. We therefore wish you all the success.

Yours in the spirit of "Batho pele"

Hlungwani SR (AAMN MHINGA L/A)

Signed: 

Date: 05/03/2015

APPENDIX 5

CODING CERTIFICATE

Qualitative Data analysis

Masters of Curationis degree (Nursing Science)

Maluleke Tsakani Millicent

THIS IS TO CERTIFY THAT:

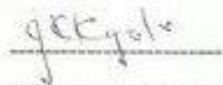
Prof. Jermina Chuene Kgole has co-coded the following qualitative data:

8 Individual interviews and field notes

For the study:

**COUPLES' EXPERIENCES ON DISCLOSURE OF HIV POSITIVE STATUS AT
THULAMELA B CLINICS, VHEMBE DISTRICT, LIMPOPO PROVINCE.**

I declare that the candidate and I have reached consensus on the major themes reflected by the data during a consensus discussion. I further declare that adequate data saturation was achieved as evidenced by repeating themes.



PROF JC KGOLE (DLitt et Phil)

APPENDIX 6

INTERVIEW SCHEDULE

SECTION 1: BIOGRAPHICAL INFORMATION

1. Age (Years)

18-29	1
30-40	2
50-60	3
60-70	4

2. Marital Status

Staying with parents but in aRelationship	1
Married	2
Cohabiting	3

3. Occupation

Employed	1
Unemployed	2

4. Highest Educational Qualification

Never attended school	1
Primary only	2
Secondary education	3
Matriculated	4
Tertiary	5

SECTION 2: INTERVIEW SCHEDULE:

Please share with me your experiences when you disclosed your HIV-positive status to your partner.

Probes (examples depending on the couple's response):

1. Please share with me why you recommend that people should disclose their status to their partners.
2. How would you describe the response you got from your partner after disclosing your status?
3. How can you explain or describe your relationship with your partner after disclosure of your status?

IN XITSONGA

SWILETELO SWA KU VUTISA VAHLAMUSERI

XIYENGE XO SUNGULA: MAHUNGU YA VUMUNHU

1. MALEMBE

Khume nhungu- makume mbirhi nkaye	1
Makumenharhu-makumemune	2
Makume ntlhanu-makume ntsevu	3
Makume ntsevu- makume nkombo	4

2. XIYIMO XA VUKATI

Ndzi tshama na vatswari kambe ndzi na mutshiveri	1
Ndzi tekiwile, ndzi tshama evukatini	2
Ndzi tshama na mutshiveri kambe a hi tekananga	3

3. XIYIMO XA NTIRHOB

A ndzi tirhi	1
Ndza tirha	2

4. TIDYONDZO TA LE HENHLA LETI NDZI TI FIKELELEKE

Andzi nghananga xikolo	1
Dyondzo ya le masungulweni	2
Ndzi hetile ntangha khume	3
Ndzi hetile tidyondyo ta kholichi kumbe yunivhesiti	4

Xiyenge xa vumbirhi

Xivutiso-nkulu:

Ndzi kombela u ndzi hlamusela leswi swi ku humeleleke loko u hlamusela xiyimo xa wena xa xitsongwa-tsongwana xa HIV ka mutshiveri wa wena.

Swivutiso swa ndzavisiso (swikombiso ku ya hi tinhlamulo ta vatekani lava vutiseriwaka):

1. Ndzi kombela u ndzi hlamusela leswaku hikwalaho ka yini u nga hlohlotelaka leswaku vanhu xa hlamusela xiyimo xa vona xa HIV eka vatshiveri vavona?
2. U nga ndzi hlamusela njhani hi ma amukelelo ya mutshiveri wa wena endzhaku ka xiyimo xa wena xa xitsongwa-tsongwana lexi xa HIV?
3. U nga byi hlamusela njhani vuxaka bya wena na mutshiveri wa wena endzhaku ka loko u nw'i hlamuserile hi xiyimo xa wena xa ku va na HIV?

APPENDIX 7

INFORMATION LETTER FOR PATIENTS

Dear participant

I am Tsakani Millicent Maluleke, a student at the University of Limpopo, Turf loop Campus. I am conducting research on the experiences of couples on disclosure of HIV-positive status at Thulamela municipality B clinics, Vhembe District, Limpopo Province.

I request you to participate in this study by sharing your HIV-positive disclosure information with me during interview session. The information that you will share with me will benefit other patients and the clinic health care providers regarding the handling of disclosure of HIV-positive status. Your participation in the study is important as it will also contribute to my completion of the degree that I have registered for at the University of Limpopo.

Your participation is voluntary and you are free to withdraw from the study at any time. Your withdrawal from the study will not disadvantage you in any form at this clinic. The information that you will share with me will be treated confidentially and anonymously. Your name will not be used during the interview session. A voice recorder will be used to capture the information and field notes will also be written, to enable me to report correctly on the interview. The voice recorder will be kept safe and only accessible to me and the supervisor of my study. If it happens that during the interview session, you experience emotional disturbances, counselling services will be provided to you at this clinic. You will not receive remuneration for participating in this study. On completion of my study I will share the information with the health care providers at seminars and conferences and as publication in journals.

Your participation in this study is highly appreciated.

IN XITSONGA: PAPILA RA MUVABYI

Mina ndzi Tsakani Millicent Maluleke, muchudeni e yunivhesiti ya n'walungu emiakweni ya Turfloop. Ndzi endla vulavisisi hi leswi humelelaka vatekani eka kuhlamuselana ka vona hi ta xiyimo xa ku va ni xitsongwatsongwana xa HIV eka tinw'wana ta swilamulela-mhango swa muganga wa Thulamela B, exifundzheni ntsongo xa Vhembe ehansi ka xifundzhankulu xa Limpopo.

Ndzi kombela leswaku mi nghenelela eka vulavisisi lebyi hi ku avelana na mina mahungu ya ku humesela ehandle ka nwina hi ta xiyimo xa nwina xa ku va ni xitsongwatsongwana xa HIV hinkarhi lowu ndzi nga ta va ndzi vutisela swivutiso mayelana na vulavisisi lebyi ndzi byi endlaka. Mahungu lawa mi nga ta avelana na mina ya ta pfuna vavabyi van'wana na vatirhi va swilamumulela-mhango hi ndlela leyi va nga endlisaka xiswona ku humesela ehandle hi ta xiyimo xa ku va na HIV. Ku nghenelela ka n'wina eka vulavisisi swi ni nkokota tani hi loko swi ta pfuneta eka ku hetisisa tidyondzo ta mina ta digiri leyi ndzi ti tsariseleke yona e yunivhesiti ya n'walungu .

Ku nghenelela ka nwina eka vulavisisi lebyi a ku ve hi ku tsakela nakambe mi tshunxekile ku tihumesa eka ndzavisiso lowu nkarhi un'wana ni un'wana. Ku tihumesa eka ndzavisiso lowu aswi nge mi tiseli vubihhi hi ndlela yin'wana eka swilamulela-mhango leswi. Mahungu lawa mi nga ta avelana na mina ya ta hlayisiwa hi ndlela ya xihundla nakambe a swi nga tiveki leswaku hin'wina mi nga ndzi nyika mahungu lawa. Vito ra wena a ri nga tirhisiwa hinkarhi wa ku vutisela swivutiso. Muchini wa ku teka mahungu na xitsalo kun'we na maphepha swi ta tirhisiwa ku tsala yan'wana ya mahungu lawa mi nga ta ma nyika ku pfuneta ku nyika mbuyelo lowu ndzi nga tawu kuma eka swivutiso leswi ndzi nga ta swi vutisa.

Muchini wa ku teka mpfumawulo wa marito wu ta vekiwa eka ndzhawu yo hlayiseka nakambe wu ta khomiwa ntsena hi mina na mulanguteri wa ndzavisiso wa mina. Loko swi humelela leswaku hi nkarhi wa ku vutisela swivutiso u hlangana na ku khunguvanyeka emoyeni, u ta chaveleriwa kwala ka xilamulela-mhango. Aku nge vi na tihakelo ta ku va u nghenelela eka ndzavisiso lowu. Loko ndzavisiso wu fika emakumu ndzi ta avelana mahungu lawa na vatirhi kuloni eka mihlangano ya vudyondzisi bya ntokoto na kuhangalasa mbuyelo hi ndlela ya buku leyi nga hlayiwaka hi munhu un'wana na un'wana.

Ku nghenelela ka wena eka ndzavisiso lowu ku amukeriwile hi ndlela ya xiyimo xa le henhla swinene.

APPENDIX 8
CONSENT FORM

UNIVERSITY OF LIMPOPO (Medunsa Campus)

ENGLISH CONSENT FORM

Statement concerning participation in a research project

Name of study: Couples' experiences on disclosure of HIV-positive status at Thulamela B clinics, Vhembe District, Limpopo Province.

I have read the information and heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name and hospital number are not revealed.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this study has been approved by the Medunsa Research Ethics Committee (MREC). I am fully aware that the results of this study will be used for scientific purposes, and my privacy is guaranteed.

I hereby give consent to participate in this study.

Name of participant:

Signature of participant:

Place:

Date:

Witness:

Statement by the Researcher

I provided verbal and written information regarding this study.

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

Name of Researcher: Signature of researcher:

Date:

Place:.....

XITSONGA PAPILA RA PFUMELELANO (CONSENT FORM)

Xitatimende mayelana na ku nghenelela eka projekte ya vulavisisi.

Vito ra projekte: Leswi swi humeleshaka vatekani eka kuhlamuselana ka vona hi ta xiyimo xa vona xa ku van a xitsongwatsongwana xa HIV eka tin'wana ta swilamulela-mhango swa muganga wa Thulamela B, exifundzheni –ntsongo xa Vhembe, ehansi ka xifundzha-nkulu xa Limpopo.

Ndzi hlayile mahungu ya swikongomelo na mbuyelo wa vulavisisi lebyi lavaka ku endliwa, nakambe ndzi nyikiwile nkarhi wo ringanela ku vutisa swivutiso. Ndzi nyikiwile nkarhi lowu ringaneleke ku ehleketsisa hi mhaka leyi. Swikongomelo na mbuyelo wa ndzavisiso swi twisiseka hi ndlela yo ringanela eka mina. A ndzi sindzisiwanga ku nghenelela hi ndlela yin'wana.

Ndza swi tiva leswaku mpfumawulo wa mina wu ta tekiwa hi muchini wo teka mpfumawulo ni leswaku muchini wu ta va kona ku ringana nkarhi wo leha. Ndza swi tiva leswaku mpfumawulo lowu nga ta tekiwa wu nga tirhisiwa eka vudyondzisi bya ntokoto lebyi nga vaka kona eka switirhiso swa gezi ku fana na ti khomphuta ta misava hinkwayo. Ndza pfumela eka leswi ntsena loko kuri leswaku vito ra mina na nambara ya xibedlhele kumbe xilamulelamhango a yi nga humeseriwi erivaleni.

Ndza swi twisisa leswaku ku nghenelela eka ndzavisiso lowu ku va hi ku tinyiketela nakambe ndi nga tihumesa eka wona nkarhi un'wana na un'wana ku nga ri na ku nyika tihlamuselo. Leswi a swi nge vi na nhlohlotelo eka vutshunguri bya mina bya ntolovelo lebyi khomaka xiyimo xa mina kumbe ku va ni nhlohlotelo eka vulanguteri lebyi ndzi byi kumaka eka muongori wa mina wa ntolovelo.

Ndza swi tiva leswaku ndzavisiso lowu wu pfumeleriwe hi Medunsa Research Ethics Committee (MREC), Yunivhesiti ya n'walungu (eka mi-ako ya Medunsa). Ndzi tiva hi vuenti leswaku mbuyelo ya ndzavisiso lowu wu ta tirhisiwa eka xikongomelo xa vulavisisi bya ntokoto nakambe wu nga hangalasiwa emisaveni hinkwayo. Ndza pfumela ntsena loko ku-ve vuhlayiseki bya mina bya tiyisisiwa.

Ndzi laha hi ku nyika pfumelelano wa ku nghenela eka ndzavisiso lowu.

Vito ra mungheneleri:

Nsayino wa mungheneleri:

Ndzhawu

Siku:

Mbhoni:

APPENDIX 9

EXAMPLE OF AN INTERVIEW CONDUCTED

Interviewer : Tsakani Millicent Maluleke Interview no: 3
Interviewee number : 3
Interview date : 16 /03/2015

Information about the Interviewee

Date of birth : 1970/02/26 Gender : Female
Marital status: Married Occupation: Unemployed
Education : High School Grade 10

Keywords: I = Interviewer
P= Interviewee

- I:** How are you mama?
- P:** I am fine, and how are you?
- I:** I am fine. As I have indicated to all of you when we were outside I will be doing research based on HIV.
- P:** Yes, you told us.
- I:** So I will be asking you questions, don't be afraid of this tape I will be using it to record our conversation, no one will know who I was talking to as I won't use your names, this book that I am having I will be using it to note some important things that I see so is it fine with you also?
- P:** Yes, So will it never be heard on radio shows?
- I:** No, it won't be on radio shows and the results will only be submitted to the Department of Health and University of Limpopo
- P:** Okay...
- I:** Yes, because they are the ones who gave me the permission to conduct this study here at Mhinga clinic so don't be afraid.
- P:** Okay.
- I:** So now I will be starting with our interview questions mama, please explain to me about your experiences when disclosing about HIV-positive status to your partner.
- P:** Hey....! Here it was tough, actually at first when I felt it, it started through headache which was non-stop and when I went to the clinic they said I must get tested for HIV, where they pricked my finger with their things, eeehh! Then they said mama your status is not good, you know fear is always within a person.
- I:** Yes you are right.
- P:** And I did not expect this.

- I: Yes....yes...
- P: When I disclosed how the results were, he started by being quiet and did not answer me, I don't know if he knew how this happened, but he then accused me of knowing where I got this whereas he brought this thing to me. Do you understand?
- I: And you know we women are at risk because men go around and shop for these things.
- P: Yes.....yes
- I: Yes ...yes... I understand.
- P: He was angry, you know being angry.
- I: Okay...
- P: Yes.
- I: Another question that I would like to ask is why do you feel that people should talk about their status to their partners, to which extent do feel this is important?
- P: What I can say about people explaining to their partners is, I feel that being quiet is not good, most people die unlike me as it was discovered while I was still strong and being able to walk with my own legs.
- I: I hear you.
- P: I did not start by being sick to an extent of being bed ridden myself so I feel it is good that people must know their status so that they can live well. Those pills that you are giving us are very much helpful because if you use them well most people look healthy and fat and if you don't use them you can die, that thing of saying I don't take treatment is not right, but sharing your status with your partner so that you take treatment and live well I feel that it is good.
- I: Okay, I thank you for that response. I wish people could hear what you said so that our communities can be rescued from this virus.
- P: Yes.
- I: As we are moving forward with our questions, how would you describe the response you got from your partner after disclosing the status?
- P: You know how it happened was on my first disclosure he refused to go for the test and said "You are the one who has it I am fine", yaaahhhh! after a little while when I was taking my treatment he started to ask for my treatment and said can you share your treatment with me? Haaaa! I told him that the treatment can never be shared, each one of us must have their own treatment. I told him to go where I got the treatment in order to get treatment, I didn't give him, iyoh how can he not go there, he went there to get his own treatment now we are using treatment both of us, at the begging hey.... the fight was big, haaaa but now everything is well.
- I: Okay ...I understand that, so how can you explain or describe your relationship with your partner after disclosure of your status? Your relationship how is it now as you said it was difficult at first how are you relating to each other now?
- P: You mean in which sense sister?
- I: I mean at home are you living being angry as you said or..... I want to hear from you.
- P: Oooohh..., as at first he was not accepting and telling himself that you who have it you are the one who brought it but if a man knows that my wife is not doing silly things he knows that

he is just saying it, he is the one who gave her those things, he will end up coming into his senses and behave well, so now we live well he does not give me any problem.

- I:** Okay... that was my last question, do you have any questions for me as a researcher, you are welcomed to ask.
- P:** Oooohhh... isn't it that most of the time we watch things from T.V, where they say a person can live with HIV for 20 years, a person like me I just have less than 10 years while having this as you know I collect treatment here so I want to know as others are saying that this treatment reaches a time where it kills this HIV completely and you will be told not to take treatment anymore is this true?
- I:** I would like to make a clarity on what you have heard, what happens is, the viral load reaches a point where it is very low to an extent that when we send your blood to Malamulele hospital for tests it is undetectable because it was suppressed by that treatment, but if you stop taking treatment it becomes active again and that's where you find people being more sick and hear others saying that the person is like that because he defaulted treatment.
- P:** Oooohhh... and it is dangerous.
- I:** Yes in that way because the person might be unlucky and no longer respond to treatment and there is no treatment for resistant HIV strains yet.
- P:** Yoh! I won't stop taking treatment, people are telling lies yoh!
- I:** it is good because you asked me as a health worker who knows about that and you understand. Thank you for your participation in this study, the results will only be submitted to Department Health and the University of Limpopo, nowhere else you won't find this on radio or TV, thank you once more.

APPENDIX 10

CONFIRMATION BY LANGUAGE EDITOR



UNIVERSITY of the
WESTERN CAPE

FACULTY OF NATURAL SCIENCES

DEPARTMENT OF MEDICAL BIOSCIENCES

Donavon C. Hiss
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Private Bag X17
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Tel: 021 959 2334

Cell: 0722001086

Fax: 021 959 1563

E-mail: dhiss@uwc.ac.za or hiss@gmx.us

29 September 2015

To Whom it May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the MCur thesis by **Tsakani Millicent Maluleke**, titled: **“Couples’ Experiences on Disclosure of HIV-positive Status at Thulamela B Clinic, Vhembe District, Limpopo Province.”**

Sincerely Yours

A handwritten signature in black ink, appearing to be 'D. Hiss'.

Dip. Freelance Journalism, Dip. Creative Writing, MSc (Medicine), PhD