

**EXPLORING THE NARRATIVES OF HIV STATUS DISCLOSURE BY
PEOPLE LIVING WITH HIV: THE SOCIAL CONSTRUCTIONIST
APPROACH**

by

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DECLARATION

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I declare that the above dissertation is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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ABSTRACT

This research focused on the experiences of HIV disclosure to significant others amongst people living with HIV. The aim of the research was to explore how people living with HIV experience disclosure of their HIV positive status to their significant others. The social constructionist perspective was utilized to gain a deeper understanding of the experience of HIV positive status disclosure to significant others. The study's sample comprised of five participants who were recruited using purposive sampling strategy. Data was collected with using face to face semi structured interviews. Themes were extracted and analysed using thematic content analysis. An analysis was made as to whom participants choose to disclose to, the reaction of the people they disclosed to, as well as their reasons for disclosing. Results were reported as the participants' experiences and noted as is or unadulterated.

Keywords: HIV/AIDS, HIV positive, significant others, HIV disclosure, PLWHA, discrimination, stigma.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
HIV	Human Immunodeficiency Virus
PLWH	People living with HIV
PLWHA	People living with HIV/AIDS
UNAIDS	United Nations Programme on HIV/AIDS
UNISA	University of South Africa
UNICEF	United Nations Children’s Fund
USAID	United State Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

CHAPTER 1

INTRODUCTION AND BACKGROUND TO THE STUDY

~~HIV~~HIV, (which is an acronym for Human Immunodeficiency Virus), continues to be one of the leading causes of death in South Africa. Despite the high ~~epidemic~~pandemic of HIV in South Africa there seems to be a veil of secrecy around infected people's HIV status which appears to somehow aggravate the spread of the disease ((HSRC report, 2005). This study is informed by scarcity of research on the challenges of HIV status disclosure as well as the experience of people who ~~made a decision~~decided to disclose their HIV positive status to significant others. The aim of the study is to get more insight as to why people living with HIV choose to disclose or not to disclose their HIV status to their significant others.

The Government, private sector and non-governmental organisations are increasingly working hard to curb the spread of HIV by rigorously embarking on awareness campaigns that are geared towards promoting awareness, prevention and encouraging disclosure. Examples of such programs include the VCT programme (Voluntary Counselling and Testing) which is pioneered by the Department of Health. The VCT program with its skilled counsellors encourages people to make an informed choice to voluntarily go for ~~Pre~~Pre and Post-test counselling and to ~~actually~~ take the HIV test. The introduction and implementation of Home Community Based Care models was another attempt to destigmatise the epidemic. This includes the involvement of different stakeholders and role players within communities in promoting ~~community-based~~community-based care, support and prevention programmes. The primary aim of this programme is to promote acceptance of those infected and affected by the epidemic and encourage openness to talk about it amongst local communities.

In South Africa, there are annual commemorative days which are observed as a way of promoting awareness and acceptance of the pandemic. The commemorative days include the ~~candle light~~candlelight memorial, condom week, red-ribbon week and world AIDS (Acquired Immune Deficiency Syndrome) day. In various communities, there are also support groups which were established to offer support, hope and promote positive living amongst the infected and affected. However, all these efforts that are geared towards curbing the spread of the ~~disease~~disease as well as promotion of HIV disclosure are going to be in vain if people living with

HIV continue to struggle to disclose their status to their significant others because of possibly the fear of discrimination and stigma. The limited research on HIV status disclosure suggests that HIV disclosure is a very sensitive and challenging task for all involved that is, the people who ~~have to~~must disclose as well as those who ~~have to~~must listen to the disclosure.

MOTIVATION OF THE STUDY

The researcher's interest in the study was ignited by his volunteering work as a counsellor at the Tshwane Multisectoral AIDS Response Unit at ~~Attridgeville~~Atteridgeville in Pretoria. The Unit is a multisectoral AIDS response programme under the Department of Health that deals with HIV/AIDS related diseases, TB (which is an acronym for Tuberculosis) and Sexually transmitted diseases. HIV/AIDS management is the core business of the unit. Part of the researcher's counselling work entailed conducting home visits with Peer Educators in communities which is where he observed that PLWH (which is an acronym for people living with HIV) appeared to have conflicting ideas about whether to disclose or not to disclose their HIV status to significant others. The challenge seemed to stem from the advantages and disadvantages of revealing or not revealing their HIV positive status. The afore-mentioned encounter ignited the researcher's interest in investigating the factors that may influence their decision whether to disclose or not to disclose.

In the proposed study, the focus is on people living with HIV that have made the decision to disclose their status to significant others. This study explores their ~~own~~ personal experience, personal reasons and what factors may have influenced their decision to disclose. Traditionally social scientists have been criticised for emphasising 'scientific theories and research techniques rather than the words and perceptions of people they study' (Schneider, cited in Link & Phelan, 2001, p. 366). As such, the focus of the study is to explore the narratives of PLWH, their personal reasons to disclose their status and what factors may have influenced their decision to disclose to their significant others. Furthermore, many studies have been conducted focusing on HIV status disclosure and little on the self-reported reasons why they took the decision to disclose their status to their significant others.

The study of HIV status disclosure is important because risky sexual behaviour tend to manifest in different ways like the spread of HIV and other sexually transmitted diseases. It is important for the researcher to conduct the study as this will assist in prevention, treatment, care

and behavioural change to those infected and affected by the disease. In addition, the self-reported reasons for disclosure would be valuable to the literature of HIV status disclosure.

From a health promotion point of view, HIV disclosure is viewed as the foundation of prevention of HIV transmission to partners (Tshweneagae, Oss ~~&and~~ Mgutshini, 2015). Disclosure by PLWH can contribute to safer sex practices thereby reducing infection rates. PLWH can also benefit from medical services, care and support systems like counselling and antiretroviral drugs if they disclose their status (Van Dyk, 2005). Partial disclosure to significant others, she argues, offers psychological, emotional, physical and emotional support to the PLWH especially at the time when they are still trying to come to terms with the shock of their diagnosis. Disclosure can also encourage the recipient of the news especially significant others to change their sexual behaviour including abstaining from sexual relations, sticking to one partner, using a condom and taking HIV test and as such reducing the transmission of HIV. (Adedimajiri, 2010). The information gathered from the self-reported reasons for HIV status disclosure can add to the existing body of knowledge ~~and also~~ draw attention to areas that still need to be studied.

According to Atuyambe ~~et al., Ssekujja, Ssali, Tumwine, Nkesa, Nannungi, Ryan and Wagner~~ (2014), HIV status disclosure is very important in promoting risk reduction behaviour and in facilitating access to prevention and care. In addition, these authors are also of the opinion that people who disclose their status tend to receive support (emotional and financial support) and have strong family and relationship ties. Arrey, Bilsen, Lacor and Descheepers (2015) to the contrary, argue that although disclosure tends to have positive effects on PLWH's relationships and wellbeing, disclosure can also have negative effects for people living with HIV. The negative effects might include stigma, discrimination, violence and abandonment amongst others and these in most instances tend to act as a barrier to prevention and treatment drives.

The authors further argue that these negative effects can lead to non-disclosure and the possibility of more infections, fear of disrupting relationships and rejection amongst others. The researcher is of the opinion that the study's findings might shed some light on enabling factors that encourages people to disclose. Although disclosure is important, readiness by significant others to receive the disclosure is equally important. Hence the study also attempts to look at the experience of disclosure on the people living with HIV/ AIDS as well as their significant others'

reaction and management of the disclosure. The researcher, with the study's findings, intends to promote acceptance of HIV/AIDS by people infected and affected by HIV/AIDS, which might in turn ~~might~~ help to curb the spread of the epidemic. The study might also assist significant others ~~to gaining~~ insight in terms of effective or ineffective ways that they could be responding to the PLWH's disclosure, which could be contributing to non-disclosure and invariably to the rapid spread of the epidemic.

PROBLEM STATEMENT

The vast amount of literature supports the fact that encouraging people living with HIV to disclose their status is one of the most effective ways of promoting risk reduction and combating the spread of the disease. ~~(Atuyambe et al. (2014).~~ HIV disclosure is said to enable the PLWH access to relevant medical and psychological care, assisting them to reduce the risk of infecting or being infected by others, and most importantly creating awareness within communities that HIV is not a death sentence but a manageable disease. Despite the ~~aforementioned~~ ~~afore~~ ~~mentioned~~, most people living with HIV are still reluctant to disclose their status ~~and in this study~~ ~~and, in this study~~, the researcher aims to explore the experiences of PLWH in disclosing to significant others. However, the researcher is also of the opinion that there are some infected people who are comfortable to disclose their status. Hence, the focus of this study is on those infected people who decided to disclose to significant others for them to narrate their experience of disclosing to significant others.

According to Atuyambe et al. (2014), research on HIV disclosure to family in Sub-Saharan Africa is limited. Most studies in Africa on HIV/AIDS disclosure have focused on disclosure to sexual partners for example Oss (2012, p. 37) ~~who~~ found out that the need to disclose was amongst others to protect the 'partners from contracting the disease, through practising safe sex (condom use), living freely and positively while supporting each other'. These findings ~~only~~ might only cater for the benefits of sexual partners but ~~may~~ there ~~may is~~ still be a need ~~of~~ ~~of~~ research ~~for~~ ~~for~~ those who do not have sexual partners and still live with their families. Significant others in this study not only refer to close family, for example parents and siblings but it also includes sexual partners as well. In a study by Oss (2012), she reports that women who tested HIV positive were reluctant to share their diagnosis with their sexual partners,

preferring to tell their parents. Based on the ~~afore-mentioned~~ ~~afore mentioned~~, the researcher opted to include the sexual partner as well, ~~as part of significant others. in the reason for disclosure. in the reason for disclosure.~~

OBJECTIVES OF THE STUDY

- ~~To provide a platform for PLWH to share their personal experience about disclosing their HIV status to significant others.~~
- To make recommendations on factors that could enable disclosure to significant others.

RESEARCH DESIGN

According to Terre Blanche et al. (2006, p. 563), 'research design is a strategic framework or plan that guides research activity to ensure that sound conclusions are reached'. The current study employs an exploratory qualitative design. The research design will allow the research participants to share their lived experiences of HIV status disclosure including the reasons for making the decision to disclose their status to their significant others. The demarcated area for the study is Gauteng, Tshwane area, in Pretoria. Participants are residents of this area and were identified through their attendance of the support group based in the Tshwane Multisectoral Aids Response Unit in Atteridgeville called Thusong Learning Centre. Both males and females between the ages of 15 and 49 living with HIV/AIDS were eligible to participate in the study. The age grouping is in accordance with UNAIDS (2010) that the general population mostly affected worldwide is between 15 and 49. One of the criteria for inclusion was that participants should be living with HIV and should have disclosed to the significant others.

OUTLINE OF THE STUDY

The study's outline is comprised of six chapters. **CHAPTER 1** provides a brief introduction to literature relating to HIV status disclosure to significant others, the motivation and objectives of the study. Literature relating to HIV status disclosure by PLWH to their significant others is discussed in **CHAPTER 2**. The literature review also focuses on a brief history of the origins of HIV, the psychosocial factors associated with HIV status disclosure, disclosure of HIV positive status, factors motivating disclosure, theories of disclosure and the impact of HIV status disclosure on families. **CHAPTER 3** presents the research methods and design by focusing on the following: theoretical paradigm including social constructionist framework, research design including the qualitative approach, sampling criteria, methods of

data collection, data analysis and ethical considerations. Data analysis and results are presented in **CHAPTER 4**. In addition, a thematic content analysis used to identify themes, categories subcategories and meanings from the participants' narrated experiences are also described. **CHAPTER 5** presents a detailed discussion of the findings of the current study with reference to relevant literature pertaining to the concept of HIV status disclosure to significant others. The discussions is based on the findings of the themes that were identified in the previous chapter. **CHAPTER 6** focuses on the conclusions drawn from the previously discussed chapters. The chapter also provides an evaluation of the strengths and limitations of the study. Finally, the chapter focuses on the recommendations needed for further studies.

CHAPTER 2

LITERATURE REVIEW

In this chapter, literature relating to HIV status disclosure is discussed. Information gathered from previous studies is used to provide an understanding of what is meant by HIV status disclosure and its consequences. The chapter provides a brief history of the origins of HIV and considers infection rates as well as disclosure of HIV status. Disclosure rates of people living with HIV/AIDS and the impact of HIV disclosure provide the backdrop of the discussion on infection rates. The chapter also focuses on factors influencing the decision to tell or not to tell and those that affect nondisclosure. —The controversy around HIV disclosure and psychological effects on HIV status disclosure are given consideration. Theories of disclosure and basic rights and ethical guidelines around HIV status disclosure are discussed in the concluding sections of the chapter.

A BRIEF HISTORY OF THE ORIGINS OF HIV IN SOUTH AFRICA

There are many theories about the origins of HIV in the world. Whilst some argue that the disease is a manufactured virus by the government to kill black people (Ross, Essien, & Torres, (2006), others argue that HIV originated from the transmission of SIV (which is an acronym for simian immunodeficiency virus) from the African primates infected with the SIV which is an acronym for simian immunodeficiency virus to humans (Sharp & Hahn, 2011). Furthermore, others blame contaminated polio vaccines (Koprowski, 2018) as the cause of HIV. In South Africa, the transmission of HIV is said to be influenced by four main factors which are:

- homosexuality
- migrant labour
- mining and
- trade prostitution (Shell, 2000).

This section is not intended to serve as a complete account of South Africa's HIV/AIDS epidemic history~~history~~, but it briefly highlights some of the main factors that have been documented in the literature on the historical context of HIV/AIDS within the South African context.

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THE INFLUENCE OF HOMOSEXUALITY ON HIV TRANSMISSION

According to Shell (2000), the first two AIDS cases that were first diagnosed in 1982 in South Africa were found amongst homosexual men. Homosexuality was said to be the dominant mode of HIV transmission during the 1980's and was overtaken by heterosexual transmission in the beginning of the 1990's. Wilton (2014) argues that anal sex which is the dominant mode of intercourse by homosexual men carry a significant risk of HIV transmission than vaginal sex. As a result, this might have contributed to the high infection rate of HIV and the deaths of many homosexual men during the 1980s (Shell, 2000).

Globally, HIV/AIDS gained prominence in the international scientific community as a disease of homosexual men. Accordingly, the earliest data on HIV/AIDS (that is, data for the period 1983-1986) in South Africa focused mostly on homosexual men. It was only in 1990 that antenatal clinic attendees (pregnant women) were tested for HIV/AIDS in South Africa. The national ~~estimates of HIV prevalence in SA, like in other countries, is~~ estimates of HIV prevalence in SA, like in other countries, are based on data from pregnant women tested at antenatal clinics and national household surveys where it involves sampling a proportional cross section of society. The antenatal surveillance programme involves the annual testing of the blood of pregnant women in the public health sector who visit antenatal clinics. This programme began with the first national antenatal survey amongst women in SA in 1990. This survey indicated that 0.8% of pregnant women tested were found to be HIV positive (Van Dyk, 2012; 8). In the past antenatal data at public antenatal clinics has been the source of information for HIV infections, although it has limitations by focusing on a select group which is sexually active women between ages 15 and 49 years who use public health services in designated surveillance areas. These estimates do not include men, younger women and old age groups. They may lead to over estimation and under estimation of the HIV infection (Brookes, Shisana & Richter 2004, p. 1).

Based on the ~~aforementioned~~ afore mentioned, one might argue that 1990 was the first year for which substantial and credible population level data on heterosexually transmitted HIV/AIDS existed in South Africa. Although pre 1990 data on heterosexually contracted HIV/AIDS was available, it is non-specific given that heterosexual, paediatric HIV/AIDS were reported collectively until that time. As the primary agency tracking HIV/AIDS in South Africa during

the early 1980s, the bias evident in state data is indicative of the apartheid state's stance on HIV/AIDS. Building on the premature and preliminary notions of the international scientific community to justify its stance, the apartheid state targeted homosexual men as the purveyors of this deadly and at the time still mysterious disease. The bias response by South African government to the scourge of HIV/AIDS could be argued to have contributed to the current spread of the epidemic. The apartheid state's initial dogmatic, ignorant and impractical response to HIV/AIDS could have facilitated the virus' sustained spread through the majority heterosexual population. Unnoticed and unchallenged, HIV/AIDS was thus allowed to grow in silence within the heterosexual population during the mid to late 1980s.

THE INFLUENCE OF MIGRANT LABOUR ON HIV TRANSMISSION

In 1987, after the establishment of the AIDS unit of the South African Institute for Medical Research, tests focusing on miners in South Africa revealed the prevalence of HIV/AIDS in some miners from Malawi, Zimbabwe and Mozambique (Schovic, (2014). She argues that HIV positive migrants travelled to the south and concentrated settlement in South Africa and contributed to the spread of the disease. Furthermore, she argues that through the apartheid government's Bantustan or Native homeland policies, including forced labour migration, many black men went to Johannesburg mines to work. They then had sexual relations with females from the surrounding areas and started infecting them with the disease. Those that did not have the disease contracted the disease and took it back home to their wives. The back and forth migration played a very important role in spreading HIV.

THE INFLUENCE OF MINING ON HIV TRANSMISSION

The migrant labour had a significant impact in the mining sector on the transmission of HIV (Corno & de Walque, (2012). Based on their study of mines, migration and HIV/AIDS in Southern Africa, they found that there is a possibility of HIV transmission for mine workers aged between 30-44 years and that women married or cohabiting with mineworkers are more likely to be HIV positive.

THE INFLUENCE OF TRADE PROSTITUTION ON THE TRANSMISSION OF HIV

According to Schovic (2014), by the late 1990 sexual workers were infected with the disease in the area of Johannesburg, South Africa. —Poverty, which is associated with transactional sex practice, forced women to be sex workers and contributed to the spread of HIV

Bhunu, Mhlanga & Mushayabasa (2014). In their study exploring the impact of prostitution on HIV/AIDS transmission, Bhunu et al. (2014) found that the more the prevalence of prostitution in a community, the higher the chances of being infected with HIV and if already infected, the higher the chances of being infected with another HIV strain. de Bruyn (1998) on the other hand compels us to view the documented influence of the prostitution trade with extreme caution as he argues that the sex worker's working conditions, for instance, is not an easy one in that they work and live in an environment that stigmatizes and marginalizes them in many ways from society. Most of the time they find themselves in a situation where they are blamed by society for their positive status. HIV/AIDS and discrimination discussion paper by de Bruyn (1998) cites a story of a police officer, who, when detaining an HIV positive prostitute, loudly announced for all to hear that she was positive. So, based on the aforementioned one could argue that the marginalised groups such as sex workers will continue to be reluctant to disclose their status and this will not enable them to access appropriate medical care and support, further aggravating the spread of the epidemic. (Human rights, women and HIV/AIDS, 2000). (United Nations Agency for International Development, 2002).

HIV PREVALENCE AND INFECTION RATES

Statistics South Africa views HIV prevalence as the percentage of people that are HIV positive in the population out of the total population at a given point in time. They report that HIV statistics in 2017 stood at 12.6% of the population, which implies that 7.06 million people are HIV positive (Statistics South Africa midyear population estimates of 2018). It has been estimated that 36.7 million people were infected worldwide in 2015 UNICEF (2016). In South Africa it has been estimated that 7 million people have been infected in 2015 which is the biggest HIV pandemic in the world UNAIDS (2016). New infections are reported every day even though there are many interventions that include campaigns, education programmes by government and non- government organisations to combat it. According to the Statistics South Africa midyear population estimates of 2018, the total number of persons living with HIV in South Africa increased from an estimated 4,25, 25 million in 2002 to 7,52 million by 2018. For 2018, an estimated 13,1, 1% of the total population were found to be HIV positive. Approximately one-fifth of South African women in their reproductive ages (15 – 49 years) are HIV positive. HIV prevalence among the youth aged 15–24 has declined over time from 6,7% in 2002 to 5,5% in 2018.

It is clear from Table 2.1 below that the prevalence of HIV in the South African provinces has increased from 2015 to 2017 (The fifth South African National HIV Prevalence, incidence, behaviour and communication survey, 2017), but has since decreased slightly according to the statistics depicted in table 2.2. The province with the highest prevalence remains KwaZulu-Natal.

The prevalence of HIV in South African provinces during 2015, 2016 and 2017.

Province	2015:2015 :(%)	2016: (%)	2017: (%)
KwaZulu-Natal	32.5	27.0	25.8
Mpumalanga	27.3	22.8	23.1
Gauteng	23.9	17.6	15.5
Free State	27.9	25.5	18.5
North West	23.0	22.7	17.7
Eastern Cape	18.0	25.2	15.2
Limpopo	11.4	17.2	13.7
Northern Cape	10.1	13.9	9.2
Western Cape	7.1	12.6	5.3

(The fifth South African National HIV Prevalence, incidence, behaviour and communication survey, 2017)

The provinces with high prevalence rates in the period 2015 - 2017 were KwaZulu-Natal, Mpumalanga, North West, Gauteng and the Free State, but in 2012 Kwa-Zulu- Natal, Mpumalanga and the Free State were among the provinces with the highest prevalence.

Table 2.2:

The prevalence of HIV in South African Provinces during 2017

Province	Rate: %
KwaZulu-Natal	25.8
Mpumalanga	23.1
Gauteng	15.5
Free State	18.5
North West	17.7
Eastern Cape	15.2
Limpopo	13.7
Northern Cape	9.2
Western Cape	5.3

(The fifth South African National HIV Prevalence, incidence, behaviour and communication survey, 2017)

During the period 2015 – 2017, the Western Cape was the lowest and the Northern Cape and Limpopo slightly higher than the Western Cape and this tendency remained in 2015. The only province with a slight decline in the prevalence rate from 2015 - 2017 was the Western Cape. The National rate also increased during the period 2000 to 2015 from 22.4% to 24.8%. Although progress is being made in South Africa to get more PLWH on Antiretroviral treatment as well as encouraging them to disclose their HIV status in order to curb the scourge of HIV, HIV continues to be a burden as it is disproportionately affecting different provinces and high risk groups especially black Africans, adolescent girls and young women. It is apparent from Table 2.1 that HIV incidence has decreased from the 2015 estimates, yet remains high, particularly among female youth aged 15 - 24 years.

DISCLOSURE OF HIV POSITIVE STATUS

According Bravo, Edwards, Rolnick [& Elwyn \(2010\)](#), disclosure of HIV positive diagnosis is one of the greatest challenges facing PLWH. The decision whether to disclose or not to disclose one's HIV positive status is difficult and is a life-long process. Furthermore, Leask, Elford, Bor, Miller, [& Johnson \(1997\)](#), argue that the stigma and discrimination that surrounds HIV/AIDS can possibly inhibit disclosure because of the association with sexual activities for example infidelity, sexual orientation like homosexuality and drug use. Conversely, not telling others about one's HIV status may make it difficult for one not to get social support.

Disclosure is important in the management of HIV (Norman, Chopra & Kadiyala, 2007). They argue that one ~~has to~~ must disclose his/her status if one ~~has to~~ must gain entry into center treatment programs and is also important to adherence to treatment regimens and support. Although disclosure is paramount, it cannot be a once off event. It ~~has to~~ must be a ~~be~~ gradual ~~a~~ process which needs to be planned and informed. It often takes many years for people to disclose their status (Fair, Allen, Trexler, Osherow & D'Angelo, 2016). ~~Hence, Markland, an engineer for De Beers mining company took almost 9 years to disclose his HIV status to his manager. He believed that if PLWA cannot disclose their status fully, limited disclosure could be an option. Furthermore, he indicates that disclosure is important for two reasons, namely, that it is important to disclose to your doctor in order to get correct medical treatment and also to your sexual partner to reduce the risk of infecting them and also re-infecting yourself in the process (S. A Labour Bulletin, p. 72).~~

~~Although most researchers agree with Odongo (2001), it is important to acknowledge that despite the number of people, who continuously disclose their status, there is still a stigma attached ~~attached~~ and people react differently towards those living with HIV/AIDS. Margolese (2005) (Almeleh, 2006) argues that there is no prescribed effective way to disclose HIV status to someone, in the same vein, there is no certain way to gauge people's reactions. However, asking one questions such as these before ~~disclosing could somehow help~~: have I accepted my HIV positive status, whom do I want to tell and why do I want to tell? How much is this person that I intend disclosing to knowledgeable about HIV/AIDS, ~~How~~ how much am I ready to share or are they ready to hear, ~~How~~ how will disclosing my status affect me and how will it affect the people around me? It is also important to choose the conducive environment in which one feels comfortable. (Margolese, (2005), (Almeleh, 2006)~~

It is important to also highlight the fact that other people living with HIV might opt for non-disclosure which has its own consequences that might include lack of support from significant others, risk of infecting others and being re-infected and not being able to receive critical medical care. With non-disclosure, there is high possibility of significant others' psychological well-being becoming affected since they may experience feelings of guilt, confusion or anger when they find out about the individual's illness, especially if ~~it~~ they discover after the individual gets seriously sick or has died (Van Dyk, 2005) (Canadian AIDS network and society, Montreal, 1998).

According to the International Centre for Research on women (ICRW), (2005), which lead a USAID – funded research initiative in three African Countries and in Vietnam to investigate the causes; manifestations and consequences of HIV/AIDS related stigma and subsequent discriminatory acts, words with negative connotations to describe PLWHA are part of daily conversation and are used in rumours, gossip, and even in the media. For example, PLWHA in Tanzania are referred to as “maiti inayotembea” (walking corpse) and “marehemu mtarajiwa” (expected to die). Such terms changes with visible progression of the disease. For example, healthy-looking PLWHA are called “nyambizi” (submarine), but PLWHA exhibiting signs of AIDS are called “utakufa kilo mbili” (you will die weighing two kilos). The situation is no different in South Africa where names are attached to HIV. Such names include “Mangama” (names), Sephamola/phamokate (something that grabs), three little words/Z3 and many others. Several women interviewed by Philippa Garson, a research fellow at 'the HIV/AIDS and the Media Project', run by the Perinatal HIV Research Unit and the school of journalism at the University of the Witwatersrand, said they would not disclose their status to family members or friends, because of the "way they talk about people with HIV" (IRIN PLUS NEWS, June (2005).

Most studies documented the consequences of disclosure as gender-related, for example, they argue that disclosure is more difficult for women because stigma and discrimination is much stronger against them. Although most of the time women are infected by their partners; they are often blamed for the spread of the disease. It is because of these difficulties that women tend to keep their status a secret which increases their risk of re-infection and are consequently not being able to access appropriate medical care and support (Human rights, women and HIV/AIDS, 2000). (United Nations Agency for International Development, 2002).

Disclosure of HIV status can be stressful, characterized by either withdrawal of love and support or by non-acceptance. It is important to be mindful of the possible consequences attached to disclosure and non-disclosure. With disclosure, one risk being stigmatized as indicated above, rejected, discriminated against, blamed, losing economic support, physically (exposed to violence) and emotionally abused and having family relationships disrupted. It is widely accepted that disclosure is an essential component of combating the spread of HIV (Tshwenegetal, 2015). (Odongo, 2001); (Makland, 2002). It is however also important to distinguish between different levels/

types of disclosure namely full disclosure, partial disclosure and non-disclosure. The former involves going public with one's HIV positive status, including to friends, family, colleagues, relevant organizations, media and the broader community. Partial disclosure on the other hand is about telling a selected, trusted and close family and friends in confidence about one's status and ~~non-disclosure~~ non-disclosure means not telling anyone about one's status ([Rodkjaer, Sodermann, Ostergaard & Lomborg, 2011](#)). ~~(Report on East African Universities responding to HIV/AIDS (2001))~~.

SELECTIVE/PARTIAL DISCLOSURE

In the current study, selective/partial disclosure refers to a process where an HIV positive individual voluntarily tells selected individuals about his/her HIV status. Based on his research findings, Khan (2004) argues that the family is "the best" place for initial disclosure of one's HIV status and an important foundation of support to prepare before disclosing to others because the family offers social support and emotional well-being. With regards to sexual partners in the family, the need to disclose is motivated by the desire to get their partners to test for HIV and know their status. According to research findings by Almeleh (2006), families that are based on reciprocal obligations between members are the ones to offer social support and emotional well-being. These family members have taken care of each other for many years and built a mutual trusting relationship. However, not all families offer social support and emotional well-being. According to Atuyambe et al. (2014), families where women depend on their husbands for financial support do not disclose their status to them because of fear of rejection, fear of violence and fear of loss of economic support.

According to WHO (2005), the family can help the HIV infected member with adherence to ~~treatment, and~~ treatment and improve their quality of life. Disclosure to family tends to benefit the HIV infected member and is encouraged as the best place where the HIV infected member can be accepted and supported. Significant others can also help PLWH to accept their HIV status and reduce the stress of coping alone. Ssali et al. (2010) found that husbands and wives disclosed for ethical reasons as well. They found that both are driven by the desire to protect the other from HIV infection. If the female spouse is the one that is infected, she would disclose to the male spouse and encourage him to use a condom and protect himself from infection. If it is the male spouse that is infected, he would disclose to the female spouse so that she must look

after the children should he die. They argue that disclosure among spouses also promotes honesty in relationships.

Disclosure does not only apply to spouses in a family context or children having to tell their parents, but also to parents having to tell their children. However, according to Van Dyk (2012), HIV positive mothers do not tell their children of their HIV positive status but delay disclosing to them on the grounds that they are too young to understand the nature of HIV/AIDS, that it is not in the best interest of the child and sometimes exclude them from the topic because it is not an appropriate topic for children to discuss (that is taboo). She contends that parents' non-disclosure of their HIV positive status ~~make~~ makes them (children) feel guilty, anxious, depressed and lonely unlike children who are informed of their parents' HIV positive status who experience less anxiety and are supportive of their HIV positive parents i.e. emotionally and physically. Ssali et al. (2010) maintain that older women are more likely to disclose to their children who are old enough to understand the meaning and circumstances of living with HIV. They argue that these children can offer support (financial, material and emotional) and strengthen the relationship ties. However, disclosing to children need to be done with proper consideration to their age and level of understanding by the HIV positive parents because it has positive and negative effects.

Maintaining control over treatment options also compels one to disclose to selected individuals. These include healthcare professionals in clinics health care workers in community settings that provide informal support for patients on ARV. Many treatment programmes that are ~~focused on~~ adherence to complex treatment regimens are dependent on the individual disclosing his/her HIV positive status. Norman et al. (2007, p.2) state that “[a]ccess to other forms of care such as home-based care, non-governmental organisations (NGO) support and specific social grants depend on the disclosure of HIV status”. Selective disclosure can have a positive impact on the lives of PLWH. Not only will it enable the family and the community support networks through better psychological management of the disease but also through the proper management of the disease.

FULL DISCLOSURE

Full disclosure or disclosure to everyone does not mean disclosing to everyone an HIV individual come across, but to everyone in their network (Rodkjaer et al., Sodermann,

[Ostergaard & Lomborg, \(2011\)](#). By informing everyone in his/her network, the HIV positive individual wants to be accepted as he/she is. This strategy tends to lessen the burden of living with secrets and emotional strain that someone might find out that he/she is HIV positive. They further argue that disclosing to everyone encourage people to get HIV counselling and testing and thereby knowing their status and it also helps in reducing stigma surrounding HIV/AIDS. However, Van Dyk (2005) describes disclosure as telling or revealing one's HIV status to the public. It does not only refer to everyone in the HIV infected network but to the general public including health providers and those that can help in accessing social benefits (e.g. social grants, information and food supplies from government or non-government organisations).

NON-DISCLOSURE

HIV/AIDS related stigma and discrimination is an important factor that predispose people not to disclose their HIV positive status ([Atuyambe et al., \(2014\)](#)). Fear of embarrassment, blame, criticism and disruption of family relationships also tend to lead to non-disclosure ([Gari, Hable, & Markos, \(2010\)](#)). According to ([Atuyambe et al., \(2014\)](#)), women's non-disclosure of their HIV positive status stems from among other things, fear of rejection, fear of violence and fear of loss of economic support especially where women depend on the male partner for financial support. According to Van Dyk (2012), some PLWH at the ~~work place~~ workplace especially those in leadership position fear losing their reputation and respect from their subordinates. Based on their studies, [Rodkjaer et al., \(2011\)](#) found that emotion stress like guilt, shame and living a double life are characteristic of PLWH who do not disclose their HIV status. Van Dyk (2012) lists ~~a number of~~ several disadvantages of non-disclosure. These include:

- Living a lie-always having to lie about where one was after visiting a clinic due to HIV related matters
- Emotional problems- low self-esteem, depression and suicidal ideation
- Relationship problems- withdrawal from friends and being afraid to start a new relationship
- Personality changes- distrust and bitterness
- Behaviour problems- alcohol and or drug abuse

DISCLOSURE RATES OF PEOPLE LIVING WITH HIV/AIDS

A review paper by Maman ~~&and~~ Medley (2004) on Gender dimensions of HIV status disclosure to sexual partners found that there were high disclosure rates in developed countries than in developing countries. They found that rates of disclosure to sexual partners are higher among women in the developed world (average 71%; range: 42% - 100%) compared to women in the developing world (average 52%; range: 16% - 86%). They also found that 3% - 10% of people in the United States of America chose not to disclose their status to anyone which represents developed countries and 10% - 78% of people in the developing countries chose not to disclose their status to anyone. ~~A number of~~Several studies reported that rates of HIV disclosure are generally low, although they differ from one country to the other Makin, Forsyth, Visser, Sikkema, Neufeld ~~&and and~~ Jeffrey (2008). In studies conducted in Sub-Saharan Africa including 3 in Tanzania, 3 in Rwanda, 3 in Kenya, 2 in Burkina Faso, 1 in Uganda, 1 in South Africa, 1 in the Democratic Republic of Congo and 1 in Thailand it was found that between 16.7% to 86% of women attending the antenatal care chose not to disclose their status to their partners (Bulletin World-~~-(~~2004).

Generally, disclosure rates differ between studies and countries. In a study by Ebuenyi, Ogoina, Ikuabe, Harry, Inatimi ~~&and~~ Chukwueke (2014, p.1) on the prevalence, pattern and determinants of disclosure of HIV status disclosure in an Anti-Retroviral therapy clinic in the Niger Delta Region of Nigeria, they found that the '71% of females studied, 62% disclosed to their current sexual partners with students having the least of disclosure rates'. ~~The majority of~~Most of the study participants preferred to disclose to family members (57%) than to former sexual partners (2.5%) or friends (4.9 %)'. Results in this study suggest low disclosure rates in the Delta Region and there is a need to encourage disclosure to past sexual partners and students. In their studies Seid, Wasie ~~&and~~ Admassu (2012) of Disclosure of HIV positive result to a sexual partner among adult clinical service users in Kemissie District, North Ethiopia, found that 91% of participants had disclosed their HIV status to their partners. However, they argue that the high disclosure rate may be the result of difference in population characteristics and clinical settings whilst some studies took place in community settings and some on women only.

Research studies have shown that the increase in disclosure rates has may have been influenced by counselling received by PLWH on matters relating to disclosure. Furthermore, the

increase in disclosure rates may have also been influenced by adherence to ART (which is an acronym for Antiretroviral Treatment) whereby one is bound to disclose one's HIV positive status. Deribe, Woldemichael, Wondafrash, Haile ~~&and~~ Amberbi, (2008) assert that it is easier for PLWH who have known their status for a significant time and accepted it, to disclose their status unlike Amoran (2012) who in his studies of predictors of disclosure of sero-status to sexual partners among people living with HIV/AIDS in Ogun State, Nigeria found low disclosure rates of 50% due to the fact that PLWH in the study were recently diagnosed since the introduction of HAART (which is an acronym for Highly Active Antiretroviral Therapy) approximately a year prior to the survey. The author suggests that the lower rates of disclosure in this study might be insufficient knowledge about treatment services and the nature of the disease in the target group of investigation. The other reason for the increase in disclosure rates is that disclosure occurs more among PLWH who live in urban areas where HIV support services and information are available (Gari et al., (2010).

FACTORS INFLUENCING THE DECISION TO TELL OR NOT TO TELL

According to Almeleh (2006), it is important for people who have just been ~~diagnosed~~diagnosed with HIV to accept and feel comfortable of their status before they can tell others. They should think through all the pros and cons and take time to think about the implications and reactions they are going to get from family or recipients of their disclosure. They argue that this will prepare them to deal with any response or reaction they will get from the persons they will disclose to. He argues that one way to prepare the recipient for disclosure is to evaluate the knowledge and understanding the recipient has about HIV and Aids. Knowing what the recipient knows and understand about HIV and Aids will enable the person living with HIV to know what to say to his/her target of disclosure. Furthermore, he argues that it is important for PLWH to assess the reaction of their recipient of disclosure before the actual disclosure by talking about HIV in general. He asserts that this will give an HIV positive individual an idea as to whether the recipient of the disclosure, in this case the significant other, will react negatively or positively or will be supportive or not.

According to Atuyambe et al_ (2014), Maman et al_ (2014) and Ssali et al_ (2010), one of the reasons for HIV status disclosure by PLWH was social support. They argue that social support including financial aid, practical help like adherence to ARV treatment emotional and

psychological support was one of the reasons why PLWH disclosed to their significant others. Conversely, according to Weiner, Battles ~~&and~~ Heileman (2000), disclosure of an HIV diagnosis can also be a debilitating experience to the infected as much as learning about the initial diagnosis itself.

Derlega, Winstead, Green, Serovic, ~~&and~~ Elwood, (2004) assume that the reasons for and against disclosure by PLWH can be divided into three categories which are the self, other and relationship-related benefits and risks faced by infected. Based on their assumption, self-focused reasons for disclosure include psychological and tangible benefits. Other-focused reasons for disclosure may include educating others about HIV and protecting others from being infected with the disease. The relationship-focused reasons for disclosure entails the benefits associated with being in a close and supportive relationship. Conversely, the self-focused reasons for not disclosing one's HIV status include fear of discrimination and ostracism. Other-focused reason for disclosure includes protecting others from being upset. Relationship-focused reasons for not disclosing one's HIV status include fear of disclosing to someone whom one does not know very well. An exposition of the reasons to disclose or not to disclose are as ~~follows:-~~ follows: -

SOCIAL SUPPORT

Social support is defined in ~~many different ways~~ many ways. According to Qiao, Li ~~&and~~ Stanton (2014), whilst some definitions of social support focus on the structure of social support for example, support networks and the quality of social support for example, the satisfaction of the support, some focus on the functions of the social support for example emotional, appraisal, informational and instrumental support. Ssali et al. (2010), in their studies of reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV Care in Uganda, found that there are a number of social support factors influencing their decision to disclose their status which entail the ~~following:-~~ following: -

- to receive support including emotional, financial and material support and to be allowed to obtain treatment.
- to help others with HIV prevention including encouraging others to test for HIV, to protect others from HIV infection by encouraging condom use and educating others about HIV transmission and prevention.

- to strengthen relationship ties including being honest, faithful, loyal and supportive especially to one's partner.
- to explain changes including physical, behavioural and emotional changes (especially if one is not already on ARV treatment already).

The desire to strengthen the relationship between partners was also cited by Nkya, Davies, Nzioka ~~&and~~ Mithwani (2010) in their studies of Outcome and barriers of disclosure of HIV serostatus among infected women in Kilifi District Hospital. They found that research participants who tested positive ~~to sexual partners~~ were more likely to disclose to their stable sexual partners than to their casual sexual partners. The results are also cited by Makin et al. (2008) ~~who.~~ ~~They~~ assert that women who have been long in their relationships with their partners and those that have built their relationship on trust and love are more likely to disclose than women who are in casual relationships or women who had multiple sexual partners. In their studies of Female disclosure of HIV-positive serostatus to sex partners, Sullivan, Voss ~~&and~~ LI (2010) found that self- efficacy motivated women to disclose their HIV positive status to their sex partners. Women who had faith in their ability to know when it was safe to tell their sexual partners about their status were more likely to ~~disclose.~~ ~~report doing.~~

In their studies of Factors affecting disclosure in South African HIV-positive pregnant women, Makin et al. (2008) found that women who were married and discussed HIV testing with their husbands before taking the HIV test, were more likely to tell their partners their HIV test results. They also found that there was a connection between education and disclosure whereby a woman's education had no influence whether she disclosed or not but there was the likelihood that she would disclose to her partner if he had a tertiary education. However, Amoran (2012) found that PLWH who are educated are more likely to disclose their status to their sexual partner than those who are not. The researcher also found that PLWH who are married, who are from a monogamous type of a family, and those that know that their partners are HIV positive are more likely to disclose their status to their sexual partners. Deribe et al (2008), concurs with Amoran (2012) but in their studies found that it is not only knowing the partners' HIV-positive status that is associated with disclosure, but also knowing the ~~part~~ners' negative status is associated with HIV status disclosure.

According to Serovic ~~&and~~ Mosack (2003) men disclosed for different reasons from the ones stated above. In their studies of reasons for HIV disclosure or nondisclosure to casual partners, they found that men's reason for disclosure was that of duty. They found that men believed that it was their responsibility to tell their partners, that their partners had the right to know and to protect their partners from infection.

Arrey ~~et al., Bilsen, Lacer and Deschepper~~ (2015) found different reasons for disclosure from their studies of "It's my secret": Fear of disclosure among women living with HIV/AIDS in Belgium. They found out that participants disclosed their status because they needed to talk to someone else other than a medical professional. Other participants' reason to disclose was that they needed children. The need to have children was of paramount importance especially to those women who did not have children or pregnant at the time of their HIV diagnosis. This need was encouraged by social and cultural values of the importance of having children and being a mother despite being HIV positive. The other motivation to disclose their HIV status was to protect their loved ones or promote HIV prevention through condom use, abstinence or sticking to one partner (Ssali et al., 2010).

The need to fall pregnant also motivates woman to disclose their HIV status to their partners as well as to their health care workers Rhodes, Cu-Urin ~~&and~~ Rana (2016). Since the introduction of ART, most PLWH can live a fulfilling and productive life. HIV positive women who want children can be educated on the options available for falling pregnant without contracting the disease. They include timed unprotected intercourse, intrauterine insemination (IUI) and vitro fertilization (Rhodes et al. 2016). Timed unprotected sex refers to the procedure whereby couples have unprotected sex (without a condom) when the woman is ovulating i.e. 14 days before menstruation starts. This mostly applies when the male is the one who is HIV positive and is risky for the woman to be infected but less risky if the male partner is on ARVs. If the male partner is HIV negative, then the risks become high for him to be infected.

Intrauterine insemination can be used whereby a sample of male ejaculated semen of an HIV negative male is taken and the sperm washed to make the sample more concentrated. From there, the concentrated sample is placed in the uterus. Vitro fertilization as discussed by Rhodes et al. (2016) refers to a procedure whereby mature eggs of a female either HIV positive or negative are fertilized by a sperm in a lab. The other options explained by Rhodes et al. (2016),

are donor insemination that entails the HIV negative female partner getting a donor sperm from an HIV negative donor. The female who is HIV positive must also ~~has to be~~ educated on PMCT (which is an acronym for prevention of mother-to-child transmission) together with the importance of adhering to ARV treatment to make sure the child does not contract the disease. She must also be warned of other ways that can make the child contract the disease like breast feeding and selective caesarean section.

FACTORS INFLUENCING NON-DISCLOSURE

In their studies of “It’s my secret”: Fear of disclosure among women living with HIV/AIDS in Belgium, Arrey et al. (2015) also found that the reasons for women nondisclosure were fear of desertion, fear of emotional abuse and fear of disturbing the relationship with their partners. Derlega et al. (2004) mention the right to privacy and blaming oneself as the reasons not to disclose one’s HIV status irrespective of how one is related to the target of disclosure. Ssali et al. (2010) in their studies of reasons for disclosure of HIV status by people living with HIV/AIDS and HIV care in Uganda also found that fear of upsetting the disclosure target, fear of verbal or physical violence and fear of dismissal was amongst other reasons for not disclosing one’s HIV status. In the study of Predictors of disclosure of sero-status to sexual partners among people living with HIV/AIDS in Ogun State , Nigeria, Amoran (2012) found that substance use and self-image were barriers to HIV status disclosure. The researcher also found PLWH who have more than one sexual partner were less likely to disclose their status.

According to Rodkjaer et al. (2011), HIV/AIDS does not only affect the physical health of infected ~~individuals, but~~ individuals but tends to result in psychological and social difficulties possibly due to associated stigma and discrimination for the infected and affected. Goffman (cited in Ahmedani 2011, p.1) define stigma as “an attribute that is deeply discrediting” and belittles an individual “from a whole and usual person to a tainted, discounted one”.

He further argues that these degrading views attributed to people when their qualities or features are regarded as inferior to the general views of the ~~societies~~ society’s values. This definition implies that stigma derives from socially constructed meanings and Major and O’Brien (2005) concur and assert that stigma is socially constructed. As such, HIV/AIDS related stigma is not a corporeal thing that is tangible or material ~~thing~~ but a socially constructed view embedded in socially constructed meanings. It also includes internalised stigma, which

“happens when PLHIV begin to believe the negative things that those around them say or think” (HSRC (2015, p.9), anticipated stigma which refers to the expectation of being treated negatively in the future due to one’s HIV positive status (Turan, Budhwani, Fazeli, Browning, Raper, Mugavero, ~~&~~ Turan, (2017) and courtesy stigma which is stigma resulting from association with people living with a HIV (Florum-Smith ~~&~~ De Santis, (2012).

In the context of the current study it implies that HIV as a disease fits all qualifications for stigma ~~and also~~ include activities such as insults, gossip, violence and rejection levelled against people living with HIV/AIDS by other people. As a result, stigma tends to hamper the decision to disclose one’s HIV positive status due to these negative reactions from the community. Discrimination which is “the unfair and unjust treatment of an individual based on his or her real or perceived HIV status” (HSRC, (2015, p. 9) tends to result from the negative reactions levelled against PLWH and is also a contributing factor that leads to non-disclosure.

Furthermore, secondary stigma, that is stigma directed at family (Salter ~~et al., Go, Le Minh, Gregowski, Ha, Rudolph, Latkin, Celentano and Quan~~ (2010) also tend to hinder HIV status disclosure to families. According to research studies by Li, Wu, Wu, Jia, Lieber ~~&~~ Lu (2008) on Impacts of HIV/AIDS Stigma on Family Identity and Interactions in China, they found that HIV related stigma affected the whole family in that it brought shame to the family identity, negatively affected family relations and social networks in the community. According to the HSRC (2015), stigma and discrimination deprive PLWH of their basic human rights and worsen the impact of the disease. ~~The—Furthermore, the—~~ report also asserts that stigma and discrimination also ~~happens~~happen in relation to other forms of social stigmatisation including class-based inequalities, xenophobia, drug use and physical disabilities. “This increases both exclusion and devaluation of PLWH leading to double or multiple stigma” (HSRC, 2015, p.9). Following these revelations, disclosure is unlikely to take place for fear of stigma and discrimination.

Ojikutu, Pathak, Srithanaviboonchai, Limbada, Friedman ~~&~~ Li (2016) in their studies of Community, cultural norms, stigma and disclosure to sexual partners among women living with HIV in Thailand found that anticipated stigma and symptoms of depression, age of women and perceived community HIV stigma deterred HIV status disclosure. PLWH who had

symptoms of depression suffered from internalised stigma which hinders disclosure to sexual partners and others. They also found out that older women were less likely to disclose unlike their younger ~~child-bearing~~childbearing counterparts. Younger females still needed to bear children and advise on PMTCT. Finally, perceived community stigma which is ~~community~~community-based belief systems that devalue PLWH may also lead to nondisclosure.

Research studies have revealed that disclosure is an acute and recurrent stressor for many HIV infected individuals, regardless of ~~whether or not~~whether they choose to reveal their status or not. According to Holt, Court, Vedhara, Nott, Holmes ~~&~~ Snow (1998), it appears that disclosure is not only associated with issues of accessibility and efficacy of social support but is also related to an individual's stage of infection and state of health. Furthermore, the patterns of disclosure suggest that it may play a dual role in the infected individuals. That is, it represents a stressor while also serving as a means of accessing tangible and emotional support, which may in turn help in the effectiveness of coping and psychological adjustment to the disease.

The results of their studies of homosexual and bisexual men on the role of disclosure in coping with HIV infection were presented in three stages, which are immediately after HIV diagnosis, during the asymptomatic stage and the symptomatic stage (Holt et al., 1998). They found that disclosure was an eminent stressor immediately after the HIV diagnosis. During this stage, the majority of PLWH opt not to disclose their status while trying to come to terms with their diagnosis including denial and self-isolation. Self-isolation also offered them the time to contemplate the uncertainties relating to the reactions from others.

During the asymptomatic stage that is the stage where the HIV infected individuals do "not exhibit any of the physical characteristics of their disease" (Holt et al., 1998, p. 57), disclosure and non-disclosure ~~were~~used as ~~a~~ ~~strategies~~strategies for coping with the disease. On a personal basis, disclosure was used as a mechanism to access social support and reduce the stress related to non-disclosure while non-disclosure was used a mechanism for coming to terms with the disease before worrying about the reactions from others. On a relationship basis, non-disclosure was used as a mechanism of avoiding social relationship disruptions. Similarly, Hays, Mckusick, Pollack, Hilliard, Hoff ~~&~~ Coates (1993) in their studies reported that some of the different reasons for non-disclosure were not to worry others, fear of discrimination, fear of disrupting relationships and emotional self-protection. ~~Again~~On a relationship basis,

disclosure was used as a way of sharing responsibility for sex and it indicated intimacy and trust within a relationship.

These afore mentioned results were also reported by Nkaya et al. (2008) who found that disclosure to sexual partners strengthened the relationship. Similar to the asymptomatic stage, Holt et al (1998) found that PLWH in the symptomatic stage used disclosure as a mechanism to access social support especially as a result of deteriorating health. Physical changes in their appearance compelled them to disclose their status and as a result undermined their independence and self-esteem. They also report that fear of death also prompted PLWH to disclose their status. In the context of sexual relationships, PLWH disclosed their status to promote safe sex and strengthen partner relationships.

CONTROVERCY AROUND HIV DISCLOSURE IN SOUTH AFRICA

Disclosure of one's HIV/AIDS positive status is a very controversial issue in Africa. According to WHO (2005, p. 11), "the stigma associated with HIV/AIDS is likely to have an impact in Western Europe whereas it is much more intense in African countries and Eastern Europe". This point of view is shared by Norman et al. (2007) who indicate that levels of HIV/AIDS disclosure are low especially in developing countries like South Africa due to the role of stigma. They assert that Africans are more traditionally and culturally inclined and more concerned about secrecy and confidentiality where HIV/AIDS is concerned for fear of stigma and ostracism by the community. Disclosure can have a devastating effect on PLWH due to stigma surrounding HIV/AIDS in black communities for example the case of Lona Malafane who was raped and then murdered after disclosing her status to her attackers in Khayelitsha outside Cape Town (<http://www.theguardian.com/world/2003/dec/22/southafrica.aids>).

According to Kalichman &and Simbayi (2004), traditional beliefs about the cause of HIV/AIDS are rooted in spiritual, supernatural and witchcraft which are seldom spoken about by the community. They recognise immediate cause and ultimate cause of a disease or misfortune and attribute it to other spiritual, supernatural powers or witchcraft. These traditional beliefs about the cause of HIV/AIDS are in some instances related to issues around stigma within the South African context. Attributing HIV infection to witchcraft and concealing the fact that their loved one died of HIV/AIDS related diseases may be another way of helping the bereaved family to avoid feeling stigmatised and ostracised by the community. The case in point is the story of

Fana Khaba also known as DJ Khabzela. He was a Johannesburg Radio DJ who rejected HAART that is Highly Active Antiretroviral Therapy and died after unsuccessfully looking for another alternative treatment. His death was attributed to witchcraft and his fiancé Sibongile was blamed for it (McGregor, (2005).

PSYCHOLOGICAL EFFECTS OF HIV STATUS DISCLOSURE

The psychological response to an HIV diagnosis can have far reaching consequences whether one has disclosed or not disclosed one's HIV positive status. Fear of stigma and discrimination can induce psychological distress and lead one to isolation especially if one has not disclosed one's HIV positive status. According to Fabianova (2011), the psychological distress can in turn result in feelings of anxiety, low self-esteem guilt feelings, denial, anger, aggression and suicide behaviour. Feelings of anxiety that entail uneasiness or nervousness associated with the disease are often experienced by PLWH. These feelings are a result of among other things, the risks of being infected with other opportunistic diseases, the risks of infecting sexual partners and concerns over privacy and disclosure issues (Fabianova, 2011). According to Sadock, Sadock & Ruiz (2015) depression which is noticeable by feelings of guilt, shame, blame, fatigue and worthlessness is often experienced by PLWH when they are at their weakest that is after the initial diagnosis and when they are ostracised by their targets of disclosure. These feelings that may stem from the fact that HIV is usually associated with socially unacceptable activities like prostitution, homosexuality and drug use, coupled with stigma from the community, makes it difficult for PLWH to disclose their status and predispose them to suicide. There are also guilt feelings about what the disease will mean to the family of the infected especially their children (Fabianova, 2011).

Self-esteem which is defined as “the ability to appreciate oneself and treat oneself with dignity and love” (Fabianova, (2011, p. 117) is often threatened. The possibility of being rejected by friends, colleagues and family can lead to loss of self-esteem, loss of confidence and loss of a sense of social identity. Self-esteem is also lowered as a result of the changing physique of the HIV infected individual and his diminishing strength.

Denial, anger and aggression characterise people infected with HIV especially those who have not dealt properly with the initial diagnosis (Fabianova, (2011). He asserts that some HIV infected individuals often deny their status and can lead to poor management of the disease.

However, Van Dyk (2012), postulate that denial can be a protective mechanism in dealing with HIV diagnosis because it reduces emotional stress and helps HIV infected individuals a chance to relax and recuperate from the emotional trauma. Denial especially at the time of the diagnosis could assist the diagnosed individual to cope with the initial shock of the diagnosis as acceptance may not happen immediately.

Furthermore, Fabianova (2011) states that PLWH are often angry and aggressive. They are often angry with themselves because of contracting the disease, angry at those who infected them, not knowing what the future holds for them, angry with others because they feel they are not treated fairly enough by the society and anger is often followed by aggression in frustrating situations and may be directed at suitable targets.

The experience of depression also makes it difficult for one to cope and manage the disease and this in turn can result in non-adherence to antiretroviral treatment (Visser, Mundell, deVilliers, Sikkema, & Jefferys (2005). According to Visser et al. (2005), disclosure can reduce the devastating effects emanating from non-disclosure of HIV status diagnosis. Disclosure can also lower stress levels and contribute to better psychological health (Deribe, et al., 2008). Disclosure can also help one to seek support in accessing medical treatment, social support and cope with living with the disease (Visser et al. (2005).

THEORIES OF DISCLOSURE

Serovich, Craft & Yoon (2007) explain the motivation for disclosure from ~~three~~ theoretical approaches, the disease progression theory, ~~and~~ the competing consequence theory and communication privacy management theory.

THE DISEASE PROGRESSION THEORY

The disease progression theory is based on the assumption that the HIV positive person disclose his/her status 'when HIV progress to full-blown AIDS, making it impossible to hide one's status i.e. when one become symptomatic' (Serovic, Lim & Mason, 2008, p. 2). During this stage, physical signs and symptoms of their illness begin to appear. At the psychological level depression including affective symptoms (anxiety and apathy) and cognitive symptoms (suicidal thoughts and guilt) characterize the infected individuals. Finally, hospitalization of the HIV/AIDS infected individuals. In this situation the infected individual with opportunistic

diseases like TB and pneumonia will need treatment, care and support. The specific type of support also plays a role in the disclosure process. Economic support is important for PLWH who are dependent on others for their daily subsistence.

Based on the research findings by Almeleh (2006), PLWH are motivated to disclose to their significant others so that they know the appropriate treatment for HIV specific illness. ~~According to social exchange theorists stated in Maman et al. (2014, p. 5), 'people maximize the profits of their relationships by avoiding those relationships that will cost them the most socially, emotionally or otherwise, and they seek out relationships that will maximise those dimensions'. Using this approach to their research, they found out that 'PLWH weighed the anticipated costs and benefits when deciding whether or not to disclose to their family' (Maman et al., 2014, p. 5). This situation of reducing risks and increasing benefits motivates PLWH to disclose to their selected recipients.~~

THE CONSEQUENCE THEORY

Contrary to the linear disease progression theory, the consequence theory ~~is based on the assumption~~ assumes that 'disease progression influence disclosure through individuals' perception of the consequences anticipated as a result of disclosure' (Serovic et al., 2008, p. 24). The HIV infected individual evaluates the risks and benefits of disclosing his/her status and then disclose accordingly. According to research results by Serovic et al. (2008), the cost for disclosing their HIV positive status, women are potentially at risk to threat of violence and can provoke feelings of anxiety. Stigma, discrimination and ostracism are some of the costs that would deter PLWH to disclose their HIV status. The benefits or positive rewards include the acquisition of emotional resources for example relief from sharing a home-related chore.

According to social exchange theorists stated in Maman et al. (2014, p. 5), 'people maximize the profits of their relationships by avoiding those relationships that will cost them the most socially, emotionally or otherwise, and they seek out relationships that will maximise those dimensions'. Using this approach to their research, they found out that PLWH weighed the anticipated costs and benefits when deciding ~~whether or not~~ whether to disclose to their family. This situation of reducing risks and increasing benefits motivates PLWH to disclose to their selected recipients.

Based on his research studies, Almeleh (2006, p. 17), found that the motivation for disclosure was 'access to health-related social support (socially-focused)'. Educating others about HIV/AIDS entails countering misconceptions that lead to stigma and discrimination around the relationship between HIV/AIDS and health (Van Dyk, 2012). Educating others was mostly done by PLWH who have not experienced opportunistic infections, who were diagnosed while pregnant, while others were on ARV's or on PMTC. The other motivation to disclose their HIV status was to protect their loved ones or promote HIV prevention through condom use, abstinence or sticking to one partner (Ssali et al., 2010).

COMMUNICATION PRIVACY MANAGEMENT (CPM) THEORY

The communication privacy management theory ~~explain~~explains the way people make decisions about revealing or concealing private information about themselves (Petronio, (2004). She believes that privacy is important to understanding disclosure and views disclosure from two aspects that are content and process. Content refers to the private information to be disclosed. In the current study, it refers to HIV-positive status. The process describes how the information is disclosed. In the current study, it is demonstrated by identification of initial reasons for HIV testing, initial reactions to disclosure and outcomes of disclosure.

According to Kennedy-Lightsey, Martin, Thompson, Himes ~~&and~~ Clingerman (2012), the CPM theory is described as consisting of privacy boundaries whereby individuals believe they own their private information and have a right to control whether the information is revealed as well as to whom it is disclosed to. Consequently, once the information is shared with ~~the~~ the recipient or target of disclosure, the owner of the information no longer ~~have~~has sole control over its dispersion. Co-owners of information explicitly or implicitly coordinate privacy boundaries and make the same choices as the owners about who gets access to the private information. However, it becomes difficult sometimes for co-owners to manage other people's privacy boundaries and as a ~~result privacy management breakdowns~~ result privacy management breakdown occurs which Petronio (2004) calls privacy turbulence. According to Greene, Yep ~~&~~ Petronio (2003), people develop privacy rules that are based on five criteria in order to decide whether to disclose or conceal their private information. The criteria are culture, motivation, gender, context and risk benefit.

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Culture

The CPM theory postulates that culture is important in developing privacy rules. Cultural expectations may affect and influence disclosure decisions. According to Maile (2003), talking about sex is probably a taboo in most African cultures. The taboo applies mostly to infected younger people who cannot freely talk to adults about sexual issues. Furthermore, women have been socialized into a culture that supports silencing of their thoughts, feelings and needs (DeMarco, Miller, Patsdaughter, Chisholm & Grindel, 1998). As a ~~result~~ result, women are unlikely to disclose their HIV status due to the societal expectations that discourage freedom of expression.

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The motivations people have regarding privacy have an important influence on ~~whether or not~~ whether they will disclose their private information. Personal needs, achievements and goals ~~are~~ can influence privacy rule making. —Owners of information can form ~~particular relationships~~ relationships that can lead to disclosure of private information to the confidante. For ~~example~~ example, PLWH who are motivated to disclose for emotional and psychological support.

Context

Traumatic events can disrupt the influence of culture and motivation when people construct their rules for privacy. The diagnoses of HIV, natural disaster, sexual abuse are some of the traumatic events that can lead one to craft privacy boundaries that are initially inaccessible to anyone. The owners of information first struggle to cope and later may talk about their experiences when they are ready to do so.

Gender

Gender and sexual orientation also have an influence on whether one will reveal or conceal one's private information. Popular knowledge suggests that women disclose more than men do, yet research on this issue is inconclusive as to which gender disclose more than the other. In their studies of gender differences in HIV status disclosure among HIV positive service users, Deribe, Woldemichael, Bernard ~~&and~~ Yakob (2009) found that there was no substantial difference among men and women in relation to HIV status disclosure. In contrast, a study on self-

disclosure of HIV serostatus in recently diagnosed patients in South Africa, found that being male was associated with non-disclosure of HIV status (Olley, Seedat, & Stein, 2004).

Risk/benefit

The risk/benefit criterion describes how owners of private information assess the risks relative to the benefits of disclosure. For ~~example~~~~example~~, if the risk of violence, ostracism, stigma and discrimination is too high, disclosure may be withheld. However, if the perceived benefits for example gaining social support and stress relief outweigh the risks, then disclosure is likely to follow. As a result, the risk and benefit are taken into consideration when one decides whether to disclose or not to disclose one's HIV positive status.

According to CPM theory, PLWH uses the ~~above-mentioned~~~~above-mentioned~~ criterion when deciding whether to disclose or not to disclose their private information, that is their HIV positive status.

THE IMPACT OF DISCLOSURE

According to Bravo et al. (2010), PLWH are very cautious in their interpersonal and social relationships and often withdraw from their social networks. They tend to avoid social contact for fear of stigma and ~~discrimination~~~~discrimination~~, and this leads to low self-esteem and self-isolation. Maman et al. (2014) and WHO (2005) indicate that family members are often the targets of disclosure. However, black familial structures do not always conform to Western familial structures of an urban self-contained nuclear unit Khan (2005). Black African familial structures often include extended family members including grandparents, uncles and aunts. Based on research results of his studies, Almeleh (2006, p. 18) found that 'the most common disclosure recipients ~~was~~~~were~~ the HIV positive person's mother'. This is ~~due to the fact that~~~~since~~ after being looked after so long by kin and household members, one feels obliged to tell them about one's HIV status. As a result, one can rest assured that one will receive social support after disclosure to the family.

In their studies of Psychological trauma following disclosure to significant others in women living with HIV and AIDS, Atibioke, ~~&~~~~and~~ Osinowo (2013), found that there were negative consequences after disclosure to significant others. These include stigma and discrimination, ostracism, loss of employment, verbal abuse and family or marriage disruptions.

As a result of these consequences, participants experienced psychological trauma including low self-esteem and self-isolation which impacted negatively on their health status.

According to research studies cited by Ojikutu et al. (2016), anticipated stigma has demonstrated that fear of discrimination leads to psychological pain, reduced quality of life and reduced management of medical treatment. This in turn can lead to non-disclosure of one's HIV positive status. The study of factors related to HIV disclosure in two South African communities by Norman et al. (2005) found that PLWH who had successfully disclosed their status regained their freedom that was taken from them by their HIV positive status and family support empowered those who disclosed to them to cope with their financial and emotional challenges. They also found that disclosure increased opportunities to access to social and material resources that are important in alleviating the effects of HIV on one's life.

According to WHO (2005) affected significant others experience more or less the same psychosocial emotions as do their HIV positive infected family members after disclosure of HIV positive status. These emotions include feelings of loneliness, helplessness, anger and depression. Van Dyk (2005) further mentions the following as having an impact on the lives of the affected others by HIV infected individuals:

- Affected others anticipate the loss of having an HIV infected member and issues of loss are introduced in the relationship exacerbating an already depressed family.
- Affected others often suffer as a result of untimely death. This applies mostly to people who are young (i.e. between the ages of 20 and 35). This leads to a situation whereby parents outlive their children and grandparents having to take care of their grandchildren.
- Since disclosure has its pros and cons, affected others are sometimes shocked by the news. They may either opt to care and support the infected others or reject the significant other because of stigma surrounding the disease.
- Affected others ~~must often often have to~~ play the role of care giver which they are neither prepared for nor trained for. This can be a stressful and strenuous effort and depending on the relationship between the infected and affected, the affected can either endure the difficulties until the infected get better or abandon the infected individual.
- Deterioration of mental functioning of the infected individual can hasten the grieving process for fear of losing their loved one.

- In many African societies, talking about sex related issues is still a taboo and children are excluded from discussions surrounding HIV. Children very often see and hear everything about their loved ones but never get the opportunity to ask nor talk about their parents' plight.

BASIC RIGHTS, ETHICAL GUIDELINES AND HIV STATUS DISCLOSURE

According to the Bill of Rights stipulated in the Constitution of South Africa (1996), every South African citizen has the right, among others, to dignity, equality, non-discrimination, privacy, access to health care, the right to social security and social grants, the right to labour practices and the right to confidentiality. No citizen, as such, should be unfairly discriminated against on the grounds of HIV status including race, sex, marital status and religion.

THE RIGHTS OF PEOPLE LIVING WITH HIV/AIDS

The Basic Rights of PLWH prescribe that PLWH should have the same rights as those that apply to all the citizens of the country, Health for men staff (2015). The Constitution protects people's rights to privacy and there are no laws in South Africa that force PLWH to tell their partners about their HIV status. PLWH face many kinds of discrimination, stigma and victimisation which may lead to non-disclosure of their status (Barrett-Grant, Fine, Heywood & Strode, (2003). They face a lot of discrimination from employment opportunities, insurance policies, medical aid schemes, victimisation at work and school and their status is often disclosed without their consent.

ETHICAL GUIDELINES ON HIV DISCLOSURE AND NON-DISCLOSURE AMONG HEALTH CARE WORKERS

According to HPCSA (Health Professions Council of South Africa) (2008), Guidelines for good practice in the health care professions which refers to the –Ethical guidelines for good practice in the health care professions, a patient's HIV-positive status should be treated as confidential. Confidentiality regarding a patient's HIV status also extends to other health care practitioners. Health care professionals may not be informed of a patient's HIV status without the patient's consent. Concerning partner disclosure, the HPCSA stipulates that health care professionals should encourage their HIV positive patients to disclose their status to their sexual partners in order to let them undergo voluntary counselling and testing (VCT). If the patient refuses to tell his partner, then, the health care practitioner can use her discretion whether or not

to tell the patient's sexual partner. When deciding whether to tell or not to tell, the health care practitioner should take into consideration the possible risk of HIV infection to the patient's sexual partner and the risks to the patient for example ostracism. The decision must also be made after taking the rights of both parties into consideration. If the health care practitioner decides to divulge the information against the patient's wishes, the health care practitioner can go ahead after informing the patient of his intentions and accept full responsibility of the ultimate consequences.

According to Barrett-Grant et al. (2003), not even the family has the right to know the patient's HIV status although the health care practitioner should inform the patient of the importance of disclosure. The health care practitioner should also inform the patient that his members of the family or next of kin may acquire access to his medical records after his death.

The legal and ethical requirements and considerations of the HIV-positive person further confound HIV disclosure. The HIV infected individual has the right to keep his HIV-positive status confidential, and it is also the health care practitioners' responsibility to keep the HIV-positive person's status confidential. Conversely, health care practitioners have the responsibility to warn sexual partners or significant others of an infected person where there is a risk of transmission and as such, they have to divulge the information. As result, the health care practitioner and the infected individual find themselves in a predicament.

CONCLUSION

According to results of the literature reviewed, stigma and discrimination associated with HIV/AIDS positive status promotes non-disclosure and unsafe sexual behaviour that leads to the spread of the disease. There seems to be both advantages and disadvantages in disclosing one's HIV positive status. However, the need for one to disclose his/her HIV positive status has the added advantage of getting social support, accessing medical and social care and reduction in mortality rates and number of orphans.

CHAPTER 3

RESEARCH METHODS AND DESIGN

The chapter introduces and explains the methodology used in conducting the study. The methodological aspect of the study including research design, sampling technique, data analysis trustworthiness of the study and ethical considerations during research are discussed.

RESEARCH SETTINGS AND CONTEXT

The study was conducted among a population of PLWH attending a support group organised by the Tshwane Multisectoral AIDS Response Unit under the Department of Health at, Thusong Learning Centre, Atteridgeville, Pretoria. The support group was chosen as a population base because the researcher is a volunteer worker for the unit. The unit functions as multisectoral AIDS response programme to different types of health and social related challenges faced by the community and offers assistance through support programmes, referrals and government aid.

While doing door-to-door peer education with other peer educators contracted by the unit Tshwane Multisectoral AIDS Response Unit, the researcher noticed that the community members who were HIV positive had conflicting ideas whether to disclose or not to disclose their HIV positive status. The decision whether to tell or not to tell was influenced by the ability to benefit from among other things, social grants and accessing home base care services and the negative consequences of being stigmatised and discriminated against.

Those that had the courage to tell were invited to join the support group to share their experiences of living with HIV.

~~THEORETICAL PARADIGM~~ heoretical Paradigm

According to Terre Blanche et al (2006, p. 562) a paradigm is an “all-encompassing system of practice and thinking, which defines for researchers the nature of their enquiry ~~i.e. that is,~~ those things that can be taken for granted about the social world they are studying and the correct ways of going about studying it”. It is a framework that guides the research and the researcher to use ~~particular methods~~ methods of observing social phenomena under study. As a result, the

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proposed study will employ social constructionist framework to explore the narratives of HIV status disclosure by people living with HIV.

THE SOCIAL CONSTRUCTIONIST FRAMEWORK **he Social Constructionist Framework**

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Social constructionism is essentially concerned with explaining the process, by which people come to describe and explain the world in which they live (Harris, 2006). Social constructionism is centred on the view that in the process of perceiving and describing an experience, we construct not only our personal knowledge base about reality but also our own reality (Becvar and Becvar, 2006). From a social constructionist's perspective, individuals will attach different meanings to similar experiences. It is these differences in meanings that constitute different realities. Individuals may attach more than one meaning to an experience, which contributes to the notion of multiple realities (Harris, 2006).

The social constructionism epistemology assumes that an individual's reality arises from meanings that develop within a historical, social, and community context (Harris, 2006). Although the focus of the proposed study will be on the individuals living with HIV, it is important to remember that the individual is part of a specific context, in which they interact with other family members, the community and culture (Cunliffe, 2008). The researcher will view participants within their network of relations in an attempt to understand their experiences of living with HIV. In this way the researcher as a social constructionist believes life experiences cannot be studied out of context. One of the aims of the proposed study is to understand the experience of disclosure within the context of their relationships with significant others and the specific meanings attached to disclosure by society and culture within which people living with HIV are located. For the purpose of this study, the focus is on how meanings develop within a social, historical and community context affect meanings attached to HIV status disclosure.

Freedman and Combs (1996) developed the narrative social constructionist approach. The researcher identifies with this specific approach and made use of it to understand the personal experiences of individuals living with HIV's experience of disclosure to significant others. Freedman and Combs (1996) emphasise that there are no essential truth and that reality is

socially constructed, constituted through language, organized, and maintained through stories. These four basic ideas of social constructionism are discussed next.

There are no essential truths

One of the main objectives in social constructionist is to interpret experience. There are many possibilities for how any given experience may be interpreted (Freedman & Combs, 1996). Social constructionist thinking is fundamentally postmodern in that the individual's meanings and realities are viewed as constructed and not as absolute truths Harris (2006). The individual is viewed as the expert in his or her life and social constructionist thinking focuses on stories based on a person's lived experience, rather than on expert knowledge Cunliffe (2008). There are no essential truths

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Realities are constituted through language~~One of the main objectives in social constructionism is to interpret experience. There are many possibilities for how any given experience may be interpreted (Freedman & Combs, 1996). Social constructionist thinking is fundamentally postmodern in that the individual's meanings and realities are viewed as constructed and not as absolute truths Harris (2006). The individual is viewed as the expert in his or her own life and social constructionist thinking focuses on stories based on a person's lived experience, rather than on expert knowledge (Cunliffe, 2008).~~

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Freedman & Combs (1996), state that language is the most essential system through which humans construct reality. According to them, language tells us how to see our world as well as what we see within it. The social construction of reality is an on-going, dynamic process that is reproduced by people acting communicating on their interpretations and their knowledge of it.

~~Realities are socially constructed~~ **Realities are socially constructed**

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The social construction of reality describes how ideas, practices and beliefs come to have a reality status in a given social group (Freedman & Combs, 1996). Our realities, consciousness and ways of interacting with one another are socially constructed through our shared language, attitudes and ideas.

Realities are organised and maintained through stories~~Realities are organised and maintained through stories~~

Narratives or stories are essentially shared activities. Knowledge can be seen as that which is represented in linguistic propositions, rather than something that people possess in their heads. The social constructionist framework proposes that people live their lives according to

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stories or narratives that are embedded within the available cultural discourse (Freedman & Combs, (1996). The social constructionism epistemology is thus essentially about relationships. It focuses on the collective and communal aspect, but also on the individual's experiences within a context. It sees events as relational rather than ~~internal, and~~ ~~internal and~~ involves the creation of meaning in community with others (Hoffman, (1990). The context of people living with HIV is pivotal, and their perceptions of their reality cannot be viewed in isolation from their context. According to the researcher, social constructionism is appropriate in providing an understanding of the personal experiences people living with HIV's experience of disclosure to significant others.

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RESEARCH DESIGN

Terre Blanche et al. (2006, p. 563) defines research design as 'a strategic framework or plan that guides research activity to ensure that sound conclusions are reached'. The researcher believes that the qualitative approach is appropriate for ~~in~~ studying the experiences and understanding of PLWH with regards to disclosing their status to significant others.

QUALITATIVE APPROACH

The 'qualitative approach seeks to preserve the integrity of narrative data as an attempt to use the data to exemplify unusual or core themes embedded in context' Terre Blanche et al. (2006, p. 563). The qualitative approach is suited in the phenomenon because participants will be able to describe their experiences and help the researcher to interact and get an in-depth understanding of what people think about particular issues. Qualitative research tries to study phenomena in its naturalistic setting and interpret it in terms of the meaning people bring to it. The aim of qualitative research is to interpret and understand people's meaning of their daily experiences (Creswell, (2013). This approach attempts to describe the meaning of experience of a phenomenon, events or topic by research participants.

According to Becvar ~~&and~~ Becvaer (2006), in qualitative research, the researcher refrains from being an expert and become a co-constructionist in creating new meanings of understanding during the interaction with the participant. It is during the research, that the participants share their experiences with the researcher and the researcher drawing upon his own experience and knowledge in conducting the research that the possibility of influencing the

results of the study may occur. The researcher should acknowledge his experiences and knowledge about the observation made in order to avoid control over co-creator of new meanings of reality. The researcher believes that the qualitative approach which focuses on listening and understanding participants' perceptions and their role within the disclosure context, is appropriate to study participants narratives of HIV status disclosure.

POPULATION

Terre Blanche et al. (2006, p. 133) define population as 'the largest part from which our sample is drawn'. In our study, the target population is made of participants living with HIV and attending the support group at the Tshwane Multisectoral AID Response Unit in Atteridgeville. Both males and females between the ages of 15 and 49 living with HIV/AIDS, living with their families and disclosed their status to their significant others are eligible to participate in the study. The age grouping is in accordance with UNAIDS (2010) that the general population mostly affected worldwide is between 15 and 49.

SAMPLING

According to Terre Blanche et al. (2006) a sample is the research participants that are going to be included in the study that is drawn from the population and to which we want to generate our findings. Purposive sampling which entails the selection of specific readily available people from the population who are known to the researcher and anticipate that they would provide the type of information required for the study. The researcher will use purposive sampling since he knows the members of the support group and believe that they would provide the type of information necessary for the study. The number of participants to be used in the ~~study was~~ study was 5.

According to Creswell (2013), qualitative sample size should be large enough to obtain enough data to adequately describe the phenomenon of interest. The researcher opted to use only 5 participants as the number is enough to describe the disclosure to significant others.

Those that are eligible to be included satisfied the following criteria:

- Between the ages of 15 and 49
- Male and female
- Living with family

- Having disclosed to their family members and
- Belonging to the Multisectoral AIDS Response Unit support group based in Atteridgeville

DATA COLLECTION

Semi-structured In-depth interviews were used to collect information in the current/proposed study. 'In-depth interviews are optimal for collecting data from an individuals' personal histories, perspectives and experiences, particularly when sensitive topics are been explored' (Mack, Woodson, Mcqueen, Guest & Namey, (2005, p. 2). In-depth interview offers the researcher the opportunity to ask probing questions and thereby elicit participants' personal feelings and experiences as well as addressing sensitive issues. It also helps the researcher to clarify questions and enhance better understanding of the topic at hand. In the current study, In-depth interview assisted the researcher to gain better understanding of the experiences of the participants living with HIV associated with disclosure to their significant others. The researcher was the primary data collection tool guided by a list of questions in the form of semi-structured interviews. With the permission of the participants, the researcher used a tape recorder to capture the contents of the interviews and field notes were made to capture the non-verbal information. Field notes would also helped the researcher if the tape recorder should fail or when participantss ask the researcher to turn it off in order to divulge information that he/she will not want to be recorded (Mack et al., (-2005).

DATA ANALYSIS

Data collected from each participant was analysed using Thematic content analysis i.e. "the study of recorded human communication" Babbie (2013, p. 295). The researcher transcribed recorded interviews verbatim into written text to prepare for data analysis. All participants were proficient in English and interviews were conducted in English. Some were not that fluent and as such these interviews took place at a slower pace. According to Braun and Clærke (2006), a theme describes salient features about the data in relation to the research question and represents some meaning to the data. They mention six phases of data analysis which do not follow a linear process whereby the researcher can move from one phase to the other. The process can be circular whereby a researcher can move back and forth as required throughout the phases. The six phases are discussed below:

Phase 1: Becoming familiar with the data

The first phase of thematic data analysis entails familiarising oneself with the data. After the interview with the participant, the researcher would listen to the recorded interview and transcribe the recorded interviews into writing especially if the interviews did not need to be translated into English. The researcher should familiarise and immerse himself with the data collected by reading, re-reading, revising the text and listening to the recorded material. Then the researcher must read through the data and take notes that came to mind and helped in identifying possible themes and patterns.

Phase 2: Generating initial codes

The second phase is generating initial codes. This process involves generating a list of items that have a recurring pattern. It is also important to note that the coding process evolves through an inductive analysis and is rarely completed the first time as codes emerge throughout the research process.

Phase 3: Searching for themes

The third phase begins by examining how codes combine to form prevailing themes in the data. This phase entails searching for potential themes among all coded data extracts within those ~~singled-out~~ singled-out themes. Visual representations like mind maps and tables were used to sort-out codes into potential themes.

Phase 4: Reviewing themes

During this phase potential themes are reviewed and refined. While some themes were discarded, some were merged with others and others were edited into smaller sub-themes. The aim was to ensure that the themes and the data formed a coherent pattern.

Phase 5: Defining and naming themes

The analysis at this stage was characterised by identifying which aspects of data was being captured, what was being captured, what was interesting about the themes and why the themes

were interesting. The themes were defined according to the meaning they held for the participants and the relationship they had with one another.

Phase 6: Producing the report

Phase six involved writing the final report. The goal at this phase was to convey the complicated story of the data and present it in a clear, concise and logical manner.

In this study common concepts of everyday life will be identified and examined in relation to the context, meaning and circumstances surrounding disclosure of HIV positive status to significant others.

TRUSTWORTHINESS OF THE STUDY

Trustworthiness refers to the extent to which qualitative research can be regarded as valid and reliable just like in quantitative research (Polit & Beck, (2006). They make use of five criteria to assess trustworthiness of a qualitative research study that is credibility, dependability, transferability, confirmability and authenticity.

CREDIBILITY

Credibility refers to ‘the confidence in the truth of the data and interpretations of them’ Polit & Beck (2006, p. 4-92). In the current study, the researcher described and explained the study setting and context, the population and sample, literature review, data collection and data analysis to make sure that the study is sound.

DEPENDABILITY

According to Polit & Beck (2006, p. 4-92), dependability refers to ‘the stability (reliability) of data over time and over ~~conditions~~ conditions’. The research study should be conducted in such a way that if other researchers should investigate similar research topics, the researcher must find similar results (Guba & Lincoln, (1989). In the current study of HIV status disclosure to significant others, perceptions and experiences may change over time due to the advances made in the treatment of the disease. Antiretroviral treatment and healthy living may also influence HIV infected individuals’ decisions to disclose their status over time.

TRANSFERABILITY

Transferability refers to ‘the extent to which qualitative findings can be transferred to (or have applicability) to other settings or groups’ (Polit & Beck, 2006, p. 492). However, according to Terre Blanche et al. (2006), it is difficult to generalise findings or settings in qualitative research. One way to solve or counter the difficulty is for the researcher to give a detailed report on the research process, reasons for the choices in methods and detailed description of the research context. Another way to counter the problem is triangulation which refers to ‘the multiple perspectives against which to check one’s own position’ (Terre Blanche et al. 2006, p. 380). Triangulation can be achieved using triangulation, investigator triangulation, theory triangulation and methodological triangulation. In the current study two data collection methods were used, that is in-depth interviews and field notes to achieve triangulation.

CONFIRMABILITY

According to Polit & Beck (2006, p. 492), confirmability refers to ‘the objectivity, that is the potential to congruence between two or more independent people about the data’s accuracy, relevance or meaning’. This implies that the findings of the study are not the researchers’ own bias. To avoid the researchers’ own bias in the study or in the interpretations of the respondents’ data in the current study, the researcher will acknowledge and include his own ideas, which can influence the research findings in the form of a reflective diary in reporting the results.

AUTHENTICITY

Authenticity refers to ‘the extent to which researchers fairly and faithfully show a range of different realities’ (Polit & Beck, 2006, p. 493). In the current study, the researcher includes direct quotations from participants’ interviews and non-verbal cues during data analysis and results interpretations.

ETHICAL CONSIDERATIONS

VOLUNTARY PARTICIPATION

Voluntary participation occurs when participants in a research study take part on their own free will and knowing the benefits and risks of their involvement in the study. The researcher informed the participants of their right to opt out of the study should they wish to.

INFORMED CONSENT

Participants were given written consent forms explaining the nature of the research, risks and benefits. They were also informed of the reasons of the study and how the information collected would be used. All this information was given to participants before the interview.

ANONYMITY AND CONFIDENTIALITY

Anonymity is guaranteed when participants' personal details are not included in the study. Participants are given pseudo names to protect their identity. Only demographic details such as age and relationship status will be included in the study. Confidentiality occurs when participants are assured that their private ~~information~~information, they divulge to the researcher will not be disclosed publicly.

INFORMED CONSENT

Participants were given written consent forms explaining the nature of the research, risks and benefits. They were also ~~be~~ informed of the reasons for conducting the study and how the information collected would be used. All this information was given to them before the interview.

~~Anonymity and confidentiality~~

Participants were assured of the security of their well-being. The researcher also informed them of how the study will benefit them directly and indirectly and how it will benefit the community at large. According to Norman, Chopra ~~&and~~ Kadiyala (2007), understanding the issues about HIV positive status disclosure can lead to effective public policy.

~~NON-MALEFICENCE~~NON-MALEFICENCE

The researcher must ensure that no harm befalls research participants as a result of participating in the research study. Since disclosure of HIV positive status is a very sensitive topic, participants were provided with professional counselling by a clinical psychologist from the University of South Africa should they need it. Respecting participants' autonomy, allowing voluntary participation and maintaining anonymity and confidentiality are acts of non-maleficence. In the current study, none of the research participants needed professional counselling during interviews even though they were informed of the availability of a professional counsellor should they need it.

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PERMISSION

Before the research can commence, permission to conduct the study ~~was~~^{is} requested from the Director of the Tshwane Multisectoral AIDS Response Unit and ethical clearance ~~was~~^{is} sought from UNISA's ethics committee.

CONCLUSION

This chapter described the methodology to be employed during the study. The research design, population, sampling methods, data collection methods, data analysis methods that ~~were~~^{are to be} used in the proposed study were described. Trustworthiness of the study and ethical issues were also discussed.

CHAPTER 4

DATA ANALYSIS AND PRESENTATION OF RESULTS

This chapter presents the analysis and findings from the study. The chapter begins by presenting ~~plot testing and~~ the biographical details of the participants. This is followed by data analysis, tabulation of themes, identification of categories and subcategories as well as discussions of findings of the study.

PILOT TESTING

The participants were selected according to the criteria specified in chapter 3. A brief description of each of the participants is given and pseudonyms are used for the purposes of confidentiality and anonymity.

Participant 1- Kate is a 46-year-old ~~woman~~~~lady~~ who is employed as a contract worker. She is married under customary law and has three children. She learned of her HIV positive status in 1996. She was always sick and consulted numerous doctors for help. She was given medicine which would help her for some time and then fall sick again. She finally tested for HIV and was told she was positive. Her former partner who learned of his status before he tried to rape her virgin daughter with the hope of getting rid of the disease, passed away as a result of the disease. She informed her current husband of her status. He accepted and did not reject her. Her husband has not tested for HIV. The first two children are from the previous relationships before she got married. After getting married she got pregnant and she went for PMTCT and her son is HIV-negative. They are now using condoms whenever they have sexual intercourse. Kate says it is important to disclose to at least one person. She says one should not keep one's status to oneself so that one should get help when needed. She says one should at least trust one person who would care for one in the time of one's distress.

Participant 2- Jane is a 36-year-old ~~woman~~~~lady~~ who is employed as a contract worker and a single parent. She learned of her HIV positive status in 2007. She learned of her HIV-positive status when she went to the clinic for a bad cough. She also learned that she was pregnant. She was traumatized but received counselling from the clinic. She went home and disclosed to her mother and grandmother. They accepted her and told her that as long as she has been counselled and taking her medication there was no problem. She said she always used ~~ds~~ condoms whenever

she had^s sexual intercourse. She said one of the reasons she disclosed her status was that she could not keep a secret and as a result wanted to relieve the burden of carrying a secret. She said if one want^{eds} to disclose one's HIV-positive status, then it is fine, but if one did^{oes} not want to disclose one's HIV-positive status then let one be allowed to keep it secret. However, she said the problem in keeping the matter to oneself is that one will not have peace and one will not take one's medication correctly. She said disclosure would help one to relieve the burden of keeping a secret.

Participant 3- Sue, who is unemployed, is a 36-year-old single ~~woman~~mother of two. She learned of her status in 2002. She learned of her HIV-positive status when she was pregnant at the clinic. When she was diagnosed, she did not have any opportunistic diseases that needed medical attention. The first person she disclosed her status to was a nurse she used to work with who in turn advised her to disclose. She first disclosed to her aunt who cried bitterly and thought she was going to die but did not reject her. She then disclosed to her mother who was already told by her aunt. He mother was not supportive. She had a problem in telling her youngest daughter. She had to pray and prepare herself before telling her. Her daughter accepted her and did not reject her. She said she had to prepare herself because she wanted her child to love her and support her. She did not have a problem in disclosing to friends because she did not care what they would say about her. She said it will depend on who you disclose your status to. She said if it is family one should prepare oneself because one does not know if one is going to be rejected or judged.

Participant 4- Sam is a 49-year-old unemployed single man. He learned of his HIV-positive status in 1999. He was admitted for TB when he was diagnosed with HIV. In those days ART was not available for PLWH. He was discharged and then readmitted again for Multi Drug Resistant (MDR) TB. He is currently living alone. He said he used to love women and never used condoms. He said he did not use condoms because he believed he would never contract HIV since he was having sexual intercourse with beautiful women only. He is currently not involved in a relationship. Although he uses condoms whenever he has sexual intercourse, he is no longer interested in steady relationships. The first person he disclosed his status to was his friend. She accepted and comforted him. He then disclosed to his mother who accepted him. He said he does not have any problem in disclosing his status to anyone.

Participant 5- Liz, who is unemployed, is a 48-year-old ~~woman~~^{lady} who is a single mother of two. She learned of her HIV status in 2002. She was referred to a doctor because she had a back problem and he tested her and found that she was HIV-positive. She never experienced any opportunistic diseases that are common in PLWH like TB. At first, she did not want to disclose her status to anybody. She wanted to write her family a letter that she was HIV-positive after committing suicide. She decided to disclose after 5 years because she could not accept her status. She disclosed to her sister who accepted her and even gave her courage to take her antiretroviral treatment. She said she preferred disclosing to her family and people who do not know her and are not from her neighbourhood. She said people who know her and are from her neighbourhood would laugh at her should they know that she is HIV positive.

DATA ANALYSIS

Thematic content analysis ~~was~~^{will be} used as a method of analysis. The ~~tape recorded~~^{tape-recorded} interviews ~~were~~^{was} transcribed by the ~~researcher~~^{researcher} ~~see (Annexure E and F) for the guiding interview schedule and the interview script including field notes since all participants could speak English.~~ The process of coding was used to search and generate broader categories and themes. The broader categories and themes that emerged from the units of analysis were further explored and this process was repeated until an inclusive and comprehensive coding process of generating categories and subcategories emerged. Categories and subcategories were grouped together to form themes. The researcher used tabulation and frequencies to present the data. Five themes emerged from the data.

The themes that were identified were:

1. Reasons for testing
2. Initial reaction after diagnosis
3. Perception of living with HIV
4. Reasons for disclosure
5. Initial reaction to disclosure

BIOGRAPHICAL DATA

This section describes the characteristics of the participants who took part in the study. The biographical data collected include age, gender marital status, schooling and employment

status of the participants. All participants were positive and had disclosed their status to their significant others.

Table 4.1
Biographical data of the participants

Age	Number
20-29	0
30-39	2
40-49	3
Gender	
Female	4
Male	1
Marital status	
Single	1
Cohabiting	1
Widow	1
Casual relationship	1
Married (customary)	1
Employment status	
Unemployed	3
Full-time employment	1
Part-time employment	1

Educational level	
Never attended school	0
Up to grade 7	1
Grade 8 to 10	2
Grade 12	1
Tertiary Education	1

The participants' age range was between 30 and 49 years which is within the criteria for inclusion in the study. This is supported by literature that says the general population most affected globally is between the ages 15-49 (USAID, 2010). There were more females than males in the study, four females and one male. There was one married woman (customary marriage), one was a widow, one was cohabiting and the other was in a casual relationship.

The majority of participants were unemployed that is, three out of five. One was employed on a ~~full-time~~ full-time basis while the other was employed on a part time basis. Two participants attended school up to grade 10, one up to grade 7, one up to grade 12 and the other had a tertiary qualification.

OVERVIEW OF THEMES AND CATEGORIES FROM INTERVIEWS

Five themes emerged from the participants narratives during the in-depth interviews. Categories and subcategories also emerged from the data analysis. The themes, categories and subcategories will be presented in the tables below and discussed accordingly.

Table 4.2

Reasons for HIV testing

Theme	Category	Subcategory	Participants' narratives
Reasons for testing	Health	Own illness	I found out in 2007. It was the time my mother was forcing me to go to the clinic. She told me that she did not like the way I was coughing

			(Jane, 36). I had a back problem and ...I was given two days to consult a doctor. He tested me more than three times and confirmed that I was HIV positive (Liz, 48). At SANTA (Sam, 49).
	Family planning	Pregnancy	I found out when I was pregnant. I was supposed to be tested at the clinic and that's when I found out that I was HIV positive (Sue, 36).

THEME 1: REASONS: REASONS FOR HIV TESTING

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The reason for the majority of the participants to test their HIV status was ill health. One male participant was already admitted at SANTA (South African National Tuberculosis Association) in Pretoria for TB treatment. One participant had a back problem because she was working as a receptionist and would often help with cleaning the office. ~~“She~~ had a back problem. ~~She~~ used to be a receptionist and sometimes would help with cleaning the office. So, the last time ~~she~~ was cleaning the office ~~she~~ fell and was given two days to consult the doctor. He tested ~~her~~ more than three times and confirmed that ~~she~~ was HIV positive (Liz, 48). The other participant was forced by her mother to visit the clinic because of a bad cough.

Another category describing the reasons for HIV testing was that of family planning. The subcategory that emerged indicated that HIV testing was done when the participant was pregnant. This is part of her narrative “I found out when I was pregnant. I was supposed to be tested at the clinic and that’s when I found out that I was HIV positive” (Sue, 36).

Table 4.3

Initial reaction to diagnosis

Theme	Category	Subcategory	Participants’ narratives
Initial reaction to diagnosis	Feelings	Anger	Yoo,... <u>Yoo</u> . I was so angry (raising her voice). I ended up not being interested in men anymore (Kate, 46).
		Pain	It was so painful because I asked myself

			why me? (Sue, 36).
		Trauma and shock	They could see that I was traumatized and shocked about the results of my IV status (Jane, 36).
	Thoughts	Suicide	I wanted to write them a letter ... after I have committed suicide (Liz, 48).
		Denial	I did not believe I had HIV. I used to tell myself that I will never contract the disease (Sam, 49).

THEME 2: INITIAL REACTION TO DIAGNOSIS

This theme describes the initial reaction to diagnosis by the HIV infected participants. The main categories, which described what it meant for participants to be diagnosed with HIV, are coded by the researcher as feelings and thoughts. Further exploration of the categories yielded subcategories including anger, pain, trauma shock, suicide and denial. One participant (Jane) described her narratives as follows “[t]hey could see that I was traumatized and shocked”.

Another category describing what it meant for them to be diagnosed with HIV included the thought of suicide and denial. One participant (Liz) thought of committing suicide instead of seeking help. She described her reaction as follows: “I did not want to tell them anything. I wanted to write them a letter, informing them that I was HIV positive after I had committed suicide”. One participant (Sam) was in denial for the whole year. He could not believe that he was HIV positive. Kate, one of the participants in the current study reacted angrily after diagnosis while Sue was in pain.

Table 4.4

Perception of living with HIV

Theme	Category	Subcategory	Participants’ narratives
Perception of living with HIV	Perception by self	Accept	..., my children. I love my children very, very much. I felt that I have to see my daughters grow up in front of my eyes (Kate, 46).
		Cope	Now, I think it’s just like having a headache. Yes, I am really coping (Liz, 48).

			Ahh...most of the time I am telling myself that I ahh...I am a normal person what shall I say. There is nothing I can saysay , and I don't think too much about this disease (Jane, 36).
	Perception by others	Discrimination	They discriminated and stigmatized me. My boss also discriminated me to the extent that she would tell my clients not to let me touch them because I would infect them (Kate, 46).
	Perception by others	Stigma	She used to gossip about another HIV positive person that we both new. She used to gossip about her and telling other community members that she was going to die (Jane, 36). He looked at me and I asked him what was wrong. He said he he said he won't get killed by HIV...I said to him "you are judging me, and you might find that you are positive, and you don't know" (Sue, 36).
	Perception by others	Stigma	won't get killed by HIV...I said to him "you are judging me and you might find that you are positive and you don't know" (Sue,36).

THEME 3: PERCEPTION OF LIVING WITH HIV

This theme deals with how HIV infected participants' view their own experience of living with HIV and the perceptions of others or the community about them or people living with HIV. The main categories that describe the perceptions of living with HIV are coded by the researcher as perceptions of self and perceptions by others. Further exploration of the categories yielded subcategories including acceptance, coping, discrimination and stigma.

All participants accepted their status for different reasons. Two participants accepted their status because of their love for their children and what would happen to them should they die. One participant said: "I love my children very, very much. I felt that I have to see my daughters grow up in front of my eyes. Two participants accepted their status after being counselled by a professional counsellor or someone they could trust. The other one was shown people who have been living with HIV before him and were still alive.

The other subcategory that emerged under the perception of the self is coping. All of them are coping well with living with HIV. One participant said "Now, it's just like having a headache. Yes, I am coping" (Liz, 48). The other participant said "...I am still coping very, very well because I understand what it means to live with HIV" (Kate, 46).

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Another category that emerged from the perception of living with HIV was the perception by others. The subcategories that emerged after further exploration were discrimination and stigma. Two participants have not experienced discrimination and stigma while the other was told and knows about the person who was stigmatized. Two participants experienced stigma directly. One participants' narrative is as follows: "My boss also discriminated against me to the extent that she would tell my clients not to let me touch them because I would infect them. They discriminated me and stigmatized me" (Kate, 46). The other participant who experienced stigma directly gave the following narrative of her experience: "He looked at me and I asked him what was wrong. He said he won't get killed by HIV. I said to him you are judging ~~me~~, and you might find that you are positive and you don't know "(Sue, 36).

The participant, who was told ~~and knows the~~ about the individual living with HIV ~~who was~~ and stigmatized, described the narrative as follows: "She used to gossip about another HIV positive individual we both knew. She used to gossip about her and telling other members of the community that she was going to die" (Jane, 36).

Table 4.5

Reasons for disclosure

<u>Theme</u>	<u>Category</u>	<u>Subcategory</u>	<u>Participants' narratives</u>
<u>Reasons for disclosure</u>	<u>Self-focused</u>	<u>Support</u>	<u>At the end I told my daughter that the only thing she must do for me is to please love her mother and support her (Sue, 36).</u>
		<u>Love</u>	<u>They continue to love me. They have accepted and they love me (Liz, 48).</u>
		<u>Obligation</u>	<u>They should know that I am living with HIV (raising his voice) (Sam, 49).</u>
		<u>Adherence</u>	<u>Disclosure also helped me because they always reminded me when it was time to take my medication (Kate, 46).</u>
		<u>Relief</u>	<u>I am a person that cannot keep a secret because when I am alone, I am afraid that I will die of a heart disease (Jane, 36).</u>
		<u>Ill-health</u>	<u>I had continuous headaches...I wanted to disclose to her but could not. I ended up telling her (Sue, 36).</u>

	<u>Other-focused</u>	<u>Knowledge</u>	<u>To inform them of the person they are dealing with. They are not going to deal with that ghost (smiling) that is happy sometime sand not happy at other times (Kate, 46).</u>
	<u>Other-focused</u>	<u>Safe sex</u>	<u>So, I am pleading with you when you start dating, use condoms (Sue, 36).</u>

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THEME 4: REASONS FOR DISCLOSURE

Factors influencing disclosure to significant others were explored. Categories and subcategories describing reasons for disclosure emerged under this theme. The main categories coded by the researcher were self- focused and other-focused and subcategories that emerged after further exploration of the main categories included support, love, obligation, relief, knowledge and protection.

The category that emerged from the theme, reasons for disclosure was self-focused and the subcategories that emerged from after further exploration were support, love, obligation, adherence and relief. These are the reasons our participants expected to benefit by disclosing their HIV status to their significant others. One participant mentioned that: “At the end I told my

daughter that the only thing she must do for me is to please love her mother and support her” (Sue, 36). The reasons for her disclosure were the need to be loved and supported by her daughter.

Two participants’ reasons for disclosure were to relieve the burden of living with a secret. One said: “I am a person that cannot keep a secret because when I am alone, I am afraid that I will die of a heart disease” (Jane, 36). The other mentioned that “If I did not ~~disclosed~~disclose and they found out on their own, maybe they would have chased me away because other families chased their family away. So, I was free (deep sigh of relief)” (Kate, 46).

Two participants acknowledged the need to be reminded of taking their medication. They said that was one of the reasons of disclosing their HIV status to their significant others. Another participants’ reason for disclosure had nothing to do with support or any of the above-mentioned reasons but it was an obligation to tell his significant others about his HIV status. One of the participants’ reasons to disclose her status was ill health. She had constant headaches due to the stress of keeping her status secret to her daughter.

The other category that emerged from the theme, reasons for disclosure was the other-focused category and the subcategories that emerged after further exploration were knowledge and safe sex. With regards to the subcategory of knowledge or information one participant said “To inform them of the type of person they are dealing with. T-hey are not going to deal with that ghost (smiling) that is happy sometimes and not happy at other times” (Kate, 46). This will help their significant others to know that they (PLWH) are moody or emotional people and their significant others should be patient with them.

There was a strong feeling from some participants to disclose their status to their young children to protect them from getting infected with HIV. The use of condoms was emphasized by mothers to their daughters to reduce the risk of HIV infection. Three participants advised their daughters to practice safe sex by using condoms when they have intercourse with their boyfriends. One participant described her narrative to her child as follows: “She must be careful, she is still young and can find herself a ~~boyfriend~~boyfriend, but she must make sure she uses a condom” (Liz, 48).

Table 4.6

Initial reaction to disclosure

Theme	Category	Subcategory	Participants' narrative
Initial reaction to disclosure	Reaction by other	Sadness	She did not receive it well. She said what happened has happened (Sam, 49).
		Freedom	She was free when she heard the news from me (Kate, 46).
		Emotional	After I told her she was emotional and cried (Sue, 36).
	Reaction by self	Relief	My soul was relieved (Sam, 49). I was alright. I felt something has been removed from my heart and shoulders (Jane, 36).
		Fine	I was fine (Sue, 36).
		Encouragement	I got courage that now I am going to prove to her that even though that there is no medication; I am going to recuperate (Kate, 46).

THEME 5: INITIAL REACTION TO DISCLOSURE

This theme describes the initial reaction to disclosure by the significant others and the participants' response to their reaction. Participants described how their significant others reacted after disclosing to them their status and how they in turn responded or felt after the reactions of their significant others. Two categories emerged from this theme which is reaction by other and reaction by self. Further exploration of the two categories yielded five more subcategories. These subcategories include freedom, sadness, emotions, relief, encouragement and feeling fine. All participant got different reactions from significant others.

One participant described how his mother was ~~sad~~ saddened by the news of him being HIV positive “She did not receive it well” (Sam, 49). The other participant described how her mother was free when she heard the news from her. The other participants’ significant other was emotional and cried.

The other category that emerged from the category of reaction by self, include relief as previously mentioned. Two participants described how they were relived after the reactions they got from their significant others. The others felt just fine after the reactions they got from their significant others. The other participant was encouraged by her mother’s reaction to her disclosure. She felt the need to prove to her mother that she was going to recuperate. This is how she narrate~~s~~ her story “I got courage that now I am going to prove to her that even though there is no medication, I am going to recuperate” (Kate, 46).

CONCLUSION

Chapter 4 covered the analysis and findings of the research study. First, the demographical data of the participants was presented in a table form. This was followed by the tables that entailed the analysis of interview findings using thematic content analysis. Broader categories and subcategories were generated and grouped together to form themes. Five themes emerged after exploring the data. A short summary of the table or themes was presented after every table.

CHAPTER 5

DISCUSSIONS OF FINDINGS

This chapter discusses the findings of the current study with reference to relevant literature pertaining to the concept of HIV status disclosure to significant others. The literature referred to in the current study was relevant in contextualizing, comparing the similarities and differences to the findings from the current study. The discussion is based on the findings from the five themes that were identified in the previous chapter.

DISCUSSION OF THEMES

The five themes that emerged from the data analysis from the previous chapter are:

1. Reasons for HIV testing
2. Initial reaction after diagnosis
3. Perception of living with HIV
4. Reasons for disclosure
5. Initial reaction to disclosure

Two main reasons for HIV testing were identified by participants in the current study. They reported going for HIV testing due to health concerns and family planning. Ill health and pregnancy were given as the reasons for HIV testing. Similar findings were reported by Almeleh (2006) in her study focusing on why people disclose their HIV status. They found that people went for HIV testing because they were either sick or pregnant. ~~Shisana et al., Rehle, Simbayi, Parker, Zuma, Bhana, Connolly, Joosten and Pilay (2005) According to (HSRC, 2005) report on in their study of HIV prevalence in South Africa, also showed that there is~~ a considerable ~~amount~~ number of respondents who used voluntary testing because they were either sick or pregnant.

None of the research participants went for voluntary HIV testing while they were not infected with HIV. One of the research participants in the current [study](#) went for HIV testing when his health had deteriorated significantly. He was already admitted for other opportunistic diseases that are commonly found in PLWH, Tuberculosis when diagnosed with HIV. It is not clear when the other participant whose health had deteriorated significantly went for HIV testing.

The other participant went for HIV testing when she was pregnant as a standard practice that all pregnant women visiting public clinics or hospital must undergo HIV testing. The fourth participant in the current study went for HIV testing because she had a bad cough while the final participant went for HIV testing because she had back problems. Compared to the other three participants, the latter two participants' early detection or diagnosis of HIV treatment and adherence to treatment improved their health considerably. These findings are in keeping with the report by Obermeyer ~~&and~~ Osborne (2007, p. 1) in their study of the utilization of testing and counselling that 'HIV testing is the gateway to treatment, care and prevention'. They also found out that the main reason why people do not take HIV test was fear. Two participants in the current study mentioned the importance of HIV testing and knowing one's status. One said nowadays everyone seems to be HIV positive and one cannot say he/she is negative until taking the HIV test.

INITIAL REACTION TO DIAGNOSIS

Participants in the current study described their initial reactions to diagnosis with HIV. Their reactions were divided into feelings and thoughts that is how they felt after being told that they were HIV positive and what they thought after being told they were HIV positive. There were no physical reactions from the participants after disclosure. Feelings of anger, emotional pain, trauma and shock were described by the participants. Denial and suicidal thoughts were described by the participants. According to Van Dyk (2012), people who are diagnosed with HIV are predisposed to psychological, emotional, social and spiritual challenges. She argues that feelings of anger directed towards other people and often towards themselves characterize these people. In the current study one participant (Kate), mentioned how angry she became towards her former fiancé and men in general for infecting her with the disease. However, she did not mention or indicate any anger towards herself for contracting the disease as proposed by Fabianova (2011). She seems not to be directing part of the anger towards herself for contracting the disease but only to her former fiancé and to men in general.

Similar to our current study, some people experience trauma and shock after HIV diagnosis. They were extremely upset or distressed by the news that they are HIV positive and experienced emotional pain (Van Dyk, 2012). One of the participants in the current study (Jane), who said her initial reaction after diagnosis was traumatic and shocking, experienced feelings of

anxiety. Feelings of anxiety are keeping with Fabianova (2011) assertions that people who are diagnosed with HIV often experience feelings of anxiety. She was distressed about dying, had feelings of uneasiness as to what is going to happen to her and whether her life will change or will remain the same. Her appraisal of the situation was reassured by the counsellor who told her that she will not change and advised her to take her treatment.

In their studies of illness appraisals and depression in the first year after diagnosis, Moskowitz, Wrubel, Hult, Maurer ~~&and~~ Acree (2013) found that one of the initial illness appraisals was concern with death. They also found that reappraisal of the situation which is very often the coping strategy used to manage this type of threat follows the initial appraisal. The participant (Jane) in the current study initial appraisal of the situation as concerning death is in keeping with Moskowitz et al. (2013) findings of the initial appraisal of the situation. However, reappraisal which was found to be the strategy used to manage this type of threat did not follow the initial appraisal as reported by Moskowitz et al. (2013). The participant in the current study liked the post HIV test counselling she received and changed her initial fearful appraisal. She also mentioned how grateful she was for the counselling.

This was not the case with the other two participants who also thought that they were going to die. One participant (Sue) amongst the two, reaction to diagnosis included emotional pain and denial, which is in keeping with Holt et al.'s (1998) assertion that emotional pain and denial is often the reaction after HIV diagnosis. The other participant amongst the two (Sam), also appraised his situation as fateful and was made dire than the two because medication (ARV treatment) was not freely available at the time in South Africa when he was diagnosed. His situation was also exacerbated by the fact that he was admitted and treated for Multi Drug Resistant Tuberculosis (MDR).

People who are diagnosed with HIV are also predisposed to suicidal thoughts and denial (Cooperman & Simoni, 2005). In the current study one participant was inclined to commit suicide while two of them were in denial. The findings from the current study that one of the participants thought of committing suicide after HIV diagnosis is similar to the findings by Cooperman ~~&and~~ Simoni (2005) in their study of suicidal ideation and attempted suicide among women living with HIV/AIDS and Govender ~~and~~ Schlebusch (2012) in their study of hopelessness, depression and suicidal ideation. The two studies found out that people who have been

diagnosed with HIV have suicidal ideation and tend to attempt suicide. Van Dyk (2012, p. 294) report that ‘the risk of suicide as being 36 times greater in individuals with HIV infection’.

The participant (Liz) in the current study had feelings of hate. She did not understand her life anymore and stopped socializing. These feelings are similar to some of the mood indicators that are linked with suicidal thinking according to Govender ~~&and~~ Schlebusch (2012). According to Van Dyk (2012), one cannot ~~make the assumption~~assume that depression causes ~~suicide~~suicide, but she believes that there is a correlation between suicide and depression. Although depression was not evident in the participant in the current study, Govender ~~&and~~ Schlebusch (2012) in their study of hopelessness, depression and suicidal ideation in HIV-positive persons, found out that many PLWH have high levels of depressive symptoms and those with these symptoms had high levels of suicidal ideation or thought.

The participant in the current study (Liz) also mentions that she was abused before she was diagnosed with HIV. According to research studies by Cooperman ~~&and~~ Simoni (2005) on suicidal ideation and attempted suicide among women living with HIV/AIDS, it was found out that one of the factors that predisposed people/women to suicidal thinking and suicide attempts was sexual abuse which appears to be in agreement with the narratives of the participant in the current study. They also found out that women who have children were more predisposed to think of suicide or attempt suicide which is also in keeping with the participant in the current study (Liz).

Two participants in the current study were in denial after being diagnosed with HIV. The participant in the current study (Sue), who could not accept her status and was in denial said ‘two minutes I would say it’s ok I’m fine. Two minutes I would say why me?’ The participant reaction to HIV diagnosis is supported by Van Holt et al. (1998) who assert that most PLWH or diagnosed with HIV experience denial. Although the authors are not specific on the duration of the denial phase after initial diagnosis, ~~#they~~they maintains that it is a necessary reaction when the HIV infected individuals are not ready to accept their diagnosis. The authors argue that denial will give the HIV infected individuals time to think about how others will react to their HIV positive status.

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The other participant in the current study (Sam) could not accept his status as well. His denial was exacerbated by misinformation or lack of knowledge about the cause of HIV. He believed that one cannot get infected with the HIV virus if one was only having unprotected sex with beautiful women. He believed that HIV only infected women who were not beautiful. He tried hard to remember the woman who was not beautiful who might have infected her but to no avail.

PERCEPTION OF LIVING WITH HIV

The two main categories identified or described by the researcher on how the participants viewed themselves in living with HIV and on how others viewed them in living with HIV were discussed by the researcher. How the participants in the current study viewed themselves in living with HIV includes acceptance and coping with the disease. The description on how others viewed them in living with HIV, include discrimination and stigma.

All participants in the current study accepted their status for different reasons as already mentioned in preceding subsections. One participant (Liz) accepted her status after disclosing to her family and to a lady that that encouraged her to disclose to her status to her family. They accepted her. The positive commitment she made to take her medication and living a healthy lifestyle including ~~daily training~~~~everyday exercising~~ also encouraged her to accept her status. The response of her family in accepting her also helped her to accept her status. Her commitment to taking her medication i.e. adhering to ARV treatment and living a healthy lifestyle encouraged her to accept her status. Nam, Fielding, Avalos, Dickinson, Gaolathe ~~&and~~ Geissler (2008) in their studies of the relationship of acceptance or denial of HIV status to antiretroviral adherence among adult HIV patients found that acceptance to HIV status, avoidance to internalized stigma and having a supportive target of disclosure were important aspects associated with good adherence. These findings appear to ~~be in agreement~~~~agree~~ with the narratives of the participants in the current study.

Two participants in the current study (Sue and Kate) reported that they accepted their status because of their children. One of them (Kate) mentioned that her children grew up without their father and she wanted to see them grow up. She is also encouraged by the availability of ARV's which were not freely available when she was first diagnosed with HIV 21 years ago. The other participant (Sue) also accepted her status because of her children. She was

worried what would happen if she would die. They gave her a reason to live. The other reason for her to accept her status was that it seemed to her that 90% of people are living with HIV, so she is not the only one.

The other participant in the current study (Jane) accepted her status because of the support of her mother and grandmother gave her after disclosing her status to them. Her mother and grandmother also encouraged her and supported her in taking her medication. Her narratives are in agreement with reports by Atuyambe et al. (2014) on their study of HIV/AIDS status disclosure increases support, behavioural change and HIV prevention in the long term, which found that when PLWH disclose their status to their family and friends they often receive positive reactions including adherence to ARV treatment.

The other factor that made the participant in the current study (Jane), [to accept her HIV positive status](#) -was the counselling she received after testing HIV positive. She was happy and grateful for the counselling she received. -However, according to Van Dyk (2012), the counsellor's role is not solving the clients' problems but to help the client or HIV infected individual to assess his/her problems and the choices he or she has in addressing that problem. We do not know exactly what the counsellor said to her (Jane), but counselling should be in accordance with what Van Dyk (2012) proposes.

The final participant in our current study (Sam), took time to accept his status 'almost the whole year'. -There was no medication when he was diagnosed, his thoughts in trying to remember who might have infected [him](#) and the fact that he was already being treated for MDR made it difficult for him to accept his status. A social worker who was counselling him showed him people who survived by eating healthy food and were also diagnosed with HIV before him.

All the participants in the current study reported that they were coping with living with HIV. In their study of disclosure and non-disclosure among people newly diagnosed with HIV, Hult et al (2012, p. 2) define coping as 'the thoughts and behaviours a person uses to regulate distress or manage the problem causing distress and can include aspects of disclosure such as disclosing to garner social support and even decisions not to disclose HIV status'. In their study they found that selective disclosure (strategic disclosure) was not regarded as stressful but as a

means to get emotional support or as a way of relieving the burden of carrying difficult news. These findings appear to be similar to the ones of the participants in the current study (Jane) who narrates that disclosing to her mother and grandmother who supported her and relieved her burden of carrying difficult news. Reassuring their love for her and their support made her experience of living with HIV more bearable. Her use of condoms whenever she has sexual intercourse also made it possible for her to cope with HIV since she is protecting herself against reinfection and infecting others.

One participant in the current study (Kate) mentioned that she managed to cope with HIV or made her experience more bearable by abstaining. She was diagnosed with HIV in 1996 and abstained for 9 years. She mentions that she also managed to cope with living with HIV because she knew what it meant to live with the disease, loved herself more and was not angry with people who do not know how to live with the disease. After the introduction of ARV's and the use of condoms whenever she had intercourse with her partner made it better for her to cope with living with HIV.

Two other participants reported coping with living with the disease. The availability of ARV treatment made them to be able to cope with the disease. However, one of the participants in the current study (Sue) also mentioned the fact that joining a support group was also important for her to make her experience of living with HIV more bearable. She narrates that because she is a person who “always want to know what is going on” and is not afraid to disclose her status to people she does not know, joining a support group will help her gain more information about living with HIV. The importance of joining a support group for knowledge about HIV appears to be similar to the findings made by Bateganya, Amenyewe, Uchechi, Roxo ~~&and~~ Dong (2015) on the impact of support groups for people living with HIV on clinical outcomes. They found that support groups improve disclosure with the potential to prevent HIV infection. However, their findings are not certain about future or further transmission.

Furthermore, Paudeh ~~&and~~ Baral (2015) in their studies of women living with HIV/AIDS (WLHA) battling stigma, discrimination and denial and the role of support groups as a coping strategy also found out among other things, that women who participated in support groups are empowered to appreciate themselves and improve their emotional and physical lives. As a ~~result~~ result, support groups help PLWH to cope with living with HIV.

One coping strategy used by one of the participants in the current study (Liz), was to hide her status from neighbours or community at large. She said she rather disclosed to people who do not know her than those who knew her and lived nearby avoiding ~~to be being~~ labelled and enable her to deal with her diagnosis. This finding appears to ~~be in agreement~~agree with studies by Arrey ~~et al., Bilsen, Laeor and Descheppers~~ (2015). In their studies of fear of disclosure among sub-Saharan migrant women living with HIV in Belgium, they found out that one of the coping strategies in living with HIV was to hide their status from outsiders or others and revealing their status to selected individuals in their lives.

The final participant in our current study (Sam) managed to cope with the experience of living with HIV by eating vegetables, especially cabbage. When he was initially diagnosed with HIV in 1999 there was no medication for the disease. He managed to cope with the disease for five years by eating vegetables and abstaining. Although eating vegetables has not been proven to sustain the life of an HIV infected person, Van Dyk (2012) mentions that PLWH have to eat defensively and follow the necessary food safety guidelines. She recommends fruits and vegetables that are properly washed and not sprayed with pesticides. Her recommendations are based on the fact that PLWH immune system is weak and vulnerable to food that can easily cause illness. After the introduction of ARV's and when he was healed from MDR, he started using condoms to protect himself against reinfection and infecting others. Disclosure also helped him to cope with the disease especially to the newly HIV diagnosed persons. Condom use and disclosure to others also helped him to cope with living HIV.

Perceptions by others ~~wase~~ere one of the two main categories identified by the researcher. How others including the community view PLWH included two subcategories of discrimination and stigma. The participants in the current study narrated how others viewed them and those living with HIV.

Two of the participants in the current study experienced discrimination on a personal level although one was not specific. The participant in the current study (Kate) who experienced discrimination on a personal level mentioned how her former employer at a hair salon discriminated against her based on her HIV positive status. The findings seem to be in keeping with the studies by Cloete, Simbayi, Kalichman, Strebel ~~&and~~ Henda (2008). In their studies of stigma and discrimination experiences of HIV-positive men who have sex with other men

(MSM) in Cape Town, South Africa, they found that HIV positive MSM experienced greater isolation and discrimination including housing or employment as a result of their HIV positive status while HIV positive men having sex with women (MSW) had similar experiences but to a lesser extent than (MSM).

The other participant in the current study (Jane) mentioned that she was discriminated by her extended family but without going into detail. The other three participants never experienced discrimination. One participant in the study (Liz) only disclosed to her family which did not discriminate against her, the other participants (Sue) did not experience it even though she disclosed to her support group and the last one (Sam), did not experience it ~~from~~ those he disclosed to, be it family or the community at large.

Three of the participants in the current study never experienced stigma against them although one participant (Jane), knows someone who was stigmatized in her neighbourhood. The other two participants experienced stigma directly. The one participant in the current study (Jane), who knows of someone her community stigmatized by gossiping about her that she was going to die is a typical example of stigmatization as presented in chapter 2. These narratives are supported by research findings by Arrey et al. (2015) that gossiping is a form of stigma levelled against PLWH.

The other participant in the current study (Kate) who experienced stigma mentioned how people would clean the chair she was sitting on because they despised her due to her HIV positive status. Despising or looking down or devaluing people due to their HIV positive status fits the definition of stigma mentioned in (chapter 2). The final participant in the current study (Sue), who also experienced stigma directly, mentioned that she was told that she was going to die because of her HIV status. This is also in keeping with the definition of stigma whereby PLWH are devaluated and discredited by the community. She had lost weight as a result of the disease and the community ~~presumed~~presumed, she was HIV positive and labelled her as such. The other two participants in the current study have never experienced stigmatization against them.

REASONS FOR DISCLOSURE

According to Serovich et al (2007, p. 1) HIV status disclosure has been described as a 'sensitive issue often causing stress and apprehension due to the uncertainty of how people would react'. As a result, significant others can provide the infected individuals with emotional support in dealing with or coping with the stress of disclosure. According to studies conducted in Africa, approximately 80%-90% of people living with HIV have disclosed to someone else (Ssali et al. (2010). In the current study all participants have disclosed to their significant others.

The reasons described by the participants in the current study as having influenced them to tell their significant others of their HIV positive status were divided into self-focused and other focused (see chapter 4). The self-focused reasons for disclosure were mostly concerned with what the participant hoped to gain from their significant others. The perceived benefits of disclosure to significant others were emotional and physical support, the need to be loved, helping with adherence to ARV treatment since all were on ARV treatment, a sense of relief and freedom from the burden of keeping the disease a secret and a sense of responsibility or obligation to disclose to one's family or mother. Participants felt that since the introduction of ARV treatment, the disease was regarded as a chronic illness and no longer as a death sentence. These self-focused findings were supported by studies in the literature.

According to Ssali et al. (2010), Maman et al. (2014) and Serovic et al. (2007), one of the reasons for HIV status disclosure by PLWH was support. Emotional support was very important for PLWH to help in the alleviation of stress and other psychological challenges. As one participant in the current study (Kate) puts it, 'they are not going to deal with that ghost (smiling) that is happy sometimes and not happy at other times. They know me now, that when I'm like this, then there seems to be something wrong. They will take care of me or send someone to talk to me and find out if there is anything wrong'. This participant acknowledges the need for emotional support since she tends to be moody at times. After disclosing to them, her family would understand her better and give her the necessary support.

The other participant in the current study (Sue) who was also very ill and admitted to ward 19 at Kalafong hospital also mentioned the need for support. She mentioned that her daughter must love and support her. She also acknowledges the need for support when she said, 'even

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if they will talk about you, they will be supportive'. The need for support was mentioned by two participants in the current study (Kate and Sue) who were very sick and needed support from their significant others. The other two participants (Jane and Liz) did not have such experience that is being seriously ill since being diagnosed with HIV. Early diagnosis and adherence to ARV treatment helped them not to seek physical support unlike (Kate and Sue). Jane and Liz never experienced opportunistic diseases. They mostly needed emotional support from their families. As Jane puts it 'they supported me and gave me strength everyday'.

Adherence to treatment was one of the reasons why participant in the current study disclosed their HIV status to their significant others. This finding is also supported by Maman et al. (2014) who found that disclosure of HIV status contributed to better adherence to ARV treatment. Two of the participants in the current study who were very ill mentioned the need to be helped with adherence to their ARV treatment. The other three did not have a problem with adherence and that was not one of the reasons why they disclosed their status.

Feelings of relief and freedom resulting from disclosure were described by two of the ~~participant~~ participants in the current study. Similar factors influencing disclosure were identified by Serovic and Mosack (2003) and Maman et al. (2014). One participant in the current study (Jane) mentioned how she could not keep a secret and how she ~~was seared-off~~ feared dying of a heart attack if she kept a secret. This is how she narrates her story after disclosing to her mother and grandmother, 'I felt like something has been removed from my heart and shoulders'. The other participant in the current study (Kate) also mentioned how she was free after disclosing her status to her mother. She said that she did not know how they would react if they found out on their own. 'maybe they would have chased me away because other families chased their family members away. ~~So~~ So, I was free (deep sigh of relief)'. Sam, the only male participant in the current study, also mentioned that his soul was relieved after disclosing his HIV positive status to his mother. These results appear to ~~be in agreement~~ agree with results by Memon, Glazebrook, Campaign and Ngoma (2007) in their studies of mental health and disclosure of HIV status in Zambian adolescents. They found that positive mental health among those who disclosed their status.

Advanced stage of the disease was reported as a factor contributing to disclosure in the current study. Kate, one of the participants in the current study, disclosed her HIV positive status

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when her health had deteriorated to the ~~point~~point, she could not hide her status anymore. This is how she tells her story 'I was so critical that she could not understand why I was not getting better...So I ended up telling her that eish mama...for me not to get better is because the disease I have is not curable'. Ill health was also the reason why PLWH disclosed their status. This is in keeping with studies from the literature. Ssali et al. (2010) found that disclosure of HIV status was also influenced by ill health. One participant in the current study, (Sue) mentioned how stress was going to kill her if she did not disclose to her daughter. She had severe headaches that were caused by stress emanating from keeping her status secret to her daughter.

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The other self-focused factor that contributed to HIV status disclosure was a sense of responsibility. In their studies, Serovic ~~&~~and Mosack (2003) found four ~~factor~~factors set of reasons for disclosing. These were responsibility and a sense of duty, teaching others about HIV, relationship consequence and being emotionally free or relieved. One of the participants in the study (Sam) mentioned that his significant others should know that he is HIV positive.

Interviewer: You wanted them to know.

Interviewee: They should know that I am living with HIV (raising his voice).

The other-focused reasons for disclosure were mostly concerned with safe sex and knowledge about HIV. Safe sex as the reason for HIV status disclosure was in keeping with studies from the literature. Ssali et al. (2010) found that PLWH other-focused reasons for disclosure were to protect others from contracting the disease especially their children. Participants in the current study mentioned the need to teach their children to use condoms as a form of protection against HIV infection. One participant in the current study ~~Sue~~Sue, mentions how she advised her daughter to practice safe sex 'so I am pleading with you that when you start dating, use condoms. I am pleading with you because if you don't, there will be consequences. It's either you will get pregnant or you will be HIV positive'.

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Kate, one of the participants in the current study who is married (customary) is not explicit in her narratives about disclosing her HIV status to her husband. However, she made mention of using condoms when she had intercourse with her husband to prevent HIV transmission.

The second other-focused reason for HIV status disclosure is knowledge about HIV. In his studies on what is the impact of HIV on families Van Empelen (2005) found that disclosure

improves the existing knowledge about HIV and its transmission. This is in keeping with what Sue, one of the participants in the current study spoke about when she mentioned that she is always looking for knowledge when she joined a support group and disclosed her status, was able to get more information about HIV. She did not only join the support group to seek information, but she also disclosed to her friends who were HIV positive with the intention of sharing information or knowledge about HIV.

INITIAL REACTION TO DISCLOSURE

The initial reactions of both the participants and their significant others following disclosure were described in chapter 4. Significant ~~otherstheers~~ reactions to disclosure was described including feelings of sadness, love, freedom and emotional shock. Participants' response to the initial reactions of significant others include relief or freedom, goodness and encouragement. Two participants from the current study received positive reactions from their significant others, the other two received negative reactions from their significant others while the other participant received a positive reaction but did not have an emotional content to it. They indicated that they support her and did not reject her. These findings are in keeping with research studies by Atuyambe et al. (2014). They found negative reactions by the disclosure recipients and positive reactions as well. They also found behavioural change and prevention responses e.g. condom use, abstaining and eating habits as positive reactions from the recipients. Although some of the participants in the current study received negative reactions or responses, none of them was rejected by their significant others.

In the current study none of the participants prepared their significant others before disclosing their status to them. This is contrary to the assertions made by Van Dyk (2012) that it is important to prepare the recipient of disclosure as it will make the disclosure more bearable for both of them. These assertions are shared by Almeleh (2006) who argue that it is important for PLWH to assess the reaction of the recipient of disclosure before the actual disclosure by talking about HIV in general as this will give the discloser an idea as to whether the target of disclosure will react negatively or positively or will be supportive or not.

Only one participant in the current study prepared herself before disclosing her status to her significant other. She mentioned that it was important for her to prepare herself because '...there might be consequences. Maybe she might reject me as her ~~mother~~mother, and I need

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her (stressing/emphasizing)’. It took her many years thinking of how she was going to disclose to her daughter. She had to ask the Lord strength to disclose ~~to~~ her status to her daughter. She did not prepare herself before disclosing to her relatives and friends.

Participants in the current study reported feelings of relief, happiness and encouragement after the reactions from their significant others. These feelings are supported by the findings of Hult et al. (2012). They found that PLWH felt relieved and happy after the reactions they received from those they disclosed to. However, feelings of encouragement were not one of the findings by Hult et al. (2012).

THEORIES OF DISCLOSURE

Different researchers have tried to come with different reasons why people disclose their HIV status. We will look at two different theories and discuss them with reference to the findings of the current study.

~~THE DISEASE PROGRESSION THEORY~~

The Disease progression theory

According to Serovic, Craft ~~&~~ Yoon (2007), the disease progression theory is based on the premises that PLWH are motivated to disclose their status because they can no longer hide their illness as it progress to more severe stages that can be seen by all. They argue that these major symptoms, opportunistic diseases and psychological and emotional challenges are becoming visible to everyone.

In the current study only one participant Kate disclosed her status because she could no longer hide her status. She was taken to many doctors who prescribed different medication to no avail. She even made sure that she took her medication as prescribed because she thought that maybe she was not taking her medication as prescribed (adherence) by her doctors. Her condition deteriorated to the point that she had to tell her mother she had an incurable disease (HIV). Her situation was made worse by the fact that when she was diagnosed there was no medication for HIV (ARV’s). This is the only case that is keeping with the disease progression theory. The other participants in the current study had their own reasons why they disclosed their HIV status, but none was based on the disease progression theory.

~~THE COMPETING CONSEQUENCE THEORY~~

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The competing consequence theory is based on the assumption that as the disease progress, disclosure is dependent on the perceived consequences from the confidants (Serovic et al., 2008). It suggests that as the disease progress, people assessment of the likely results of disclosure occur once rewards outweigh the costs of disclosure.

In the current study one participant Sue, evaluated the likely outcome of disclosure and after viewing the rewards being greater than the costs, disclosed to her mother and daughter. Her father and eldest daughter also knew, although she was not the one who told them. She wanted them to support her especially with adherence to her medication. Again, the rewards of teaching her children to prevent themselves from contracting the HIV virus by using condoms was greater than being rejected, stigmatized, and discriminated by them.

THE COMMUNICATION PRIVACY MANAGEMENT (CPM) THEORY

The CPM theory examines why people make decisions about disclosing or not disclosing their private information (Petronio, 2004). According to this theory, people believe they own and have the right to control their private information. As a result, they develop their own privacy rules based on five criteria which are culture, context, motivation, gender and risk/benefit (Kennedy-Lightsey, et al., 2012).

- Culture

The cultural norms and beliefs that prevailed within the discloser's environment at the time of disclosing their private information could have influenced their decisions ~~whether or not~~ to disclose their HIV positive status. Issues such as whether they believed in the traditional causes of HIV and its treatment or in the modern explanations of the causes of HIV and the use of antiretroviral treatment may have had an influence on their decisions on disclosing their status. ~~One participant Kate,~~ One participant Kate, explained how her former fiancé tried to rape her virgin daughter after being advised by a 'sangoma' that having sexual intercourse with a virgin female while being HIV positive will cure the disease. The fiancée secretly consulted the 'sangoma' and kept his status secret from Kate and her daughter. This conclusion is shared by Maile (2003) in his studies which found that talking about sex is probably taboo in most African countries. As a result, strongly held cultural beliefs about the cure of HIV tend to hinder disclosure in keeping with the CPM theory.

- Context

Traumatic events like HIV diagnosis, natural disaster, and sexual abuse are some of the traumatic events that can lead one to craft privacy boundaries that are initially inaccessible to anyone. In the current study only one participant was traumatized when diagnosed with HIV. However, with the counselling she received after her HIV test results, she was not troubled anymore and thanked the counsellor for helping her. Context in this study did not have much influence on disclosing one's HIV positive status.

- Motivation

People are motivated to disclose because of what they believe they will gain from disclosing. In the current study perceived positive outcomes included emotional and material support and feelings of relief.

- Gender

Gender and sexual orientation also have an influence on ~~whether or not~~whether one will disclose or conceal one's private information. The sample in the current study is too small to make any meaningful conclusions about the applicability of this criterion.

- Risk/benefit

This criterion refers to the perceived positive and negative outcomes following disclosure of private information. If the benefits outweigh the risks, disclosure of HIV status is likely to follow. In the context of the current study perceived and experienced benefits including emotional and material support outweighed the risk of rejection and stigma.

CONCLUSION

Chapter 5 presented a discussion on the five main themes of our data analysis or findings of the current study and compared them with relevant available literature. There were similarities and differences between findings from the current study and from the studies mentioned in the identified literature. Two theories were applied to the findings of the current study. One participant's results appeared to ~~be in agreement~~agree with the disease progression theory. The theory did not apply to the other four participants. It was also found out that the competing consequence theory did not apply to the results of the current study. Conclusions, limitations and recommendations will be discussed in the next chapter.

CHAPTER 6

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

This chapter focuses on the conclusions drawn from the previously discussed chapters, the limitations of the current study and recommendations for future research. The ~~main focus~~ focus of the chapter is on the discussions of the themes that emerged from the interviews with participants from the current study and the general findings from the in-depth interview with the participants. These themes are discussed in the context of the purpose of the study including the objectives of the study. As stated in chapter 1, the purpose of the study is to explore factors that may influence disclosure of one's HIV status to significant others. The objectives of the study are to provide a platform for PLWH to tell their personal experiences about disclosing their HIV status, to explore factors that influenced disclosure of HIV status to significant others and to make recommendations based on the results of the study on factors that could enable disclosure to significant others.

MAIN FINDINGS Reason for HIV testing

REASONS FOR HIV TESTING

It can be argued that early HIV diagnosis can be beneficial to the infected individual. Based on the results of the current study, the two participants who were diagnosed while on stages 1 and 2 (~~these are the stages characterized by among other things fatigue, muscle pains, flu like symptoms, bronchitis and so forth~~) Van Dyk (2012), did not experience opportunistic diseases because of early diagnosis and ARV treatment. The other participant amongst the two, who was diagnosed with HIV and was also found to be pregnant, was put on the mother to child prevention program to prevent the unborn child from contracting HIV.

INITIAL REACTION TO DIAGNOSIS Initial reaction to diagnosis

The participants in the current study reported different reactions to their initial HIV diagnosis. The results of the study ~~are in agreement~~ agree with Van Dyk's (2012) assertions that people who are diagnosed with HIV are predisposed to psychological, emotional, social and spiritual challenges. All participants experienced negative feelings and thoughts after diagnosis. The majority of participants, that is three out of five thought they were going to die. The thought of dying used to be a common reaction to HIV positive diagnosis especially before the

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introduction of ARV treatment. After the introduction of HIV treatment, people still think they are going to die but the thought is not as pervasive or common as before.

While the scope of the study is limited and the findings cannot be generalized to other studies, it can be argued that initial diagnosis to HIV will always entail negative reactions and predispose the newly diagnosed to psychological, emotional, social and spiritual challenges. HIV diagnosis triggers coping and adjustment strategies in response to these challenges. The two participants in the current study who were diagnosed post ARV treatment who thought they were going to die, did not take a long time to change their thought of HIV as a death sentence to a thought of a manageable chronic disease. This was different from the participant who was diagnosed ~~pre-ARV~~pre-ARV treatment who took a long time to cope with the disease.

PERCEPTION OF LIVING WITH HIV Perception of living with HIV

Although the participants in the current study had different reasons to accept and cope with their status, they first had to disclose their status to their significant others despite the possibility of rejection with the exception of one participant Sam, who was diagnosed while admitted at SANTA for TB treatment. The positive response from the targets of disclosure including support, acceptance and encouragement to ARV treatment enabled the participants to accept their HIV positive status. These results appear to be in keeping with studies by Nam et al (2008) and Atuyambe et al (2014). Nam et al (2008) in their studies of the relationship of acceptance or denial of HIV status to antiretroviral adherence, found that acceptance of HIV status, avoidance to internalized stigma and having a supportive target of disclosure were important aspects associated with good adherence. Atuyambe et al (2014) in their studies of HIV/AIDS status disclosure increases support, behavioural change and HIV prevention in the long run found that when people disclose their status to their family and friends, they often receive positive reactions including adherence to ARV treatment.

Only two participants from the current study mentioned the importance of counsellors who helped them accept their HIV status. The current study also indicates how post-counselling interventions can help PLWH to accept and cope with the disease.

The other category that emerged from this theme was how others viewed people living with HIV. Out of the five participants in the current study, two participants never experienced

stigma and discrimination against them. The reason might be that one participant, Liz only disclosed to close family members and the other participant, Sam, who disclosed to the general public did not experience stigmatization and discrimination against him. Two participants, Kate and Sue, experienced [stigma and discrimination](#) from the general public. Amongst the two, only Kate was discriminated against. One participant, Jane, report being stigmatized by relatives but did not get into details on how she was stigmatized. It can be argued that stigma and discrimination against PLWH still persist in communities where participants live. Stigma and discrimination makes it difficult or impossible for PLWH to disclose to the communities they live in which are regarded as ‘barriers to prevention and treatment’ (HSRC, 2015, p. 13). The results are inconclusive regarding this category.

~~REASON FOR DISCLOSURE~~ [Reason for disclosure](#)

Reasons for disclosure were divided into two categories. They are self-focused reasons for disclosure and other-focused reason for disclosure. The self-focused reasons for disclosure reported by the participants in the current study included support, the need to be loved, helping with adherence to ARV treatment management, a sense of relief ~~and freedom~~ [and freedom](#) and a sense of responsibility or obligation.

Four out of the five participants in the current study mentioned support as the reason for disclosure. Two participants needed emotional support while the other two whose health had deteriorated needed support with ARV treatment management. Kate mentioned how moody she was and needed her family support. ARV treatment management included making sure that PLWH take their medication and take the medication on time.

The need to be loved was also mentioned by three participants in the current study. Sue mentioned how she wanted her child to love her; Liz mentioned how her children kept on loving her and Jane mentioned how she wanted her family to love her. Three participants in the current study, which are the majority, mentioned how they were free after disclosing their status to their significant others. One of them, Sam, mentioned how he felt after disclosing his status to his mother. He said ‘my soul was relieved’. The results appear to be in keeping with the studies of ~~Menmon et al., Glazebrook, Campain and Ngoma~~ (2007) that found positive mental health among those that disclosed their status.

Most participants in the current study received support, love and freedom after disclosing their HIV status to their significant others. Although the scope of the study is limited and the findings cannot be generalized to other studies, it can be argued that disclosure to significant others is beneficial to HIV positive people.

The other-focused reasons for disclosure were not the same to all the participants in the study. They included protecting their loved ones from infection ~~through the use of using~~ condoms, improving existing knowledge about HIV and its transmission and relieving the burden of worry and confusion of their significant others who did not know what was wrong with them.

~~INITIAL REACTION TO DISCLOSURE~~ Initial reaction to disclosure

GENERAL FINDINGS AND CONCLUSIONS

All the participants had different lives that they lived before being diagnosed with HIV. The lives they lived make it difficult for the researcher to correlate them with their HIV positive diagnosis. Only one participant who used to have unprotected sexual intercourse with beautiful women can be said that he was vulnerable to contracting the disease. He did not know about HIV and how it is transmitted from one person to the other. He only knew later when he had contracted the disease. Based on the current study, all participants know about HIV and its transmission. They also know how one can protect oneself from contracting the disease. Two of them are abstaining while three of them are using condoms to protect themselves from reinfection and infecting others. They even go as far as telling other people to use condoms to protect themselves from contracting the disease. However, the information about HIV and its transmission is not enough which shows that there is still need for knowledge about HIV and its transmission. For example, they did not mention that HIV can be transmitted from mother to child or during breast feeding. They only mentioned sexual transmission and blood transfusion as ways of HIV transmission. Insufficient knowledge about HIV predisposes people to HIV infections.

STUDY LIMITATIONS

- ~~Research participants for the current study were few which make it difficult to generalize the findings to other studies.~~

- ~~Social constructionism is helpful in letting people tell their stories or experiences. Using qualitative research enables the researcher to make personal inputs based on his own knowledge. There is a possibility of that personal knowledge being flawed and might lead to wrong conclusions.~~

RECOMMENDATIONS

- The public still need to be educated about HIV and its transmission. Abstaining, being faithful and using condoms during sexual intercourse is not enough information that people can use to counter HIV infection. HIV awareness campaigns ~~have to~~must be intensified to educate people about HIV and its transmission.
- Misconceptions about the curative effect of HIV when having sexual intercourse with a young girl who is a virgin ~~have to~~must be eradicated. These misconceptions may predispose male PLWH to have unprotected sexual intercourse with young virgins and sometimes rape these young girls. A case in point is the narrative of Kate whose child was almost raped by her first fiancé who was advised by a sangoma that having sexual intercourse with a young girl who is a virgin will cure HIV.
- Measures ~~have to~~must be put in place to encourage PLWH to join support groups as they have been found to facilitate HIV status disclosure and as a source of knowledge institution about HIV and its transmission.
- HIV status disclosure should be encouraged even if it is not to significant others but to other people that the person living with HIV can trust.
- Further research studies are recommended on the issue of stigma and discrimination following disclosure. Many people who are on ARV treatment are asymptomatic and live long. This might have an impact or influence on the general public perception of PLWH being on a death row.
- Further research studies are ~~recommen~~recommended on the issue of disclosing HIV status for the benefit of others (HIV positive or not).

CONCLUSION

The purpose of the study was to explore factors that may influence disclosure of one's HIV status to significant others. The objectives of the study which were to give a platform for PLWH

to narrate their experiences of living with HIV, explore factors that influence disclosure of HIV status to significant others and recommendations based on the current study were discussed. The study used qualitative research methods to gain insight into the experiences of PLWH who disclosed their HIV positive status to their significant others. In-depth interviews were conducted with five participants who were between the ages of 36 and 49. All participants from the study narrated their personal experiences of living with HIV and their experiences of disclosing to their significant others. Positive and negative reactions were reported by their significant others. The benefits of disclosure which are some of the factors that influenced disclosure [waswere](#) recognized in the study. They include support, love and freedom. Finally, recommendations based on the study have been mentioned and could possibly enhance disclosure of HIV status to significant others.

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APPENDIX A- Copy of Permission letter request to conduct the study

52 Mongarva Street

Lotus Gardens

0008

23 September 2016

Dear Mrs K. Mashego (Director of Tshwane Multisectoral Aids Management Unit)

RE: REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT MSAMU ATTERIDGEVILLE SUPPORT GROUP

I am writing to request permission to conduct a research study at the above mentioned institution. I am currently enrolled in the Psychology Master of Arts in Research Psychology at the University of South Africa. The study is entitled **Controversy Surrounding HIV Status Disclosure: Lived Experiences Of People Living With HIV At The Tshwane Multisectoral AIDS Management Unit Atteridgeville Support Group**.

I hope that the Unit administration will allow me to recruit 6 individuals, males and females between the ages of 18 and 49 years from the MSAMU Atteridgeville support group to participate in the intended study. Interested participants who volunteer to participate will be given consent forms to sign and returned to the researcher at the beginning of the study.

If approval is granted, participants will be interviewed in a quite setting on site. The study will start immediately after the approval by UNISA ethics committee. The interview process will not take more than an hour with one participant. The results will be used for the dissertation project and individual

results of the study will remain confidential and anonymous. Should the study be published, only the results will be documented. No costs will be incurred by the unit or individual participants.

Your approval to conduct this study will be highly appreciated.

Yours faithfully

Thelonius Laka

Student Number: 07526806

APPENDIX B- informed consent letter

DEPARTMENT OF PSYCHOLOGY

Ref: Mrs Banti Mokgatlhe

Tel nr: (012) 429 8238

E-Mail: Mokgapb@unisa.ac.za

INFORMED CONSENT

PROJECT TITLE: EXPLORING NARRATIVES OF HIV STATUS DISCLOSURE BY PEOPLE LIVING WITH HIV: A CONSTRUCTIONIST APPROACH

You are invited to join a research study to examine an exploration into the experiences of people living with HIV from a Constructionist perspective. Please take whatever time you need to discuss the study with your family and friends, or anyone else you wish to. The decision to join, or not to join, is up to you.

-The envisaged study aims to explore the reasons for the decision for people living with HIV to disclose their HIV status to significant others

- To provide a platform for people living with HIV to share their personal experiences about their reasons for disclosing their HIV status

-To explore factors that could influence their decision to disclose their HIV positive status to significant others.

The proposed study will attempt to provide and may further contribute to better understanding of HIV infected individuals' reasons for making the decision to disclose their status. Understanding of the factors in making the decision to disclose one's HIV status is essential and critical to the PLWH (in accessing support) and their significant others including parents, partners, and everyone who is involved in giving support to the HIV infected individual.

WHAT IS INVOLVED IN THE STUDY?

If you decide to participate you will be asked to be involved in a semi-structured interview with the researcher. We believe this will take you 60 minutes for a period of one day. You will be asked a few questions on your experiences as an individual living with HIV and having disclosed your HIV status to significant others. The researcher will record your answers on the interview questionnaire and you may be audio recorded if you agree to the recording. The researcher may stop the study or take you out of the study at any time they judge it is in your best interest. They may also remove you from the study for various other reasons. They can do this without your consent.

You may stop participating at any time during the study if you so wish. If you decide to stop you will not lose any benefits from not participating or face any punitive measures.

RISKS

This study involves possible risks of re-experiencing any trauma that may have occurred because of being diagnosed with HIV or any trauma due to living with this disease. There may also be other risks that we cannot predict.

The researcher at this time does not foresee any risks from taking part in the study besides the risk that is stated above. However should you need psychological intervention during the study or after, a psychologist or counsellor will be appointed if need be.

BENEFITS TO TAKING PART IN THE STUDY

It is reasonable to expect the following benefits from this research: Highlighting and exploring your experience with regards to living with HIV/AIDS will increase the literature on the understanding and experience of HIV as a disease and possibly suggest strategies that may be put in place to further help people deal or live with this disease in South Africa. However, the researcher cannot guarantee that you will personally experience benefits from participating in this study. Others may benefit in the future from the information we find in this study.

CONFIDENTIALITY

We will take the following steps to keep information about you confidential, and to protect it from unauthorized disclosure, tampering, or damage:

- The interview recordings and questionnaire sheets will be held strictly confidential.
- The researcher will work with the raw data, while the research supervisor and external examiners will have access to the typed verbatim texts only.
- Any identifying details will be withheld from the questionnaire and the recordings through the use of assigned pseudonyms or random numbers. Any identifying information will be withheld and protected.
- The recordings will be kept in a secure password protected file and destroyed after 5 years.
- The questionnaires will be kept in a locked and secure cabinet and they too will be destroyed after 5 years.

INCENTIVES

There are no incentives available for the conducting of this research project.

YOUR RIGHTS AS A RESEARCH PARTICIPANT

Participation in this study is voluntary. You have the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which you are entitled, and it will not harm your relationship with your community.

CONTACTS FOR QUESTIONS OR PROBLEMS

If you have questions about the study, any problems, unexpected physical or psychological discomforts, any injuries, or think that something unusual or unexpected is happening, please contact Thelonius Laka at 0725316663 or email thelolaka@gmail.com.

Contact Ms Banti Mokgatlhe, research supervisor at the department of Psychology, University of South Africa at Mokgapb@unisa.ac.za, if you have any questions or concerns about your rights as a research participant.

STATEMENT CONCERNING PARTICIPATING IN THE RESEARCH PROJECT

I have learned and understood the aims and objectives of the proposed study and have been provided with 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 pressurised to participate in any way.

I understand that participating in the study is completely voluntary and that I may withdraw from it at any time without supplying reasons. I understand that confidentiality and anonymity will be ensured, and that my name will not be disclosed.

I know that this study has been approved by the University of South Africa Ethics Committee. I am fully aware that the results of the study will be used for scientific purposes and may be published. I agree to this, provided my privacy and anonymity is guaranteed.

I hereby give consent to participate in this study.

.....
Name of participant Signature Date Place

Statement by researcher

I provided 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.

Thelonius Laka
Name of Researcher Signature Date Place

APPENDIX C: ETHICAL CLEARANCE LETTER

Ref. No: PERC-16048



Ethical Clearance for M/D students: Research on human participants

The Ethics Committee of the Department of Psychology at Unisa have evaluated this research proposal for a Higher Degree in Psychology in light of appropriate ethical requirements, with special reference to the requirements of the Code of Conduct for Psychologists of the HPCSA.

Student Name: Laka, T. **Student no.** 7526806

Purpose of study: MA Dissertation

Supervisor/promoter: Ms. P.B. Mokgathe **Affiliation:** Department of Psychology, Unisa

Title of project:

Exploring the narratives of HIV status disclosure by people living with HIV: A social constructivist approach.

Result: Ethical clearance is granted.

The application was approved by the Ethics Committee of the Department of Psychology at Unisa on the understanding that all ethical requirements regarding informed consent, the right to withdraw from the study, the protection of participants' privacy and the confidentiality of the information will be met to the satisfaction of the supervisor.

Signed:

A handwritten signature in black ink that reads "HC Janeke".

Prof H C Janeke

[For the Ethics Committee]

Date: 27 October 2016

[Department of Psychology, Unisa]

APPENDIX D – INTERVIEW SCHEDULE

BIOGRAPHICAL INFORMATION

Date.....

Gender:.....

Age:.....

Marital Status:.....

Occupation:.....

When were you diagnosed with HIV ?.....

What is your highest level of education?.....

INTERVIEW GUIDE FOR PARTICIPANTS

Initial experiences of being diagnosed with HIV

- Can you tell me about life before you were diagnosed with HIV?
- When and how did you find out that you are HIV positive?
- What did it mean to you to be diagnosed with HIV?

Experience of living with HIV

- How would you describe your experience of living with HIV?
- What are some of the difficulties that you experienced following your diagnosis?
- How do you feel about your HIV status?
- How often do you use condoms?
- Have you accepted your status? What facilitated that process?
- How well do you think you have coped with living with HIV?
- Have you ever been discriminated against because of your HIV status?

Knowledge about HIV

- What you know about HIV?
- What do you believe are some of the causes of HIV?
- How does your community view HIV or an HIV positive person?

Experience of Disclosure

- When did you decide to disclose and why?
- What did you do to prepare yourself for the disclosure?
- Do you think it is necessary to prepare your significant others for the disclosure? Justify your argument.
- How do you think informing your significant, others of your status will benefit you and them?
- Which family member did you disclose to first and why?
- How did he/she react?
- How did this make you feel?
- What do you think were the advantages and disadvantages of your experience of disclosing to significant others?
- What do you think you needed to make your experience more bearable?
- Any additional comments.

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