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RAMIFICATIONS OF STATUS NON-DISCLOSURE BY PEOPLE LIVING

WITH HIV/AIDS IN ALICE, EASTERN CAPE

BY

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DECLARATION

I declare that the **“Ramifications of status non-disclosure by people living with HIV/AIDS (PLWHA) in Alice, Eastern Cape”** is my work. The sources I have used were acknowledged.

Signature

Date

DEDICATION

I dedicate this research project to Gugu Dlamini, who died at the hands of her community members after disclosing her status. Although you faced a tragic death, you left your footprint in the fight against HIV/AIDS in South Africa.

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I would like to express my gratitude to the following people that assisted me during the course of my study:

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ABSTRACT

Non-disclosure of HIV/AIDS status is a topical issue in South Africa and across the globe. This study explored the ramifications of status non-disclosure by people living with HIV/AIDS (PLWHA) in Alice, Eastern Cape. The study aimed to explore the benefits and opportunities associated with HIV/AIDS disclosure; to examine the underlying factors discouraging Alice PLWHA from disclosing their status; to ascertain the ramifications of HIV/AIDS non-disclosure and to describe the coping strategies PLWHA and their families adopt in dealing with the ramifications of non-disclosure.

The study employed the qualitative case study design, which was underpinned by the interpretive paradigm. The key informant's method, in-depth interviews and focus group discussions were the main data collection methods. The sample of 35 participants was selected through the purposive and snowballing sampling technique. This sample comprised of 10 PLWHA, 20 family members and 5 key informants. The data collected from this sample was analysed through thematic content analysis.

Findings indicated that PLWHA who disclosed their status accessed benefits and opportunities such as medication, psychosocial support, employment and the helping hands needed to manage their illness. In addition, the findings revealed that stigma, discrimination and socio-cultural factors inhibited some PLWHA from disclosing their status. Consequently, non-disclosure resulted in PLWHA experiencing ramifications such as internal stigma, conflict in relationships, diminished career and educational achievement.

In dealing with the ramifications of HIV/AIDS non-disclosure, PLWHA adopted both positive and negative coping strategies such as denial, self-acceptance, mediation, family therapy and engaging with faith-based and non-governmental organizations. The study recommends for robust anti-HIV/AIDS discrimination campaigns, research on internal stigma, an inclusive approach in the health care setting, enhanced partnerships between HIV/AIDS key stakeholders and the use of grants to entice NGOs into rural areas.

LIST OF ABBREVIATIONS

AIDS	: Acquired Immune Deficiency Syndrome
ATR	: African Traditional Religion
HIV	: Human Immunodeficiency Virus
PLWHA	: People Living with HIV/AIDS
SANC	: South African National AIDS Council
STDs	: Sexually Transmitted Diseases
WHO	: World Health Organisation

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CHAPTER ONE

INTRODUCTION OF THE RESEARCH

1.1 Introduction

This section introduces the study on the ramifications of status non-disclosure by PLWHA in Alice, Eastern Cape Province. South Africa is sitting on an HIV/AIDS time bomb, which, if not checked timeously, can explode with untold repercussions. This has signalled the government to put interventions in place to quell the epidemic. One such intervention is to supply people who are seropositive with anti-retroviral drugs (ARVS). People living with HIV/AIDS can be good drivers of HIV/AIDS awareness campaigns, as people listen to their messages more willingly than those who are seronegative (Allem, Leas, Caputi, Dredze, Althouse, Noar and Ayers, 2017). However, the country has a low rate of status disclosure and this is an impediment to a successful HIV/AIDS campaign (Roux-Kemp, 2013). In light of this concern, this chapter presents the background of the study, the research problem, research objectives, hypotheses of the study, delimitation of the study, research methodology, significance of the study, ethical considerations, limitations of the study, definition of concepts and the outline of the study.

1.2 Background of the Study

HIV/AIDS is a thorn in the flesh of most African countries. The World Health Organisation indicates that 25.8 million of the 36.9 million people living with HIV/AIDS are from sub-Saharan Africa (UNAIDS, 2015). Within this region, South Africa is the most affected country with 7,100,000 people living with HIV/AIDS (PLWHA) (UNAIDS, 2016). This accounts for the highest number of PLWHA in the world. This scenario poses an immense challenge to the country, which is one of Africa's economic powerhouses. Statistics from the National Health Department indicate that R43, 5

billion has been budgeted for HIV/AIDS programs for the next 3 years (Ndlovu and Meyer-Rath, 2014). Regrettably, this expenditure is unsustainable, as the economy has recorded a low economic growth rate since the 2008 global recession.

In light of the high prevalence of HIV/AIDS and the national interest in addressing the problem, an individual's HIV status remains a private issue in most cases (Roux-Kemp, 2013; Klopper, Stellenberg and van der Merwe, 2014). However, the country can only address or mitigate the effects of HIV/AIDS when people know their status and enrol in the government's ARV programme (Volberding, 2008; SANAC, 2016). Disclosure is also important to one's partner so that preventative measures can be taken timeously (Kalichaman, 2005; Ssali, Atuyambe, Tumwine, Segujja, Nekesa and Nannungi, 2010). Of equal importance is the fact people living with HIV/AIDS disclose their status publicly in the hope that the public will take the issue of HIV/AIDS more seriously and strengthen their interventions to respond to the epidemic (Volberding, 2008).

Experience dictates that a campaign presented by people living with HIV/AIDS has a greater impact on public awareness when presented by seronegative individuals (Allem et al., 2017). The fewer the PLWHA disclosing their status, the less effective the HIV/AIDS campaign (Simbayi, Kalichman, Strebel, Cloete, Henda and Mqeketo, 2007). In their analysis, Makin, Forsyth, Visser, Sikkema, Neufeld and Jeffery (2008) revealed that at the enrolment for their study, only 59% percent of the 293 HIV positive, pregnant women had disclosed their status to their partners. In another study, Sethosa and Petlzer (2005) found that 36% of 55 participants had disclosed their HIV/AIDS status but half of the participants were still having unprotected sex.

A 2007 survey of 413 men and 641 women living with HIV/AIDS found that among the 903 participants, 42% had sex without disclosing their status (Simbayi et al., 2007). Low HIV/AIDS disclosure rates are not limited to South Africa. A review of 17 developing countries, including 15 sub-Saharan African countries, revealed that the disclosure rates for PLWHA range from 16.7% to 86% (Ssali, Atuyambe, Tumwine, Segujja, Nekesa and Nannungi, 2010). These low rates of disclosure are a concern because research indicates that increased rates of status disclosure have positive benefits for PLWHA. These include practicing safer sex, adhering to treatment plans and accessing social support structures (Ssali et al., 2010).

The challenges PLWHA encounter when they disclose their status prevent most of them from enjoying the social benefits and inalienable rights enshrined in their countries' constitutions. This is because disclosure attracts stigma, discrimination and at times, violence (Barrett-Grant, Fine, Heywood and Strode, 2001). In South Africa, these challenges are apparent from the following cases. In Cape Town, a girl was murdered when she disclosed her status to her rapists (Carroll, 2003). In Durban in 1998, Gugu Dhlamini was beaten to death by a mob after she publicly disclosed her status (Barrett-Grant et al., 2001).

In a Melville, Johannesburg primary school Nkosi Johnson was refused admission because of his seropositive status (Itano, 2007; Ragimana, 2007). Although, these examples reflect the situation in South Africa, similar cases are occurring in other countries. In Dallas, America, after having sex, a mother of two was stabbed to death by her boyfriend after disclosing her status, and in Namibia 3 HIV positive individuals had their dignity violated when they were sterilised without their consent (Emily, 2013; Roseman, 2014). During the past several years, researchers have revealed several

impediments to disclosure, including power dynamics in relationships, belief systems and lack of knowledge on the importance of disclosure (Ssali et al., 2010).

The lack of knowledge and the importance of HIV/AIDS testing and disclosure can be an indicator of why 2 million South African's do not know their status (The South African Government News Agency, 2015). Studies have revealed that in environments where patriarchy and culture perpetuate power imbalances in relationships, disclosure of an HIV/AIDS positive status to a sex partner, especially by women in sub-Saharan Africa, can be fraught with negative outcomes (Wang, 2010). In recent times, the negative outcomes can include violence, abandonment, emotional and psychological abuse, as well as murder (SANAC, 2015).

Given that HIV/AIDS disproportionately affects women in South Africa, the highlighted negative outcomes can discourage some women from disclosing their status to their partners, families and caregivers. This not only undermines the country's effort to tackle the epidemic head-on, but it makes it difficult for the sub-Saharan region to achieve the sixth Millennium Development Goal (MDG) by the target date of 2015 (Ruxin, Binagwabo and Wilson, 2005). The sixth MDG aims to combat HIV/AIDS and other deadly communicable diseases (Kang'ethe, 2012; Ruxin et al., 2005).

In light of this goal, this study aimed to explore and unravel the ramifications of HIV/AIDS non-disclosure in Alice. Although there are studies on the challenges facing PLWHA in South Africa, this study contributed to the HIV/AIDS knowledge gap by exploring and unravelling the unique challenges that dissuade PLWHA in Alice from disclosing their status. Determining these challenges and suggesting ways to mitigate them will help the community to provide a climate of compassion and dignity in which

PLWHA can voluntarily disclose their status safely. Ideally, this can play a pivotal role in combating the HIV/AIDS pandemic in South Africa and sub-Saharan Africa at large.

1.3 Preliminary Literature Review

1.3.1 Stigma and discrimination

Globally, HIV/AIDS disclosure continues to be one of the most recommended public health panaceas for the control of the pandemic (Tshweneagae, Oss and Mgutshuni, 2015). The adoption of this recommendation has been limited in South Africa because stigma and discrimination remains widespread (Barrett-Grant et al., 2001; Kang'ethe, 2015). The People Living with HIV/AIDS Stigma Index Report of 2014 holds that “one third of the 10,473 PLWHA that took part in the study have experienced stigma and discrimination in their communities” (SANAC, 2015). Because of this, a third of the participants chose not to have children, while “14% decided to forgo marriage and 10% had suicidal ideation because of internalized stigma, which manifested in feelings of shame and guilt” (SANAC, 2015).

Drawing from Maslow's hierarchy of needs, the choices PLWHA have made rob them of their humanity and undermine their dignity and wellbeing (Rosdahl and Kowalski, 2008). Consequently, stigma negatively influences the life choices of PLWHA and it creates a climate of fear that deters people from being tested. This could explain why “19 million of the 35 million people living with HIV/AIDS today do not know their status” (UNAIDS, 2014).

1.3.2 The Impact of stigma and discrimination on HIV/AIDS disclosure

Stigma and discrimination prevent some PLWHA from disclosing their status to their families with the hope of protecting them from being ostracised (Stangl, 2009; Burke and Parker, 2007). In South Africa, the phenomenon of non-disclosure of HIV/AIDS to

family members is understandable given the history of communities that have segregated, ostracized and even murdered PLWHA (Ragimana, 2007).

Leah (2010) holds that this creates secrecy and isolation, which negatively affects an individual's attitude towards the disease and treatment commitments. Unfortunately, this secrecy does not last as a study conducted by Almeleh (2006) in Cape Town found that PLWHA are forced to disclose their status when they become ill. He asserts that this fuels the stigma that HIV/AIDS is a death sentence. However, this is both a stereotype and a myth as ARVs have given PLWHA renewed health and the hope of living normal lives (Kang'ethe and Xabendlinii, 2014). Consequently, secrecy and non-disclosure can place caregivers, who are usually elderly women, at risk of infection, because the health structure in most Southern African Development Community (SADC) countries cannot provide palliative care (Kang'ethe, 2010a).

Stigma and discrimination also discourages PLWHA from discussing their status with their sexual partners (Leah, 2010). This implies that negotiating for condom use becomes difficult, as this prevention method is associated with unfaithfulness, lack of trust and carrying of the disease. This hampers prevention interventions and has led to an overlying number of new infections and re-infections amongst adolescent girls and young women in sub-Saharan Africa (UNAIDS, 2014).

1.3.3 Disclosure challenges for HIV/AIDS positive women

The feminization of HIV/AIDS has contributed to the saying that HIV/AIDS has the face of a woman (Kang'ethe and Chikono, 2014; Kang'ethe and Munzara, 2014). Women tend to be affected by HIV/AIDS more than men due to their biological make up, gender inequality in some African families, cultural beliefs, cultural practices and patriarchy (Kang'ethe and Chikono, 2014). The unequal power relationships

perpetuated by patriarchy also make women susceptible to domestic violence if they disclose their status to their intimate partners. This violence emanates from the fact that women are victims of stigma and they are blamed for spreading the disease.

In South Africa, the severity of this problem is indicated by the “HIV positive AIDS” note that was found on the body of Mpho Motlough, a Soweto school teacher who, alongside her mother, was shot by her husband after disclosing her seropositive status (Treatment Action Campaign, 2000 cited in Machemedze, 2016). Another incidence was the case of Susan Teffo, who was severely burnt with a primus stove by her husband when she disclosed her HIV seropositive status (WHO, 2004). Fortunately, South Africa has implemented policies that protect women against all forms of gender-based violence (Gender Links, 2012).

The inconsistent application of policies by the police and women’s economic dependency on men inhibits most Sub-Saharan women from accessing protection against abuse (UN WOMEN, 2012). Consequently, fear of violence is cited as one of the reasons women drop out of the mother to child prevention of HIV/AIDS programmes (Kennedy, Haberlen, Amin, Baggaley and Narasimhan, 2015). This robs children of the essence of childhood as some of them die in the nascent stages of their childhood. This phenomenon also deprives these children of their inalienable right to live (Murray, 2013). Therefore, there is a need for women’s health and educational empowerment to receive priority in South Africa’s HIV/AIDS prevention campaigns.

1.3.4 The impact of culture and religion on HIV/AIDS disclosure

Scientifically, HIV/AIDS may be a broad clinical term, but it has enormous cultural significance and meaning to different people (Norridge, 2013). The cultural roots that underpin the non-medical representations of HIV/AIDS influence the way in which

people view and respond to those who disclose their status (Bailey, 2008). For instance, research revealed that in some parts of Africa, including Zaire, Botswana and Uganda, it was initially believed that women were to blame for the spread of disease (Harms, Spies and Maseko, 2010). This is the phenomenon that researchers in the field of HIV/AIDS, such as Kang'ethe, Chikono and Munzara, refer to as the feminization of HIV/AIDS (Kang'ethe and Chikono, 2014; Kang'ethe and Munzara, 2014). Researchers from these countries were of the opinion that when men are infected, their wives are suspected of infidelity; when women are infected, it is assumed they have had multiple partners.

This belief emanated from the fact that chastity is skewed in that it is demanded of women more than it is of men (Harms, Spies and Maseko, 2010). This kind of thinking is perpetuated by ignorance and lack of accurate and relevant information regarding the pandemic. Apart from this, culture is cited to have influenced the infamous myth that having sex with a virgin, or even a baby, will cure the rapist of HIV/AIDS (Kang'ethe and Xabendlini, 2014). The opinion of this researcher is that culture is dynamic and through concerted efforts to educate people a synergy can be formed on how people can be receptive to individuals that disclose their status.

Religion has its own unique interpretation of HIV/AIDS and how it is transmitted (Byamugisha, Steinitz, Williams and Zondi, 2002). The Christian perception that HIV/AIDS is the wrath of God for those who have the audacity to engage in immoral sex has had a profound impact on the stigmatization of PLWHA (Chalk, 2014). Even though most faith-based organizations adopted a non-judgmental approach towards PLWHA during the nascent stages of the disease, they contributed to the marginalization and the most insidious forms of discrimination against those who

disclosed their status (Byamugisha et al., 2002; Chalk, 2014). In the familial sphere, numerous studies have shown how families have shunned their own family members to remove the shame of having the disease (Kang'ethe, 2010b). The discrimination has been worse for gay people as some people feel that they deserve the illness due to their sexual orientation. This has had a negative impact on the fight against HIV/AIDS, as deviant groups such as gay people are at risk of transmitting the disease.

1.3.5 HIV/AIDS disclosure and negative community responses

In many countries, especially those hardest hit by the epidemic, poor community reception has had a negative impact on individuals who wish to disclose their status (Barrett-Grant et al., 2001; SANAC, 2015). The case of Gugu Dlamini's death in 1998 has led some PLWHA to live in denial of their status and they only mention opportunistic infections when asked about their status (Kalichaman, 2009; Harms, Spies and Maseko, 2010). Some people even face the challenge of dying without seeking treatment and medication (Mbonu, van den Borne and De Vries, 2009). The need to distance oneself from HIV/AIDS has not only influenced non-disclosure, but it has also resulted in people distancing themselves from healthcare facilities and social grants (Kalichman, 2009). Orphans are the worst affected as they could benefit from these social services. Consequently, this can contribute to the social problem of impoverished and child-headed families.

1.3.6 The impact of HIV/AIDS disclosure on divorce

The support of family members can play a positive role in the lives of PLWHA when they disclose their status (Li, Wu, Wu, Jia, Lieber, and Lu, 2008). Studies have shown that family members, specifically in Bantu communities like those in South Africa, form solidarity in ensuring that PLWHA follow treatment protocols. However, disclosure has

had the perfidious and ramifying effects of leading to divorce in some cases. This is due to the partners failing to come to terms with the reality of the disease and failing to surmount the pressures and ignorance imposed by stigma.

One of the most perfidious effects associated with disclosure is when the people who are disclosed do not adhere to the principles of confidentiality and they leak the information to the community, where it spirals out of control. This can wreak havoc for those who disclose their status as societies often turn their backs on the infected (Frank and Rodlash, 2013). Studies indicate that divorce tends to be gendered meaning it affects women more than men. Furthermore, divorce affects children and it can lead them to seek solace in gangs that engage in deviant criminal behaviour (Burke and Parker, 2007).

1.4 Research Problem

South Africa's low HIV/AIDS disclosure rate is undermining the country's capacity to expedite prevention measures. Patriarchy, culture, religious inclinations, stigma, divorce, separation and ignorance constitute some of the factors believed to undermine the country's disclosure rate. Due to this, lives have been destroyed, ambitions have been dashed and the stable functioning of families and communities have been disrupted when an individual's status has been disclosed, creating a volatile environment for grave injustices. The low disclosure rates are a concern because they weaken the South African HIV/AIDS prevention campaign, which is poised to benefit from factors such as intimate partner disclosure, caregiver-client disclosure and public disclosure. It is therefore crucial that challenges impeding PLWHA from disclosing their status in Alice be empirically investigated with the hope of coming up with

recommendations that can mitigate the ramifications associated with HIV/AIDS non-disclosure.

1.5 Aim

The aim of this qualitative study was to explore the ramifications of status non-disclosure by PLWHA in Alice, Eastern Cape Province.

1.6 Research Objectives

The specific objectives of this study are:

- To explore the opportunities and benefits associated with PLWHA in Alice disclosing their status.
- To examine the underlying factors discouraging PLWHA in Alice from disclosing their status.
- To ascertain the ramifications of HIV/AIDS non-disclosure by PLWHA in Alice, Eastern Cape.
- To describe the coping strategies PLWHA and their families adopt in dealing with the ramifications of HIV/AIDS non-disclosure.
- To make recommendations that could mitigate the ramifications of HIV/AIDS non-disclosure by PLWHA in Alice.

1.7 Research Questions

The following research questions guided this study.

- What are the opportunities and benefits associated with PLWHA in Alice disclosing their status?
- What are the underlying factors discouraging PLWHA in Alice from disclosing their status?

- What are the ramifications of HIV/AIDS non-disclosure by PLWHA in Alice, Eastern Cape?
- What are the strategies that PLWHA and their families adopt in dealing with the ramifications of HIV/AIDS non-disclosure?
- What recommendations can mitigate the ramifications of HIV/AIDS non-disclosure in Alice?

1.8 Theoretical Framework

1.8.1 The Labelling Theory / Social Reaction Theory

This theory can be traced back to *'Suicide'*, a book written by Emile Durkheim (Durkheim, 1897). However, in 1963 *'Outsiders'*, a book written by Howard Becker, is thought to have contributed to the development of the theory by theorising that society produces deviance (Becker, 1963). Thus, this theory is based on the assumption that no act is "criminal or deviant because deviance only arises from the imposition of social judgments on the behaviours of others" (McLaughlin and Muncie, 2013). This assumption fits well with this study because some societies view PLWHA as deviants who have not conformed to the moral and ethical codes of society.

In these societies PLWHA, are often labelled and stigmatized. Labels are a double-edged sword that has both a positive and a negative impact on the identity and the behaviour of a deviant individual (Walker, 2004). Becker holds that the internalisation of labels can negatively affect the self-worth of an individual, as the label can become the master status people use to describe the individual. This status often leads to the segregation and isolation of the deviant individual from mainstream society. This scenario largely mimics the position of the current PLWHA who, upon being diagnosed with the virus, view their identity with shame and regret. They label themselves and

can even remove themselves from mainstream society. It is this perception of themselves that makes disclosure a very difficult proposition.

In summary, Becker asserts that the internalization of labels given by society can cause deviants to develop a subculture that leads them to develop a deviant career. This can be viewed as self-fulfilling prophesy because the deviant career is characterised by the negative things associated with a given label. However, the labelling theory has been criticised for being empirically weak and because of this, a modified version of the theory was developed. Despite this criticism, the theory will be used in this study because its basic assumptions provide a framework for understanding the HIV/AIDS label and the influence it has on the ramifications of HIV/AIDS non-disclosure.

1.8.2 The Stigma Theory

This theory was promulgated in 1963 by Erving Goffman, who is recognized as one of the most prominent American sociologists of the 20th century (Amzat and Razum 2014). In his key work, *“Stigma; Notes on the Management of Spoiled Identity,”* Goffman holds that the term stigma was used by ancient Greeks to denote bodily signs intended to reveal something unusual or bad about the moral status of the signifier or offender (Goffman, 1963). Slaves, criminals and traitors were the most vulnerable groups of people who had these signs cut or burned into their flesh. Stigma is no longer limited to bodily marks as it is also recognised as a mark of shame, guilt, disgrace or any identifying characteristic that can stain an individual’s reputation (Bros et al., 2013).

Goffman posits that stigma is a phenomenon that causes an individual with an undesirable attribute to be discredited by his society. Although, they are different types

of stigma, the devaluation of self begins with the process of internal stigma. This process is characterised by an individual adopting people's discredit. It consciously or unconsciously affects an individual's psychological wellbeing thereby creating negative emotions such as fear, shame, hopelessness and condemnation.

Due to the negative connotations associated with HIV/AIDS many PLWHA find themselves in this situation and disclosure can be a difficult task for them. The opposite of internal stigma is external stigma. This is how society views an individual with a devaluing trait. Internal and external stigma are inter-dependent as they mutually reinforce and overlap each other (Haralambos and Holborn, 2008). This study adopted the stigma theory as it provides a framework for understanding the internal and external forces that inhibit HIV/AIDS disclosure. Despite that, the stigma theory is criticised for its individual focus it was used in this study because it enabled the researcher to show how stigma can undermine or promote HIV/AIDS non-disclosure.

1.9 Research Methodology

This is a systematic process of methods and approaches that are used to conduct an empirical research study. The research methodology is typically composed of the tripartite linkage of the research design, methodology and data analysis.

1.9.1 Research paradigm

This study adopted the interpretative paradigm that "is an all-encompassing system of interrelated epistemological assumptions about how human beings know the world and ontological assumptions about the nature of reality" (Thomas, 2010). A paradigm includes "methodological assumptions about the process of research and axiological assumptions about the roles of values and ethics" (Thomas, 2010). The interpretative paradigm was adopted in this study because it holds the ontology that there are

multiple realities and it adopts an interactional epistemological stance, which enables the researcher to use the qualitative methodology. Essentially, the qualitative methodology relies on the subjective relationship between the researcher and the research participants. Thus, in adopting the interpretative paradigm, the researcher was able to understand the subjective realities about the ramifications of HIV/AIDS non-disclosure.

1.9.2 Research design

This is a “blueprint or a plan” that specifies how the research will be executed in order to provide answers to the research questions (Terre Blanche, 2006). This study adopted a qualitative research approach that aimed to explore and understand the meaning that individuals or groups attribute to a social or human problem.

1.9.3 The specific research design

A qualitative case study design was used in this study. The advantage of using this strategy was that it enabled the researcher to gather descriptive in-depth information about the studies topic (Creswell, 2006).

1.9.4 Data collection process

This study used the cross sectional data collection process. This process involves the collection of data at a specific point in time (Terre Blanche, 2006). This data collection method was adopted in this study because it is relatively quick to conduct and it enables the researcher to analyse the different outcomes of the data.

1.10 Methods of Data Collection

The researcher collected data through the key informant method, in-depth-interviews and focus group discussions.

1.10.1 In-depth Interviews

This is a conversation or the most natural form of interaction between the researcher and the studies participants (Gill, Stewart, Treasure and Chadwick, 2008). Semi-structured, one-on-one, in-depth interviews were conducted in this study because they enabled the researcher to probe and elicit the subjective meaning PLWHA attach to the ramifications of HIV/AIDS non-disclosure. Despite that HIV/AIDS is a sensitive topic, in-depth interviews were appropriate for this study because they create an open environment that enables participants to express themselves freely (Gill et al., 2008).

1.10.2 Focus group discussions

Focus group discussions with five participants each were conducted in this study. They enabled the researcher to tap into the different experiences PLWHA s' families and community members had about HIV/AIDS non-disclosure and its ramifications.

1.10.3 Key informant method

The key informant method was adopted in this study because it provided the researcher with expert knowledge about the phenomenon under study. Thus, the main advantage of using the key informant method was that it enhanced the researcher's awareness towards the challenges, decisions and underlying issues associated with the ramifications of HIV/AIDS non-disclosure.

1.10.4 Research instrument

A semi-structured interview schedule was the research instrument used in this study. Essentially, this is a flexible template that enables the researcher to obtain new information during an-depth interview or a focus group discussion.

1.10.5 Research Domain and Justification

The town of Alice was the study domain. The researcher chose this rural town because patriarchy, religion and stigma are prevalent and more likely to prevent PLWHA from disclosing their status.

1.10.6 Population under Study

This is a list of the available people or categories the researcher seeks to investigate (Creswell, 2006). The target population in this study was all PLWHA, their family members, healthcare workers and key informants from Alice, Eastern Cape. However, the target population that was used in this study consisted of sero-positive individuals that were served by the central hospital and clinics in Alice. This population was appropriate for this study because it consists of participants who have in-depth knowledge about the research topic.

1.10.7 Sampling Procedure / Methodologies

This study used the non-probability sampling method where the selection of the research participants is not determined by statistical randomness (Gomm, 2008). In this light, the researcher adopted the purposive and snowball sampling technique, which relies on the availability and willingness of participants to participate. This technique was appropriate as PLWHA are not easily accessible and it enabled the researcher to select a small sample that produced in-depth information about the studies topic.

1.10.8 Sample Selection Criteria of Inclusion and Exclusion

The PLWHA in Alice who receive health services at Victoria Hospital and War Memorial clinic fit the eligibility criteria for this study. Given that HIV/AIDS has a direct and indirect effect on family members, the researcher deemed it pertinent to include

the families of those who have suffered the adverse consequences of HIV/AIDS non-disclosure. The researcher excluded all those who did not have familial relationships with PLWHA in Alice. Only healthcare workers that assist PLWHA at Victoria Hospital and at War Memorial Clinic were included in this study as they have institutional knowledge about some of the ramifications of HIV non-disclosure. Key informants such as a social activist and a social worker were included in this study because they hold regular debriefings with PLWHA.

1.10.9 Sample Size / Unit of Analysis

A sample is a subset of research participants that represent the study population. Sample size refers to the number of units that are chosen for data collection. This study included a sample of 10 PLWHA, 20 family members and 5 key informants. The small sample size of 35 people enabled the researcher to gain a thick description of the phenomenon under study. The table below presents the targeted sample of participants.

Table 1: Sample of Participants

Number	Type of data collection	Interview Sample	Set of Samples
1	In-depth Interviews	PLWHA	10
2	4 Focus group discussions	Family members	20
3	Key informants (KI)	(2) Health Workers, a social worker, a community leader and an individual from a NGO	5

			35
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1.11 Data Analysis

The thematic content analysis method was used to analyse data in this study. This method was adopted in this study because it enabled the researcher to develop emerging themes from the participant's perspectives and at the same time examine different aspects of the study (Klincewicz, 2008).

1.12 Significance of the Study

This study is significant because the recommendations and publication of this study could lead to the development of campaigns and institutional reforms that mitigate the ramifications of HIV/AIDS non-disclosure. The theoretical significance of this study is that it contributes to existing literature by indicating how the labelling and stigma theories discern the African realities of the ramifications of HIV/AIDS non-disclosure.

1.13 Research Methods Linked to the Research

Table 2: Research Methods

Research Question	Data Sources and Methods	Justification
What are the ramifications of HIV/AIDS non-disclosure?	Interviews	PLWHA will be able to provide an in-depth description of the ramifications of HIV/AIDS non-disclosure.

What are the opportunities and benefits associated with PLWHA disclosing their status?	The key informant method and focus group discussions.	The methods will enable participants to reveal how disclosure can be a useful tool in preventing the spread of the pandemic.
What coping strategies can PLWHA and their families adopt in dealing with the ramifications of status non-disclosure	The key informant method and focus group discussion.	These methods enable the participants to provide strategies that may mitigate the ramifications of non-disclosure.

1.14 Assumptions

The specific assumptions of this study are as follows:

- Stigma and discrimination are a deterrent to HIV/AIDS status disclosure.
- Socio-cultural factors are a latent driver of HIV/AIDS non-disclosure.
- Financial support and opportunities can facilitate HIV/AIDS status disclosure.

1.15. Ethical Considerations

1.15.1 The vulnerability of PLWHA

These individuals are susceptible to stigma, discrimination and violence, which not only impairs their dignity and safety, but also has repercussions for their families and communities. PLWHA in Alice are also vulnerable because they come from a poor socio-economic background. Given the sensitive nature of this study, the researcher

applied for ethical clearance from the University of Fort Hare Ethical Clearance Committee and adopted the following safeguards to protect the rights of PLWHA.

1.15.2 Informed consent

The researcher was obliged to inform the participants about all the relevant aspects of the research. This included information about the studies goals, advantages and disadvantages (Gomm, 2008). The researcher also sent a letter providing a full description of the intended study to the head of Victoria Hospital and War Memorial Clinic. Another letter was sent to the Health District Council asking for permission to enter the research field. The researcher made an official visit to the healthcare facilities where the assistance of a nurse was sought to procure the verbal and written consent of research participants.

1.15.3 Avoidance of harm

The researcher's intention was to safeguard participants from psychological, social, and cultural harm. In this regard, the researcher ensured that counselling services were available for participants that experienced emotional distress during the interviews. The interview questions were also constructed in a sensitive manner that did not discriminate or offend the participants. Furthermore, the interviews and focus group discussions were conducted in a safe environment that did not expose the participants to any harm.

1.15.4 Anonymity and confidentiality

The researcher used pseudonyms to ensure the anonymity of the respondents. All data gathered from the interviews was also analysed in a manner that protected the anonymity and confidentiality of the participants. Additionally, data collected from interviews was stored in a secure place. Most importantly, participants were informed

that data from the recorded interviews would be destroyed 5 years after the publication of the research project.

1.16 Chapter Outline

This thesis is arranged as follows.

Chapter 1: Introduction of the research. This includes the background of the study, preliminary literature review, problem statement, aim, objectives, research questions, significance of the study, theoretical framework, research methodology and ethics of the study.

Chapter 2: Literature review and theoretical framework. This chapter comprised of the legal framework and benefits of HIV/AIDS disclosure. It also included a literature discourse on the ramifications of HIV/AIDS non-disclosure. The coping strategies associated with the ramifications of HIV/AIDS non-disclosure and the two studies theories (stigma and labelling theory) were outlined.

Chapter 3: Research methodology. This chapter comprised of the qualitative research design, data collection methods, data analysis method and ethical considerations associated with this study topic.

Chapter 4: Data analysis, interpretations and presentation. Essentially, this chapter comprised of a comprehensive overview of how data was analysed and presented into different themes.

Chapter 5: Discussion of the findings, conclusion and recommendations associated with HIV/AIDS non-disclosure.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In this study, Chapter one laid the framework in which, the different phases of the research project could be formulated. Unlike Chapter 1, which is the backbone of this study, this chapter seeks to review literature pertaining to this studies topic. In this light, the outline for this chapter is as follows; the legal framework that provides for the rights of PLWHA; the benefits and opportunities of status disclosure; the challenges that influence non-disclosure; the ramifications of HIV/AIDS non-disclosure and lastly the conceptual framework that underpins the study.

2.2 Operational Definition of Terms

2.2.1 HIV/AIDS

The human immunodeficiency virus (HIV) is a chronic illness that negatively affects the CD4 cells of an individual's immune system (Deeks, Lewin and Havlir, 2013). Failure to treat this illness can lead to the development of AIDS, which is acquired immunodeficiency syndrome (Deeks, Lewin and Havlir, 2013). In South Arica, sexual transmission is the predominant mode of transmission of this illness. Although, there is no cure for HIV, it can be controlled by antiretroviral therapy (ART).

2.2.2 Disclosure

This is when an individual expresses their thoughts, feelings or experiences to others (Mize, 2013). In this study, the term disclosure encompasses the verbal or nonverbal ways PLWHA adopt in sharing their HIV- seropositive status with a confidant. Being HIV-seropositive means, that one's body is producing antibodies for HIV (Deeks, Lewin and Havlir, 2013). The antibodies are detected by a means of an HIV antibody test. This is the most common HIV test used in South Africa.

2.2.3 Panacea

This refers to a solution or remedy for difficult situations. In this study, the term panacea is used to portray HIV/AIDS disclosure as one of the solutions for preventing HIV/AIDS.

2.2.4 Perfidy

This is the state of being fraudulent and dishonest. In this study, this term refers to the idea that some PLWHA's motives for disclosing their status are not entirely honest and in the best interest of preventing the pandemic.

2.2.5 Spin-offs

This term refers to splits that derail the formation of a corporate process. The derailing aspect about the term spinoffs will be to refer to challenges that hinder PLWHA from reaping the benefits of disclosure.

2.3 The Legal Framework for the Rights of PLWHA

2.3.1 The Constitution of South Africa [Act No. 108 of 1998]

In South Africa all people, whether HIV- seronegative or HIV- seropositive, have fundamental rights they possess just because they are human beings (Rohleder, Kalichman, Swartz and Simbayi, 2009). These rights are enshrined in the Constitution, principally in the Bill of Rights, which provides for the basic rights of all citizens. The 1996 South African Constitution came into effect on the 4th of February 1997. This was a replacement of the 1993 Constitution, which was both oppressive and discriminatory (Harms, Spies and Maseko, 2010). The discriminatory nature of the 1993 Constitution can be attributed to the apartheid system (Heymann and Cassola, 2012).

2.3.2 The right to health

PLWHA have the fundamental right to health. This right is enshrined in Sections 27(1) (a) and 27 (3) of the South African Constitution, which is one of the most progressive constitution in the world (Harms, Spies and Maseko, 2010). These sections state that:

(1) *“everyone has the right to have access to health care services, including reproductive health care”*.

(3) *“no one may be refused emergency medical treatment”*.

To ensure the full protection of this right, Section 27 (2) states that the state should:

“take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights”.

The fundamental right to health is important for PLWHA as it allows them to access medical support, counselling and medication, such as antiretroviral drugs. During President Thabo Mbeki’s term in office, the state limited the distribution of these drugs, specifically Nevirapine, to research and training sites only (Harms, Spies and Maseko, 2010). Nevirapine lowers the risk of mother to child transmission of HIV during birth (Harms, Spies and Maseko, 2010). It was only after the Treatment Action Campaign case that the South African Constitutional Court found that the state’s policy was unconstitutional, as it did not fulfil the healthcare provisions provided for in the Bill of Rights (Harms, Spies and Maseko, 2010).

This watershed judgement was significant because it forced the Mbeki regime to provide ARVs to vulnerable citizens at a time when the country had a high prevalence of HIV/AIDS. This case also shows that a progressive Bill of Rights and an enlightened judiciary are important in safeguarding the right to health for PLWHA.

3.3.3The right to equality

This inalienable right is based on the idea that the law should treat people the same without discrimination. Discrimination 'is when an individual receives differential treatment that is unjust (SANAC, 2014). In the context of HIV/AIDS, discrimination can be overt or subtle, as it can range from being ostracized and to being gossiped about. According to Harms, Spies and Maseko, (2010) the equality clause in the South African Constitution is enshrined in Section 9 and it states that:

9. (1) "everyone is equal before the law and has the right to equal protection and benefit of the law."

9. (3) "The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth".

9. (4) "No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination".

The Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) (2000), gives effect to Section 9 of the Constitution by prohibiting discrimination on the grounds of an individual's HIV/AIDS status (Harms, Spies and Maseko, 2010; Judem, 2014).

Furthermore, PEPUDA reinforces the equality clause of the Constitution by outlawing forced disclosure of an HIV/AIDS status (Judem, 2014). Despite the legal and constitutional mechanisms that outlaw all forms of discrimination against PLWHA, experts are concerned that the implementation of these laws by the legal system is limited. This can be attributed to the fact that not all people are cognizant of their rights and the fact that corruption is rife within the police force (Judem, 2014; UN WOMEN, 2012). For instance, in 2013, a human rights survey conducted by the Ford Foundation found that only 10% of its participants had read any part of the Constitution and only 46% knew of its existence (Judem, 2014).

2.3.4 The right to privacy and confidentiality

This right underscores the importance of people protecting information about their personal lives from the public sphere (Makulilo, 2016). This right entails that an individual has the autonomy to choose when private health information should be made public. In this light, this right underscores that no person has the liberty to disclose information about another person's status without his/her consent. However, the right to privacy is not absolute and it can be limited when a court deems that the confidentiality of information facilitates a violation of another person's right (Makulilo, 2016).

For example, in the SADC region, the need to safeguard women from HIV/AIDS is indicated by Article 14 (e) of the Maputo Protocol. The Article states that, "women have the right to be informed on the health status of one's partner, particularly if the partner is infected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognized and best practices" (Kambarami, 2009). The right to privacy is also enshrined in Section 14 of the South African Constitution.

This section states that:

“Everyone has a right to privacy, which includes the right not to have:

- their person or home searched ;
- their property searched;
- their possessions seized;
- the privacy of their communication infringed”

In the international context, the right to privacy is also entrenched in Article 17 of the Covenant of Civil and Political Rights (ICCPR) (Makulilo, 2016). In South Africa, this covenant provides a framework for the interpretation of the Bill of Rights and revision of municipal legislation that provides for the right to privacy and confidentiality (Harms, Spies and Maseko, 2010). The legislation includes the National Health Act, while the policies include the Health Professional Council of South Africa (HPCSA), Ethical Guidelines for Good Practice with Regard to HIV (2007) and the South African Medical Association (SAMA) (Harms, Spies and Maseko, 2010; Makulilo, 2016).

2.4 National Statues and Rights for PLWHA

2.4.1 The National Health Act [No. 61 of 2003]

Section 14 of the National Health Act (NHA) states that health officials should keep information about one’s health status in private. In this regard, this section states that:

- “All information concerning a user, including information relating to his/her health status, treatment or stay in a health establishment should be confidential”.

Subject to section 15, no person may disclose any information contemplated in subsection (1) unless -

- “the user consents to that disclosure in writing”;
- “a court order or law requires that disclosure” or
- “non-disclosure of the information represents a serious threat to public health”

Confidentiality fosters trust and it enables patients, specifically PLWHA, to provide their practitioners with information that can assist them to make a good diagnosis of their illness. This trust creates a moral dilemma for doctors summoned by the law to disclose a patient’s records or HIV/AIDS status. However, the right to confidentiality is a thorny issue as medical workers sometimes violate this right through non-consensual disclosure. A classic example is when Doctor Kruger, a medical practitioner, disclosed a patient’s status to two other doctors during a game of golf (*Jansen van Vuuren v Kruger*) (Harms, Spies and Maseko, 2010).

The indignity faced by the patient and the consequent stigma and discrimination led the court to direct doctor Kruger to award the patient a ZAR 5000 financial remedy. Drawing from both the stigma and labelling theory, his remedy is limited in restoring this man’s tarnished character and social standing. Against this background, it is understandable that policies such as HPCSA Guidelines, Ethical Guidelines for Good Practice with Regard to HIV (2007) and the SAMA Guidelines on HIV Disclosure devote attention to the legal aspect of confidentiality (Makulilo, 2016).

2.5 Disclosure and Education

2.5.1 The education policy on HIV/AIDS

The South African educational policy was adopted in accordance with international norms and constitutional guarantees of the right to education, privacy and non-discrimination. According to Roux-Kemp, (2013) Section 4.4 of the policy states that:

- “Learners and educators are not compelled to disclose their status. In cases where voluntary disclosure of their status has been done, it should be treated with confidentiality”.

This policy asserts that no child should be subjected to mandatory testing and precautionary measures should be implemented to mitigate the risk of transmission in schools. This policy also asserts that HIV/AIDS education should be a core component of the school's curriculum. This is important because education can help demystify the myths and misconceptions some South Africans have about the disease.

2.6 Disclosure and Intimate Relationships

2.6.1 The Sexual Offences and Related Matters

In South Africa, there is no explicit legislation that requires PLWHA to disclose their status to their sexual partners. Despite the absence of this requirement, PLWHA still have the moral obligation to disclose their status to their sexual partners. Section 5 of the Sexual Offences and Related Matters Act states that failure to disclose one's status may result in PLWHA being charged with the intentional will to transmit HIV/AIDS (Roux-Kemp, 2013). This charge is also applicable to sexual offenders who pose the risk of deliberately transmitting HIV/AIDS to their victims. The South African Sexual Offences and Related Act can be compared to the Zimbabwean Sexual Offences Act. In this Act Section 15, criminalizes the wilful transmission of HIV/AIDS and it carries a maximum sentence of 20 years. Despite that, this heavy sentence is

supposed to act as a deterrence against the wilful transmission of HIV/AIDS very few individuals have been prosecuted (The Sentinel, 2015) .

2.7. The Benefits of HIV/AIDS Disclosure

2.7.1 Increased uptake of treatment and testing

HIV/AIDS is no longer a death sentence for individuals that disclose their status and are successfully initiated on antiretroviral treatment (Wheeler Centre, 2014: WHO, 2015). Literature shows that early initiation on ARVs not only reduces morbidity and mortality, but it also prevents opportunistic infections such as tuberculosis and other HIV/AIDS non-defining illnesses (WHO, 2015). Currently, the power of this life saving treatment is evidenced in UNAIDS Prevention Gap Report (2016) that states that, the rollout of anti-retroviral treatment has contributed to a 26% global decline in AIDS related deaths. In South Africa, the miraculous power of ARVs has not only saved 1.3 million lives since 1995, but it helped increase life expectancy from 52 years in 2004 to 61 in 2014 (UNAIDS, 2015, p. 226).

South Africa has the world's largest treatment program. In this regard, HIV/AIDS disclosure can be beneficial for seropositive individuals because they can access ARVs that keep their immune system healthy and greatly reduce the risk of them transmitting the virus to others (UNAIDS, 2016). The positive impact of ARVS in reducing HIV transmission among intimate partners has been shown in the HIV/AIDS Prevention Trails Network (HPTN) 052 study conducted among 1763 sero-discordant couples in 13 sites in Africa, Asia and America. This landmark trail showed that early initiation on ART reduces the risk of "HIV-1 transmission to the seronegative partner by 96%" (Cohen et al., 2011).

Given that sero-discordant couples are becoming Africa's biggest HIV/AIDS risk group the World Health Organisation (2012) states that early initiation on ART and self-disclosure can perhaps create opportunities for preventing onward transmission.

In as much, as the South African government has heavily invested in its treatment program, it is quite disturbing to note that some PLWHA are unaware of their status and are not accessing ARVs. In this light, self-disclosure of one's status can encourage intimate partners to go for voluntary counselling and testing (VCT) (Gari, Habte and Markos, 2010; Tshweneagae et al., 2015). According to the WHO (2012, p. 64) "couple testing and counselling can bring enormous benefits, including disclosure of HIV status to partners, stronger uptake of and adherence to ART and PMTCT interventions. In South Africa where domestic violence is a key feature of the HIV/AIDS epidemic. The VCT centre can perhaps provide women with a safe environment to disclose their status and receive the necessary support needed to adhere to their medication.

2.7. 2 Disclosure and psychosocial support

2.7.2.1 Support groups

HIV/AIDS is a stressful disease that can cause psychological and social problems, due to stigma and discrimination. The negative effect with psychological and social problems is that they can cause PLWHA to experience an existential crisis, lifestyle changes, strained interpersonal relationships and social isolation (Bravo, Edwards, Rollnick and Elwyn, 2010). However, within the HIV/AIDS discourse Liampattuong (2016) notes that community support structures such as support groups can mitigate some of the psychosocial effects of HIV/AIDS. Essentially, a support group is a safe haven, where people facing similar life situations share their experiences and provide each other with mutual support and information (WHO, 2005; Glick, Rait, Heru and Ascher, 2015, p. 335).

The advantage with this psychosocial intervention is that it is not only cost effective to implement, but it also provides PLWHA with the opportunity to improve their self-esteem and self-management skills (WHO, 2008; Wang, Shi, Chen, Peng, 2016). In this regard, HIV/AIDS disclosure is beneficial for Alice PLWHA, because they can join support groups that promote psychological resilience, social, physical, mental and emotional welling.

2.7.2.2 Peer support groups

Peer support is a “process of giving and receiving nonprofessional, nonclinical assistance from individuals who share a similar condition or circumstance (Tracy and Walter 2016, p. 143). In peer support groups, the most common benefit of receiving assistance from people who share ‘the same medical condition is that it reduces isolation and it enables an individual to receive empathy’ (Wisniewski, Chernausek and Kropp, 2012). Furthermore, Marino, Simoni, Silverstein, (2007) state that sharing a common experience fosters a sense of social acceptance and it reduces the stigma associated with HIV/AIDS.

Perhaps, another important aspect about HIV/AIDS peer support groups is that they encourage disclosure, which can become a catalyst for increasing levels of emotional support and adherence to treatment (van Royen, Essack, Roachat, Wight, Knight, Bland, Celum, 2016; WHO, 2005). Encouraging HIV/AIDS disclosure among PLWHA is important because can it can provide family members with the opportunity to participate in peer support groups. In stigmatizing societies, this opportunity is important because peer support groups can serve as a place of refuge against courtesy stigma. Equally important, peer support groups provide PLWHA with the opportunity to receive treatment and literacy support (WHO, 2008).

According to the WHO (2005), in peer support groups, the total experiences of member's fears and feelings of confusion regarding treatment are addressed by other members and support group leaders. This educational component and therapeutic focus plays an instrumental role in reducing the anxiety, fear and negative emotions associated with the disease (WHO, 2012).

In rural areas like Alice where literacy levels are low (UNAIDS, 2006), treatment support can provide PLWHA with the opportunity to de-medicalise terminology-surrounding ART. Additionally, PLWHA can access treatment partners or buddies that can help them deal with the side effects of ART. Moreover, peer support groups can play a major role in providing PLWHA with information and practical advice about how to cope with stress and depression (Fanelli and Moyo, 2008; Shi & Chen 2014). In essence, the advantage of PLWHA receiving advice that reflects the lived experiences and realities of group members is that it provides them with hope (WHO, 2012).

Studies in Tanzania have shown that hope is a powerful force that causes people to experience positive emotions and behaviours such as adhering to treatment and planning for the future (Fogarty, 2014). Therefore, in rural areas like Alice where they are limited mental health providers, peer support groups can provide people with supplementary information on how to cope with HIV/AIDS non-disclosure and its ramifications. Therefore, this research interrogated whether support groups were carrying out the mitigation role of providing care and support to both the affected and infected in Alice.

2.7.3 Spiritual support

HIV/AIDS disclosure provides PLWHA with the opportunity to access spiritual support, which can help them cope with the psychological stressors of their illness. According

to Fawcett (2017) spiritual support can have positive health outcomes for PLWHA because it 'mitigates psychiatric distress, increases health related quality of life and improves CD4 cell counts.' In deeply religious African societies, and in Saudi Arabia studies show that spiritual coping strategies such as prayers, reading the Qur'an, performing the pilgrimage to Makkah can help PLWHA accept their status and deal with existential issues such as death (Adeoye-Agboola, Evans, Hewson and Pappas 2016; Omer, Lovering and Shomiani, 2014; SANAC, 2017). In this light, spiritual support can be beneficial for Alice PLWHA because it enables them to attain holistic healing, resilience and hope for the future (Leitten and Vitillo, 2014).

2.7.4 Social support

A score of studies indicate that self-disclosure can enable PLWHA to access social support from family members that respond positively to their diagnosis (King, Katuntu, Lifshay, Packel, Batamwita, Nakayiwa, Abanga, Babirye, Lindkvist, Johansson ,Mermin and Bunnell, 2008; Maman, Rooyen and Groves, 2014). Social support denotes informational support, emotional support and instrumental support, which involves tangible assistance in the form of financial aid, labour and time (Khamarko and Myers, 2013). Research shows that the positive aspect with social support is that it provides PLWHA with the opportunity to find comfort, reassurance and positive meaning in adverse situations (Fawcett, 2017; Maman et al., 2014). This form of emotional support is important because studies show that after an HIV/AIDS diagnosis, some people are traumatised and they sink into depression, which is linked to disability and suicidal ideation (WHO, 2005; Bravo et al., 2010).

Perhaps, another important benefit of HIV/AIDS disclosure is that emotional and instrumental support from friends and family members "can increase adherence to

ARVS, as it buffers the stress associated with the illness, encourages optimism, reduces depression and improves healthful behaviours” (Khamarko and Myers, 2013 p. 5). This is evident among 236 PLWHA that took part in a quantitative study that used the psychosocial model. In this study, the authors discovered that participants that had high levels of social support had low levels of depression and therefore higher levels of adherence (Dilorio et al., 2009 cited in Bravo et al., 2010). This suggests that social support is beneficial for PLWHA because it brings in an extra set of hands, and the financial support needed to manage the complexities associated with HIV/AIDS and its treatment.

Furthermore, providing emotional support and performing instrumental tasks such as taking PLWHA to doctors’ appointments can be beneficial for affected families because it is a form of activism (Gray, 2017). Some families cannot distance themselves from this form of activism because ‘in the wake of the virus, social ties for PLWHA become precarious, and in the absence of adequate medical and social services, the home fills these gaps’ (Gray, 2017). Thus, in improvised rural areas like Alice, providing PLWHA with emotional and instrumental support can be empowering for the infected as it reverses the negative spinoffs of limited government social support. However, another important benefit of HIV/AIDS disclosure is that PLWHA can receive informational support (advice and guidance) from both formal and informal networks. According to Walker, Bamps, Burdett, Diiorio and Rothkoff, (2012) informational support is life sustaining and it provides patients with the opportunity to enhance their problem solving skills, thus in turn contributing to better health outcomes.

2.8. Opportunities associated with HIV/AIDS disclosure

HIV/AIDS disclosure provides seropositive individuals with the opportunity to take up leadership roles that enable them to advocate for the rights and needs of the infected (Volberding, 2008). McWay, (2014) states that leadership is the ability to inspire and influence others to receive a positive result. Based on the principle of “nothing about us without us”, the opportunity of being an HIV/AIDS leader is important because it plays an instrumental role in ensuring that PLWHA have a voice in the formulation of policies and programs that affect their lives (SANAC, 2017). Equally important is the fact that HIV/AIDS leaders can serve as role models that normalise disclosure and promote safer sexual behaviour among the infected and affected (Chalk, 2014).

Apart from being role models, disclosure can provide PLWHA with the opportunity to earn an income as poster babies that seek to change HIV/AIDS denial and the negative preconceptions about the disease (Ruvio and Belk, 2013). In countries like South Africa, HIV/AIDS disclosure can also provide seropositive individuals with the opportunity to access social grants. In as much, grants are perceived to make people lazy they provide a safety net for both the infected and affected (Govender, Fried, Birch, Chimbindi and Cleary, 2015). For instance, a report commissioned by the Centre for Social Development in Africa showed that grant beneficiaries usually use their monies to buy food, access health care services and transport fees (Ferreira, 2017). Therefore, in poverty-stricken environments like Alice, HIV/AIDS disclosure can enable the infected to gain employment and social protection measures.

2.9 Factors that Prevent HIV/AIDS disclosure

2.9.1 HIV/AIDS stigma and discrimination

The term stigma and discrimination refers to prejudice, negative attitudes, and abuse directed at PLWHA' (SANAC, 2015). Although there is clear evidence that families are the primary caregivers for PLWHA, studies show that HIV/AIDS stigma lurks inside the homes of the infected (SANAC, 2017; van Royen, 2016). Like modern lepers, studies have shown that some family members refuse to share food, amenities, cooking utensils with PLWHA (Setlhare, Wright and Couper, 2014; Audet, McGowan, Wallaston and Kipp, 2013). This not only destroys the notion of the family being a safe place, but it causes PLWHA to have strong emotions of shame and hopelessness (SANAC, 2017; Brown, Belue, and Airhihenbuwa, 2010)

Across the gender divide, studies have shown that the fear of social isolation and “the use of food as an expression of rejection inhibits some women from disclosing their status (WHO, 2005; Okoror, Airhihenbuwa, Shisana, Zungu-Dirwayi, Smith, Brown and Louw, 2008). Given the symbolic value associated with food and human interaction, non-disclosure can be a disservice for women’s emotional and mental wellbeing. Another factor that causes non-disclosure among PLWHA is the fear of stigma and discrimination in the health care institution. Studies have shown that the common manifestations of stigma and discrimination include “overzealous preventive measures by health care workers, denied access to treatment and an unwillingness to perform routine services to seropositive patients” (Audet et al., 2013, p. 4).

The negative spinoff with institutional stigma and discrimination is that it contributes to low disclosure, which may have a negative impact on care and prevention activities. Additionally, research shows that some PLWHA not keen on disclosing their status because they fear that health workers will breach their right to confidentiality.

Consequently, lack of confidentiality between a professional and a client can lead to mistrust, lack of honesty and no HIV/AIDS disclosure (Dyke and Alta, 2008). In societies characterised by stigma and discrimination, some PLWHA may be inhibited from publicly disclosing their status because they think that it will destroy will their lives. Studies in Malaysia have reported that some universities withhold the degrees and diplomas of PLWHA, while in countries like Cameroon LGBT AIDS activists are killed (Chalk, 2014). In Australia they are also reports that indicate that societies ostracize PLWHA. A case in point is a vile letter sent to an Australian HIV/AIDS positive women on World AIDS Day.

According to Quinn, (2015) the letter read as follows:

“We write to you as disgusted members in the community and advice you that you have never been and are not welcome here.”

“We feel justified in writing to you as we feel enough is enough and we are tired of lazy leeches like you coming here and living off our hard earned tax payer’s money”!.

“For years we have been watching you and we will be contacting authorities to inform them of all the self-serving things you seem to be able to do yet won’t work! You are not ‘disABLED’ you are simply fat, lazy and opportunistic”

“It seems you are happy to getting paid for your ‘Stigma Warrior’ pathetic speeches because it serves YOU but refuse to get a real job, pay tax and contribute to society.

You have angered many in this community and we’d like to remind you that you actually CHOSE to contract HIV! So stop feeling bloody sorry for yourself, get a job and get out of our town”.

The highlighted letter of aggression signifies that efforts to tackle stigma have been slow. Drawing from this studies theories, this letter shows that the AIDS label can cause some community members to treat the infected as outsiders.

The us versus them approach creates an environment where the rights of the infected are infringed because some community members view themselves as morally superior. However, in Africa the sad part with the injustices perpetrated against PLWHA is that there is no guarantee that the police will protect them since they are also perpetrators of HIV/AIDS stigma. For instance, in Mwanza, Malawi the police forced 11 prostitutes to take HIV tests in a public hospital and had their sero-positive results callously disclosed in an open court (Malikwa, 2015).

In as much as the prostitutes sued the government for unfair action and violation of privacy; the unjust actions by the police have dangerous public health ramifications. This is because they help spread fear and distrust about PLWHA, specifically prostitutes who are already stigmatised because of their profession, gender identity and low socio-economic status (Cameron, 2016). Therefore, the excessive use of force by the police signifies that more needs to be done to increase public awareness about AIDS and promote greater understanding of the ramifications of HIV/AIDS stigma and discrimination.

2.9.2 Socio-cultural factors associated with HIV/AIDS non-disclosure

In developing countries some PLWHA may not be keen on disclosing their status because they perceive that there is nothing to gain from the process (Gong, 2015; UNAIDS, 2000). This mentality is attributed to the fact that some African countries have broken health care systems and low ART coverage, which results in increased HIV/AIDS related deaths (Avert, 2017). The situation is further exacerbated by the fact

that discussions that relate to issues about sex and death are considered taboo (Brennan, 2014). However, in as much as cultural taboos may inhibit discussions about shameful subjects such as death, Hunter (2005) posited that life and death realities should trump cultural taboos because culture its self will be destroyed if cultural taboos are not lifted. Therefore, in rural areas like Alice, where they are public myths and misconceptions about HIV/AIDS this study interrogated the impact of socio-cultural factors on HIV/AIDS non-disclosure.

2.10 The Ramifications of HIV/AIDS Non-disclosure

2.10.1 Criminalization

The non-disclosure of one's status can cause seropositive individuals to expose their sexual partners to their illness. This can have can have legal ramifications for PLWHA. This is due to the fact that some countries have enacted laws that criminalise HIV transmission, exposure and non-disclosure (SABC Digital News, 2015). Despite that, proponents of HIV criminalisation argue that it can deter the transmission of HIV and control the spread of the virus; literature shows that it can negatively affect the lives of PLWHA. The Global Commission on HIV and the Law report (2011) revealed that in Canada and US, being convicted for HIV non-disclosure can result in an individual being registered as a sexual offender that is barred from unsupervised contact, especially with young relatives. The report also emphasised that being a registered sexual offender can result in difficulties in finding accommodation and loss of privacy.

Furthermore, the court cases of are often played out in the media, which increases stigma for both the complainant and accused (The Sentinel, 2015). This is because the media coverage for PLWHA is sometimes presented in a tone that is discriminatory and sensationalised (Chalk, 2014). For example a newspaper headline such as "AIDS

spreader approaches the Constitutional Court is not only entrenched with prejudice, but it reinforces the idea that HIV/AIDS is a shameful, disgraceful and unworthy condition that should be feared (The Sentinel 2015; Cameron, Burris and Clayton, 2008).

In as much as they are peculiar cases where criminalisation should be imposed, some “HIV/AIDS experts are concerned that this legal process can be counterproductive as it adds fuel to the fires of stigma” (Cameron et al., 2008). In the South African context HIV/AIDS experts cite that criminalisation can have a negative impact on women who are the first to know about their status, but have limited access to legal representation” (Cameron et al., 2008; SABC Digital News, 2015). In this regard, HIV/AIDS experts in South Africa recommend that in intimate relationships people should be responsible enough to know their partners status (SABC Digital News, 2015). Thus, this study sought to investigate the legal repercussions associated with HIV/AIDS non-disclosure. This is because HIV/AIDS non-disclosure is a form of social injustice as it undermines the emotional, psychological and mental wellbeing of individuals exposed to the disease.

2.10.2 Isolation

The non-disclosure of an HIV/AIDS status causes PLWHA to experience isolation (Bravo et al., 2010). Although isolation can be a protective measure against stigma, it can be a disservice because it impedes PLWHA from accessing social support, personal development training and resources (Bott and Obermeyer, 2013). Given that the last stages of HIV/AIDS are often characterised by fatality, weariness and disability, isolation can also cause caregivers to experience mental health ramifications because they will be limited in accessing support and resources from their communities (Kang’ethe, 2010). Since literature, suggests that it takes a village

for PLWHA to adhere to treatment and live a positive lifestyle. This study examined the impact non-disclosure had in isolating both the infected and affected from accessing resources needed to live a positive lifestyle.

2.11 Theoretical Framework

2.11.1 Labelling Theory

The labelling theory is based on the premise that no act is inherently deviant (Muncie, 2009). Giddens (2009) defines deviance as non-conformity to a given set of norms. In this case, nothing is inherently right or wrong about an act itself, but the negative reaction the act receives from groups of people in society is what determines if it will be labelled as deviant. This implies that deviance is based on an individual's context (Haralambos and Holborn, 2008).

Labelling theorists hypothesise that there are two types of deviance, which include primary and secondary deviance. The former refers to initial deviant acts that do not warrant societal disapproval or have an impact on an individual's image (Burfeind and Bartush, 2015). The latter refers to deviant acts that cause societal disapproval and tarnish an individual's image (Burfeind and Bartush, 2015). From this vantage point, there is nothing wrong with being diagnosed with HIV/AIDS, but what is bad is the negative label attached to the sickness. In the context of this study, the risk of being labelled sero-positive is what makes some people feel ashamed of disclosing their status.

Labels are not abstract words; they have meaning in people's lives. The Labelling theory asserts that labels become the master status of an individual (Giddens, 2009). This means that some individuals instead of being viewed as a brother, sister, uncle and aunt they become known by their labels. This generalization is problematic

because it has the cruel effect of undermining the deviant's confidence, inherent worth and dignity. Furthermore, some deviants internalize the negative connotations associated with their label. For instance, the internalisation of the negative immoral connotations associated with the HIV/AIDS label can result in some people having irresponsible behaviour that can lead to HIV/AIDS infections and reinfections. This according to the labelling theory is a manifestation of self-fulfilling prophesy. Therefore, the labelling theory was used in this study to understand the impact the HIV/AIDS label has on the ramifications of HIV/AIDS non-disclosure.

2.11.2 The Social Stigma Theory/ Stigma Theory

The sociologist Erving Goffman's stigma theory was used in this study (Amzat and Razum, 2014). This theory is based on the idea that stigma is an attribute that is deeply discrediting, resulting in an individual being mentally classified as tainted or undesirable by others (Goffman, 1963). Goffman believed that stigma manifests in three forms, that include the stigma that is associated with physical deformities; stigma that is associated with blemishes of an individual's character (moral failing) and stigma associated with tribal affiliations such as race and religion (Bros, Pryor, Reeder and Stutterheim, 2013).

Two of the major forms of stigma relevant to PLWHA are physical deformities and moral failing (Parker & Aggleton, 2003). In reference to the latter form of stigma, societies tend to moralise the HIV/AIDS epidemic because they link it with promiscuous lifestyles that warrant social disapproval. This conviction enables people to regard PLWHA as others or outcasts who can be dehumanised because they have failed to uphold community moral standards (Parker & Aggleton, 2003). This position of superiority cannot be tolerated because it prevents people from being tested and it

creates a myriad of problems for HIV/AIDS disclosure. Furthermore, it negates the universal human rights principle, which states that all human beings are created equal, regardless of any distinction or illness. Therefore, the purpose of using the stigma theory is to show that the shame attached to the HIV/AIDS label can be a double-edged sword in the lives of both the infected and affected.

2.12 Conclusion

The literature review showed that disclosure can be beneficial for PLWHA and their families. However, more needs to be done for PLWHA to disclose their status because the ramifications of HIV/AIDS non-disclosure can undermine their health and social function.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

In the previous chapter, the researcher examined literature sources pertaining to this study's topic. Existing literature outlined the panacea (benefits) and perfidy (detriments) of disclosing a seropositive status. The ramifications of HIV/AIDS non-disclosure and the coping strategies adopted by PLWHA and their families were also discussed. In concluding the chapter, the researcher provided the theories on which this study hinges on. This chapter described the research methodology, which is usually the core of any study.

The research methodology constitutes the logic of a scientific investigation and it helps others understand the general steps taken by a researcher in adopting a specific research design and the methods of data collection and analysis. This understanding not only enhances transparency but also helps the researcher to observe the principles of trustworthiness and credibility. From this perspective, this chapter discusses and explains the research design and paradigm that underpinned this studies qualitative case study. The data collection techniques, instruments, means of enhancing trustworthiness and eliminating ethical dilemmas were also outlined.

3.2 Research Methodology

The term methodology often refers to the overall approach of the research process, from the theoretical underpinnings to the collection of data and analysis. Welman, Kruger and Mitchell (2003, p. 53) contend that the research methodology is a framework that indicates the approaches, methods and techniques that are used when collecting and analysing data in research studies.

Holden and Lynch (2004, p. 6) have the opinion that the research methodology is the researcher's toolkit as it embodies all the means available for social scientists to empirically investigate a studies phenomenon. Ahmed, Opoku and Aziz (2016) hold that the research methodology is the theory that shapes the researcher's ideas with regard to the methods that will be employed to solve a research problem. In attempting to unravel this studies problem, the research methodology will enable the researcher to draw up a plan of action that achieves the studies objectives.

3.3 Research Approaches

The qualitative research approach aims to explore the meaning individuals or groups ascribe to a social or a human problem (Creswell, 2014, p.13). Burns and Grove (2011, p. 28) define qualitative research as "a systematic and subjective approach that describes life experiences and gives them meaning". However, Creswell (2014) affirms that the most distinguishing aspect about the qualitative approach is that the researcher is the research instrument. The author went on to emphasise that the positive aspect about the researcher being the research instrument is that it increases empathy, thus allowing the researcher to understand the critical facets of the phenomenon under study. With this in mind, the researcher adopted the qualitative approach because it enabled her to immerse herself in the study.

Another reason for adopting the qualitative approach was its emergent design. The advantage with this design is that it enables the researcher to adjust the research procedures and questions during the data collection and analysis process (Given, 2008). Charmaz (2006) holds that this flexible approach allows the researcher to follow leads that emerge during the course of the study. However, to reduce research bias, which is the biggest drawback of the qualitative approach, the researcher employed

triangulation. In summary, the researcher was drawn to the qualitative method due to the merits espoused by Creswell (2013, p. 44).

- The research is conducted in a natural setting where participants live and feel comfortable.
- The researcher is the key instrument for data collection and does not rely on instruments developed by other researchers.
- Studies incorporate multiple data collection methods, including interviews and observations.
- Studies incorporate an emerging and evolving design, which is subject to change when researchers conduct their field studies and collect data.
- Studies involve complex reasoning skills, including both inductive and deductive reasoning.
- Qualitative studies provide a complex and holistic picture of the problem under study.

3.4 The Specific Research Design

This study took the form of a case study. A case study is defined as an “empirical inquiry that investigates a contemporary phenomenon within its life context” (Yin, 2009, p. 18). Case studies “in their true essence, explore and investigate real life situations through a detailed contextual analysis of a limited number of events or conditions” (Savage and Fottler, 2009; Zainal, 2007, p. 2). Terre Blanche (2006) postulates that the hall mark of a case study is that it is usually descriptive in nature and it provides an in-depth analysis of individuals, units, organisations or communities. Therefore, a case study strategy was employed in this study because it enabled the researcher to provide an in-depth analysis of the ramifications of HIV/AIDS non-disclosure in Alice.

3.5 Research Paradigm

The term paradigm was derived from the Greek word *paradeigma*, which means pattern or example (Killam and Carter, 2013 p. 5; Ilachinski 2001, p. 608). According to Killam and Carter (2013), Thomas Kuhn established the contemporary meaning of this Greek word. In his analysis Kuhn (1962), used the term to describe an intellectual framework in which scientists describe a set of viewpoints, assumptions and patterns about how the world works. According to Terre Blanche et al. (2006, p. 40) the assumptions are focused on the interrelated systems of ontology, epistemology, methodology, axiology and rhetoric. Essentially, ontology identifies the nature of reality, whereas epistemology refers to the doctrine of knowledge that specifies the nature of the relationship between the researcher and what can be known (May, 2011).

Mertens (2014) contends that methodology refers to how the researcher goes about studying whatever he or she believes can be known, while axiology identifies the value of a study. Lastly, rhetoric refers to the language of the study (Creswell, 2009). Although these assumptions address different aspects of a research study, they form a paradigm that provides the researcher with information about their studies research design, methods of data collection and analysis.

3.5.1 The interpretative paradigm

The roots of this paradigm lie in various disciplines, such as Dilthey's philosophy of hermeneutics and Mead's social psychology (Creswell, 2009). The interpretative paradigm is described as an umbrella term for a group of philosophies that share assumptions about how people develop and construct their social world (Creswell, 2009). The ontology for the interpretive paradigm is based on the belief that they are multiple mental constructs (Schwandt, 2001 cited in Mertens, 2005). This ontology is

suited for this study because it is reflected that PLWHA have different ways of interpreting their experiences of the ramifications of HIV/AIDS non-disclosure.

The interpretative paradigm hinges on an inter-subjective, epistemological stance towards reality. This epistemology specifies that one cannot distance themselves from what they want to know (Terra Blanche, 2006) .This means that the researcher and participant are interlocked in an interactive and collaborative relationship with each other (Mertens, 2010, p.19). This leads to individual realities being co-constructed by both the researcher and the participant. This epistemology was a fitting choice for this study because it allowed the researcher to inductively understand and interpret the feelings PLWHA have towards the studies topic.

The epistemology led the researcher to adopt a methodology that was primarily qualitative. Briefly, this methodology is applicable to this study because it employs a holistic approach to discovering participants' behaviour, opinions and experiences (Denzin and Lincoln, 2011, p. 3; Alvermann and Mallozzi, 2010, p. 1). Furthermore, qualitative data collection methods such as interviews create an environment that allows the researcher to have in-depth, informative discussions about the study's' topic (Terre Blanche et al., 2006). Moreover, this methodology was adopted in this study because it acknowledges that research can be value-laden due to the researcher's experiences and knowledge about the topic.

Brown, (2008) holds that research becomes value-laden "when the beliefs, class and culture of the researcher pose a threat to the collection and interpretation of data". In order to mitigate any bias from threatening this study's data collection, the researcher employed reflexivity (Creswell, 2013). This is when the researcher openly discusses how their personal, cultural and historical experiences obstruct the

credibility of a study (Hennink, 2014). In essence, the purpose of discussing the interpretative paradigm was to outline the link it has with the qualitative methodology.

3.6 Research Design

This is a strategic framework of action, or a plan that guides the researcher to ensure that valid conclusions are drawn from the study. The research design can be likened to a blueprint that guides architects in preparing for the construction of buildings (Terre Blanche, 2006). Like building plans, this blueprint explicitly provides the researcher with information on how the research should be conducted. Given that qualitative researchers tend to adopt designs that are open and fluid, this study adopted an explorative and descriptive design.

3.6.1 Exploratory and descriptive design

An explorative study provides an in-depth exploration of a single process or concept (Wood and Kerr, 2011). It is commonly associated with uncharted areas of research or lesser-studied topics. A descriptive design examines one or more characteristics of a specific population (Wood and Kerr, 2011). This design is relevant in this study as it allows the researcher to identify and document different characteristics of a phenomenon (Schmidt and Brown, 2011). Given that HIV/AIDS non-disclosure is a topical issue, the explorative, descriptive design assisted the researcher to provide a holistic picture of how Alice PLWHA, experience the ramifications of HIV/AIDS non-disclosure.

3.7 Methods of Data Collection

Data collection is typically the process of acquiring subjects and systematically collecting information that is connected with achieving the studies research objectives (Burns and Grove, 2014). Creswell (2014) posits that the “qualitative data collection

steps include setting the study's boundaries, collecting information through semi structured observations, interviews, documents, visual materials, as well as establishing the protocol of recording information". However, the main disadvantage of collecting information with qualitative methods is that the processes can be time-consuming (Terre Blanche 2006, p. 297). Despite this disadvantage, the researcher chose these methods because they produce rich information that is not readily available through other means.

3.7.1 In-depth interviews

In this study, semi-structured, one-on-one, in-depth interviews were employed as a data collection method (May, 2011). In-depth interviews are generally an intensive technique used to elicit the verbal and non-verbal meaning of lived experiences. The strength of interviews lies in the fact that they produce highly credible results (Rubin and Rubin, 2011). However, in-depth interviews are criticized for losing focus because participants use their own discretion in answering broad, open-ended questions. According to May (2011), this disadvantage can be turned into an advantage as the participants can reveal new ways of understanding a problem. Discussing this criticism was important as it reminded the researcher to steer the interview so that research questions could be answered succinctly. In order to understand the participants' experiences without preconceived conceptions and prejudice, the researcher practiced bracketing, which allows a researcher to suspend any presuppositions about the research topic (Burns and Grove, 2003, p. 380).

3.7.2 Focus group discussions (FDGs)

Focus group is a term used to describe an interview conducted with a small group of people who share a common concern or experience (Terre Blanche, 2006). The purpose of a focus group is to draw some conclusions about a population under study

(Stewart and Shamdasani, 2014). However, the major disadvantage with focus group discussions is that they produce a large volume of data that is costly to analyse. However, this data can be beneficial for researchers as it allows them to crosscheck information collected from other sources (Hennink, 2014). This study employed focus group discussions to allow PLWHA's families to share their experiences, perceptions and attitudes towards the ramifications of HIV/AIDS non-disclosure. Given that HIV/AIDS disclosure is a sensitive topic, the researcher highlighted the importance of upholding confidentiality about issues discussed in the focus groups.

3.7.3 Key informant method

Key informants are individuals who contribute expert knowledge about a phenomenon under study. The ability to answer questions in a broad dimension and provide social patterns linked to human experiences is what sets key informants apart from individuals who provide generic opinions about a topic. To avoid bias and distortion by key informants, the information they provided was compared with data from interviews and focus groups. The cross-examination was crucial in enhancing the rigor of the study (Given, 2008). In essence, key informants were relevant in this study because they provided a framework for understanding the psychological, social and emotional ramifications associated with HIV/AIDS non-disclosure in Alice.

3.8 Data Collection Instrument

3.8.1 Interview schedule

This study adopted a semi-structured interview guide. Stewart and Shamdasani (2014) define an interview guide as a tool that establishes the agenda for interviews and focus group discussions. An interview guide lists themes to be covered in an interview (Whiting, 2008, p. 16; Terre Blanche et al., 1999, p. 37). The advantage of an interview guide is that it provides the researcher with the opportunity to ask questions that

emerge from the interviews. This study adopted an interview guide because it has a flexible template that enables the researcher to ask questions that arise from an interview.

3.9 Data Collection Processes

The data collection method for this study was cross-sectional. Cross-sectional data refers to data that is collected at one point in time (Krishnaswamy, Appa and Mathirajan, 2006). The researcher collected data between 1 July 2016 and 31 July 2016. The cross-sectional approach was suitable for this study because it is cost effective. While collecting the required data, participants had the prerogative to use the language they felt comfortable speaking. This resulted in most of them sharing their experiences in English, Zulu and Xhosa. In line with the university's code of ethics, the researcher communicated with the participants and gatekeepers prior to the commencement of the study. Emails and phone calls reached out to these individuals before the letter of consent was sent to them (see Appendix B).

3.10 Research Domain

The town of Alice under the Nkonkobe Municipality was the study's research domain. This town is located in one of the poorest provinces in South Africa. This rural community is characterised by patriarchy, religious and cultural beliefs that fuel the stigmatization of PLWHA. Furthermore, the operation of support structures is ad hoc and this poses problems for people coping with the challenges of HIV/AIDS disclosure (Kang'ethe and Mutopa, 2014). Therefore, the researcher chose Alice because it provides her with the opportunity to access a diverse sample that can contribute rich data towards the studies topic.

3.11 Population under Study

A population is composed of “all the available elements a researcher seeks to investigate in their study” (Terra Blanche et al., 2006 p.133). Burns and Grove (2010), define a population as the “total set from which the units of a study are chosen”. Reid and Bojanic (2009) assert that a population is a group of individuals that represent the target population from which the sample is drawn. The population for this study was all the people that live with HIV in Alice. However, due to financial and time constraints, it is not feasible for the whole population to be studied. As a result, those who were included in this study were a representation of the population under study.

3.12 Sample Size / Unit of Analysis

A sample can be viewed as a subset of the research population. De vos, Strydom, Fouche, and Delport (2005) define the sample size as the number of units that are chosen when data is collected. The consensus among most authors is that qualitative studies adopt a small sample, as they are “interested in a thick description of the case” (Burns and Grove, 2010). Thus, the unit of analysis for this study comprised of 10 PLWHA from Alice. Additionally, a sample of 20 family members was chosen for this study. This sample participated in (4) focus group discussions with five participants each. A sample of five key informants was included in this study and it comprised two (2) health professionals; one (1) official from a non-governmental organization; one (1) social worker and one (1) community leader from Alice. This sample is represented in table 3.1 :

Table 3: Presentation of Units of Analysis

Units	Method of Data collection	Sample interview	Groups of Samples
1	Focus group	Family members of PLWA	5 x 4

2	In-depth Interview	PLWHA	1 x 10
3	Key Informant Method	Health practitioners, officials from civic organizations and a community leader.	5
Total			35

3.13 Sampling Method and Technique(s)

Probability and non-probability sampling methods are the two dominant sampling procedures in social sciences research. The probability sampling procedure chooses participants according to statistical randomness, thus ensuring that every individual has an equal chance to participate in a study (Terre Blanche et al., 2006). The non-probability sampling method allows the researcher to select individuals and sites that can facilitate a better understanding of the phenomenon under study (Burns and Grove, 2010). The researcher adopted the purposive, non-probability sampling technique because PLWHA are found at medical centres within Alice. Given the sensitive nature of this studies topic, the purposive sampling technique was used in tandem with the snowball sampling technique (Rubin and Babbie, 2008).

3.13.1 Sampling selection criteria

This criterion stipulates the characteristics that research participants should possess (Burns and Grove, 2010). In this regard, the inclusion sampling criteria for this study was as follows:

- The PLWHA should be from Alice, which is the research domain.
- They must be between the ages of 18-55 years.

- The family members and key informants must have experiential and expert knowledge towards the ramifications of HIV/AIDS non-disclosure.

3.13.2 Exclusion Criteria

This criterion stipulated the characteristics that the researcher used to exclude participants from being part of the target population (Burns and Groove, 2010). The PLWHA from other parts of South Africa were excluded from this study because the study was context bound. The researcher also excluded family members that did not have experiential knowledge about the benefits and ramifications of HIV/AIDS non-disclosure. The health care workers that had no knowledge about the ramifications of HIV/AIDS non-disclosure were excluded from the study. Similarly, key informants that did not have expert knowledge about HIV/AIDS non-disclosure were excluded from this study.

3.14 Data Analysis

Data analysis means categorizing, ordering, manipulating and summing up data so that answers for research questions can be obtained (Burns and Grove, 2010; Creswell, 2009). Burns and Grove (2010) emphasise that in qualitative studies the data analysis process is not only eclectic and ongoing, but it also rigorous and highly creative. Therefore, in this qualitative study data collection was done concurrently with data analysis. This was in line with Silverman (2010)'s assertion that data analysis starts as one gathers data.

The thematic content analysis method was used to analyse data in this study. This method enabled the researcher to develop emerging themes out of participant's experiences and at the same time examine different aspects of the study (Smith, 2013). In generating the themes, the researcher made use of coding. Burns and

Groove (2010) state that coding is a process that involves the reading of data, breaking down of texts to subparts and attaching labels to texts.

3.15 Trustworthiness and Credibility of the Study

Trustworthiness in qualitative research can be likened to validity and reliability in quantitative research (Feig and Strokes, 2011, p. 176). Schmidt and Brown (2011) state that trustworthiness refers to the “authenticity and truthfulness of findings in qualitative research”. According to De vos, Strydom, Fouche and Delport (2005), the criteria for determining the trustworthiness and credibility of qualitative research is established by employing the following norms: credibility, transferability, dependability and conformability.

3.15.1 Credibility

Credibility in qualitative research is similar to internal validity in quantitative research (Schmidt and Brown, 2011). However, in a qualitative study, credibility is generally described as the extent to which research results can be believed by the researcher and other users (Hays and Singh, 2012, p. 217). Establishing credibility in qualitative studies is essential because it determines whether research findings are consistent with collected data. Therefore, in this study, credibility was obtained by employing triangulation (Polit and Beck, 2010). This is when two or more methods are used to validate research results. In this regard, the researcher collected data through interviews, focus group discussions and the key informant method. This was also supplemented by a literature review and theoretical triangulation (Creswell, 2003, p.196).

3.15.2 Transferability

Transferability refers to the idea that research findings may be applicable in similar situations (Savin-Baden and Major, 2012). According to Lincoln and Guba (1985, p. 124), transferability is when a reader passes judgment that the research findings of a particular study might be analogous in their own study. Therefore, in order to establish transferability, Chilisa (2012, p. 69) suggests that a thick description of the research setting will enable the readers to decide the applicability of research findings to their own studies. Hence, in order to ensure transferability, a thick description of this research area was provided.

3.15.3 Dependability

Dependability refers to the extent at which the same research findings can be replicated in a similar environment (Polit and Beck, 2010). Lincoln and Guba (1985, p. 229) contend that dependability is also concerned with providing explanations for changes that would have occurred during the research processes. Therefore, in this study, dependability was ensured through a reflexive journal was used to document the entire research process. Furthermore, an inquiry audit by the researcher's supervisor was conducted to establish whether the research findings could be replicated. An Inquiry audit is a process where data concerning the entire research process is examined and criticized by an external reviewer (Savin-Baden and Major, 2012).

3.15.4 Conformability

In qualitative research, conformability is the extent to which peers can validate the collection and analysis of data, including the relevance of research findings (Eriksson and Kovalainen, 2015). According to Mertens (2009, p. 260), conformability means that data is not only accurate and dependable, but it can be traced back to its source.

Hence, in order to establish conformability in this study, a reflexive journal was used to provide a systematic documentation of the entire data collection and analysis processes. Furthermore, a concurrent conformability and dependability audit was conducted to ensure that data is accurate and traceable (Stommel and Willis, 2004, p. 288).

3.16 Ethical Considerations

3.16.1 Informed consent

The right to informed consent is concerned with the procedures that provide prospective participants with information needed to make a rational decision about participating in a study (Polit and Beck, 2010). In line with this right, the researcher provided all the participants with a full explanation about the nature of the study. The researcher also provided the participants with consent forms that documented their voluntary and informed participation. Additionally, the research participants were adequately informed about the use of a voice recorder prior to the study. Furthermore, the researcher reiterated to the participants that they had the right to ask questions pertaining to the study and they could withdraw their participation at any time.

3.16.2 Avoiding harm

Avoiding harm is a basic human right that requires the researcher to protect the participants from physical, emotional and psychological harm (Burns and Grove, 2007). Given that HIV/AIDS is a sensitive issue that racks havoc into the lives of both the infected and affected the researcher protected the identities of the participants through pseudo names. Furthermore, the participants that suffered from the psychological pain of recalling painful experiences were referred to a medico social worker stationed at both Victoria Hospital and War Memorial Clinic.

3.17 Conclusion

The research methodology is regarded as the most important part of a research project as it provides a framework for understanding the logic behind the study's paradigm, data collection and analysis method. This chapter outlined the core assumptions of the interpretive paradigm and the qualitative case study design that ensured that the researcher obtained the intended results. Lastly, the researcher outlined the trustworthiness and ethical standards that ensured that the results of this study were obtained in a credible way.

CHAPTER FOUR

DATA ANALYSIS, INTERPRETATION AND FINDINGS

4.1 Introduction

This Chapter is a sequel to Chapter 3, which provided an overview of how the qualitative research methodology enabled the researcher to collect data pertaining to the ramifications of HIV/AIDS non-disclosure. In essence, this chapter analyses, interprets and presents the study's findings. Essentially, data analysis is about categorizing, ordering, manipulating and summing up of data with the intention of obtaining answers to the research questions (Creswell, 2009). On the other hand, data interpretation deduces the meaning of summed up data. The presentation of findings deals with the relaying of data in an organized manner, for example in the form of thematic clusters (Creswell, 2009). In this light, this study's findings will be presented in different themes.

4.2 The Demographic Profile of the Research Participants

The following tables provide an overview of the demographic profile of all the participants in this study. The demographic characteristics include the participants' age, gender, educational level, religious affiliation, tribe and marital status. The purpose of presenting this demographic information is to provide a comprehensive description of the participants. In order to protect the participants' right to confidentiality, pseudonyms in the form of numbers were utilised to represent each research participant.

Table 4 below provides an overview of the demographic profile of PLWHA.

Table 4: People Living with HIV/AIDS (PLWHA)

PARTICIPANT	GENDER	AGE	EDUCATION	RELIGION	TRIBE	MARITAL STATUS	EMPLOYMENT STATUS
1	Male	43	Secondary	ATR	Xhosa	Divorced	Unemployed
2	Female	55	Secondary	ATR	Zulu	Widowed	Employed
3	Male	28	Tertiary	Christian	Xhosa	Single	Unemployed
4	Female	29	Tertiary	Christian	Xhosa	Married	Employed
5	Female	23	Secondary	Christian	Zulu	Cohabiting	Unemployed
6	Male	38	Secondary	Christian	Xhosa	Divorced	Unemployed
7	Female	26	Secondary	Christian	Xhosa	Cohabiting	Unemployed
8	Female	36	Tertiary	Christian	Venda	Cohabiting	Employed
9	Female	42	Primary	ATR	Xhosa	Married	Unemployed
10	Female	18	Secondary	Christian	Xhosa	Single	Unemployed

4.3 Age and Gender of PLWHA

The research findings indicate that PLWHA were of diverse ages ranging from 18 to 55 years. This indicates that HIV/AIDS cuts across all reproductive age groups, with a preponderance of those affected being in the 18 to 30 age group. The scenario reveals that HIV/AIDS is likely to lower the productivity of those infected, thereby affecting the country's Gross Domestic Product (GDP). Due to stigma, which young people are bound to face, many young people living with HIV/AIDS may be discouraged from disclosing their status. In reference to gender, the majority of the participants were women. This implies that HIV/AIDS is a gender-skewed disease that adversely affects women more than men. However, given that women are subjugated due to fact that some African societies lean on patriarchy, women must find it difficult to disclose their status.

4.4 Education and Employment Status of PLWHA

The study findings showed that the majority of the participants had attained primary and secondary education, while the minority had achieved tertiary education. This

demographic information depicts that access to basic education is a reality for most South Africans as opposed to access to tertiary education. Furthermore, low educational attainment could signify that the research participants are limited in conceptualising the benefits of HIV/AIDS disclosure. Low education levels among the PLWHA could also be associated with unemployment and poverty.

4.5 Religious and Tribal Affiliations of PLWHA

This study's findings revealed that the majority of the participants were Christians, while a minority of the participants were members of the African Traditional Religion (ATR). The different religious affiliations of PLWHA indicates that people in South Africa exercise their right to religious freedom. In reference to the tribal affiliations, the majority of the participants were Xhosa and the other participants were Zulu and Venda. This demographic information confirms that geographically the Xhosa people dominate the Eastern Cape Province due to the apartheid segregation system. The religious and tribal affiliations of PLWHA in Alice indicates that they use different socio-religious lenses to understand the studies topic.

4.6 The Marital Status of PLWHA

The findings from this study indicate that the majority of PLWHA were cohabiting, while the minority were single, married, divorced or widowed. This demographic information indicates the possibility that marital dysfunction is a driver of HIV/AIDS infections. These shades of marital dynamics could also indicate that people are less conservative about their sexual relationships. On the other hand, the scenario could mean that HIV/AIDS could also be a cause of marital dysfunction. Thus, lack of marital stability could present a challenge to those who wish to disclose their status.

4.7 Demographic Characteristics of PLWHA's Families

Table 5: PLWHA's Families

PARTICIPANT	GENDER	AGE	EDUCATIONAL LEVEL	RELIGIOUS AFILIATION	TRIBE	EMPLOYMENT STATUS
11	Female	45	Primary	ATR	Xhosa	Unemployed
12	Female	64	Primary	Christianity	Xhosa	Unemployed
13	Male	31	Secondary	Christianity	Xhosa	Unemployed
14	Female	32	Tertiary	Christianity	Xhosa	Employed
15	Male	60	Primary	ATR	Xhosa	Unemployed
16	Male	45	Secondary	Christianity	Xhosa	Employed
17	Male	39	Tertiary	Christianity	Xhosa	Employed
18	Female	50	Primary	ATR	Zulu	Unemployed
19	Female	23	Tertiary	Christianity	Xhosa	Unemployed
20	Female	25	Secondary	Christianity	Xhosa	Unemployed
21	Male	56	Secondary	Christianity	Venda	Unemployed
22	Female	34	Secondary	Christianity	Xhosa	Unemployed
23	Female	41	Primary	Christianity	Xhosa	Unemployed
24	Female	36	Secondary	ATR	Xhosa	Employed
25	Male	29	Tertiary	Christianity	Xhosa	Employed
26	Female	20	Tertiary	Christianity	Xhosa	Unemployed
27	Female	59	Secondary	Christianity	Xhosa	Unemployed
28	Female	62	Primary	Christianity	Xhosa	Unemployed
29	Female	51	Primary	ATR	Zulu	Unemployed
30	Female	18	Secondary	Christianity	Xhosa	Unemployed

4.8 The Age and Gender of PLWHA's Families

The research findings revealed that the age of PLWHA's family members ranged from 18 to 64 years. This means that HIV/AIDS affects family members of all ages. This age range is important because it provides the researcher with the guarantee that the

participants have the cognitive ability to provide diverse views on the ramifications of HIV/AIDS non-disclosure. Additionally, the age range signifies that the family members are likely to be productive caregivers. In reference to gender, the research findings show that the most dominant family members for PLWHA are mature women. This implies that caregiving is gender skewed, with women mainly fulfilling the role of supporting PLWHA. This poses a challenge to the HIV/AIDS campaign, as male caregivers are needed to support and encourage disclosure within the male fraternity. Furthermore, the preponderance of women in caregiving roles denies the HIV/AIDS campaign the financial and leadership muscle of men.

4.9 Education and Employment Status of PLWHA's Families

The research findings allude to the fact that the majority of the participants had low educational attainment. For example, the majority of the participants either had primary or secondary education, while a minority of them had a tertiary education. In reference to employment status, the study's findings show that PLWHA's families were not formally employed because they did not possess the educational prerequisites for holding good jobs. The low educational and employment status of the participants confirms that most of them survive on state grants. This impoverished socio-economic environment does not guarantee that PLWHA will have a supportive environment when they disclose their status.

4.10 The Religious and Tribal Affiliations of PLWHA's Families

The study's findings showed that Christianity and ATR were the most dominant religions. In reference to tribal affiliations, the demographic information shows that most of the participants are from the Xhosa tribe, while the rest of the participants belong to the Zulu tribe. Belonging to a religion signalled that family members were likely to offer PLWHA love and compassion that is emphasised in most religions.

On the other hand, this demographic information confirms that culture and religion are an inseparable part of humanity. The intractable relationship between culture and religion moves the researcher closer to achieving the study's objectives, because the participants can provide intimate and reliable knowledge about the ramifications of HIV/AIDS non-disclosure.

4.11 The Demographic Information of Key Informants

Table 6: Key Informants

Participant	Age	Gender	Occupation	Organisation	Ethnicity	Educational Level	Marital Status
31	50	Male	Manager	NGO	Xhosa	Tertiary	Married
32	46	Male	Community Leader	Community Leader	Xhosa	Diploma	Married
33	55	Female	Social Worker	Isibindi, Creating circles of care	Xhosa	Tertiary	Married
34	53	Female	Nurse	Hospital	Xhosa	Tertiary	Married
35	40	Female	Nurse	Clinic	Xhosa	Tertiary	Married

4.12 Age, Education, Gender and Marital Status of Key Informants

The age of the key informants ranged from 40 to 55 years and most of the key informants had obtained degrees, while only one possessed a diploma. This gives credence to the fact that the key informants could provide the researcher with sound expert and academic knowledge about the ramifications of HIV/AIDS non-disclosure. In reference to gender, the demographic information presented a gender-skewed phenomenon as most of the key informants were women. This is not surprising as women traditionally dominate occupations such as nursing and social work. The key informants' gender does not affect their professional prowess.

However, the gender skewedness of the key informants could affect disclosure. This is because the presence of men could enhance male involvement in these female dominated careers. Additionally, it could motivate HIV/AIDS disclosure and access to medical services by men. The fact that the key informants work in different institutions and are married gives credence to the fact that they can provide a holistic picture with regard to the studies topic.

4.13 Response Rate of Research Participants

The researcher targeted 35 participants and all of them took part in this study. This translates to a 100% response rate as the researcher conducted one-on-one, in-depth interviews and FGDs with the intended participants. However, this successful response rate can be attributed to the sampling approach that allowed the researcher to acquire participants that were willing to participate in the study. In the case of an unsuccessful call, the researcher immediately substituted that participant with another who was willing to participate in the study. This ensured that the researcher involved people who were ready to be investigated with regard to HIV/AIDS disclosure.

4.14 The Panacea of HIV/AIDS Disclosure

4.14.1 Access to medication

The research findings indicated that HIV/AIDS disclosure opened the door for PLWHA to access medication that provided them with the second chance to pursue their dreams and goals. Most of the participants revealed that receiving medication allowed them to further their studies and obtain employment opportunities that increased their sense of empowerment. A few of the participants also cited that another hidden benefit of accessing free medication was that their family members and relatives could extend a helping hand towards their upkeep because they were no longer afraid that their

finances would be exhausted by the exorbitant cost of ARVS. These are some of the respondent's sentiments:

"I was diagnosed with HIV/AIDS in 2009 after I became bedridden. I was put on treatment even though I did not have hope because my CD4 count was only 24. However, my family members were eager to see my recovery and they stayed with me till my CD count rose to 300. The emotional and physical support that they provided me with has contributed to me getting back on my feet and continuing my spaza shop that looks after me and my son"

"I disclosed my status so that I could receive the free gift of treatment ... I did not have money to buy the medication and my family members were tired of me sinking their finances. Fortunately, it has been 10 years after receiving my diagnosis and I have managed to save money to enrol for my undergraduate studies... I am currently working towards my master's degree in social work because I want to help PLWHA that suffer in silence"

The sentiments relayed above indicate that HIV/AIDS disclosure provides PLWHA with the opportunity to access free medication that restores their health. Through the free medication provided by the government, PLWHA can be economically productive citizens who can further their education. The fact that access to medication enables some PLWHA to contribute to human development is an indication that the South African government should continue to strengthen the HIV/AIDS testing and treatment campaign so that the infected can look forward to a prolonged life.

4.14.2 Psychological benefits of HIV/AIDS disclosure

The study's findings indicated that HIV/AIDS disclosure has the proclivity to reduce the psychological pangs associated with having a hidden stigmatised identity. Most of

the respondents revealed that disclosing their status, particularly to supportive family members, reduced their level of stress, anxiety and depression. The participants also mentioned that the love, empathy and hope exhibited by family members and friends provided them with the opportunity to take their medication openly and to visit the local clinic for medical check-ups. These are some of the participant's sentiments:

"When I had not disclosed my status, I was always worried and I felt depressed... as the situation worsened, I had to disclose my status to my sister and it made me feel light. She was supportive to such an extent that she volunteered to be my treatment partner and she is constantly encouraging me to take good care of myself"

"I did not tell anyone about my diagnosis for 2 months and I would write about my feelings in a journal. This did not really help me because I was often angry.... I decided to disclose my status to my family and this helped me offload my emotions. My family gave me so much support because they did not want me to feel bad about having the disease".

In contrast to the above sentiments, a few of the participants were mortified that disclosing their status had turned their family members and friends against them. This is because their loved ones blamed them for contracting a shameful disease. The disappointed PLWHA cited that lack of psychological support from their family members lowered their self-esteem because their relatives involuntarily spread the news of their status to other community members. These participants expressed the following sentiments:

"When I revealed my status, I was left without family support because they said that I was irresponsible and I would die like my parents, but the worst part of it

was that my cousin brother would get drunk and disclose my status in the beer hall”

“It is difficult to disclose your status because sometimes children do not accept you and also relatives call you bad names like you are a bitch. But at the end of the day, you need to talk about your status especially with the people whom you stay with because when you get sick, they should know what is it that you are sick with.... they should also know how to protect themselves and be able to give you treatment”

The scenario above shows that HIV/AIDS disclosure has both negative and positive outcomes. On the positive side, disclosure can improve the psychological, physical, emotional and moral wellbeing of PLWHA. However, on the negative side disclosure can result in family members turning their backs on their sick relatives. This negative attitude is a sign that the government needs to strengthen grassroots educational campaigns that teach people to be receptive to those who disclose their seropositive status.

4.14.3 Access to support structures

The study findings indicated that HIV/AIDS disclosure provided PLWHA with the benefit of accessing support structures such as the voluntary counselling unit and support groups. In reference to the voluntary counselling unit (VCT), some of the respondents were of the opinion that the clinics and mobile centres around Alice provided them with the opportunity to receive free services such as testing, counselling and preventive devices that assisted them in preventing the spread of the disease. Although the respondents claimed that counselling played a crucial role in changing their perceptions about disclosure, allaying their fears and uncertainty associated with

HIV/AIDS, PLWHA were quick to highlight that the counsellors were limited in addressing some of their special needs. These were some of the sentiments expressed by the participants:

“The voluntary counselling and testing centres are usually in an open space. I think they are important because they have counsellors that help you to disclose your status to your partner if you are afraid that they will react badly to your diagnosis.”

“I think these structures are important because they have charts and pamphlets that provide both the infected and affected with information on how to avoid the risks of infection and re-infections in their relationships, but I think it’s not good that the VCT does not cater for the different needs of PLWHA”

The findings of the study depicted that the VCT is a strong vehicle for HIV/AIDS prevention. This is evident from the fact that increased acceptance of voluntary and confidential counselling makes it easy for the infected to enrol for the government’s treatment program. However, some of the limitations experienced by the VCT could be mitigated if the government, in partnership with various stakeholders, contribute resources towards the establishment of new comprehensive care packages.

4.14.4 Support groups

The findings of the study indicated that support groups provide PLWHA with the benefit of creating social networks that enhanced their collaborative ties. The participants also revealed that support groups were a safe space that enabled them to learn from seasoned health care professionals. Apart from being a safe space, the participants also mentioned that support groups provide the youth with the incredible opportunity of accessing mentors that taught them about being self-reliant, developing character

and relationship skills. However, not all the participants are able to access support groups due to age, gender and distance barriers. These are some of the participants' sentiments:

"It is helpful to disclose your status in a support group. You can get advice on how to deal with the disease, where to go for medical help, and through storytelling, you will learn that you are not alone, as many people have gone through the same situation as you. However, the challenge for us older PLWHA is that, whilst we are open and candid about issues of how we got infected, we have to guard against doing so strongly, least we risk losing face"

"Support groups offered me an enabling platform to meet a mentor and learn about self-motivation, self-discipline and decision making in order to function constructively in society"

These statements indicate that support groups are a safe haven in which PLWHA can simultaneously learn and teach one another about various issues such as adherence, stigma and discrimination. The internet and social media platforms, such as "WhatsApp", can perhaps break the distance and money barrier that makes support groups inaccessible for some PLWHA.

4.14.5 Education for the youth and other sexually active individuals

The findings of the study showed that HIV/AIDS disclosure is a worthwhile educational pursuit. This is because it helps people, particularly the youth to understand the social forces that make people fall prey to the disease and the importance of using preventive contraceptives such as condoms. The participants also mentioned that for parents living with HIV/AIDS, disclosure provided them with the opportunity to inform their

children about their seropositive status and the importance of taking their medication.

Below are some of the sentiments of the participants:

“After I was diagnosed with the disease, I kept my status a secret. It was after some months that I took my husband’s medical records and showed them to my children. I explained to them that their father died of the disease without telling me or taking treatment. I explained to them that I needed their support in taking treatment so that I could live longer and not die. Ever since, this discussion, the children have been very supportive in my endeavour to take treatment and following clinic appointments because they do not want me to die like their father”

“My parents never discussed with me anything related to my sexual behaviour When I experienced my first menstruation cycle, I screamed because I did not understand what was happening... I only discovered I was pregnant and infected when I was rushed to the hospital after collapsing in the bathroom... sometimes I think that if my mother had spoken to me about the risks of unprotected sex, I would probably not be positive today.”

“HIV/AIDS disclosure has drawn me closer to my mother. She has told me what she learnt about the disease and I accompany her to HIV/AIDS programs. With the increased intimacy, and show of affection, we try to eat dinner together so that we take treatment on time and I am starting to share with her my problems”.

The statements above indicate that an age appropriate framework should be used to teach the youth and other sexually active individuals about HIV/AIDS. The ripple effect of sensitizing the youth about sexual health issues is that it can enhance prevention

campaigns and instil in them ideas about healthy relationships. In essence, PLWHA can use disclosure as an entry point for counselling and advising sexually active individuals about making informed choices regarding sexual health matters. This proactive approach by PLWHA is not only preventative in nature, but it provides the youth with the opportunity to become healthy, productive citizens that can contribute to human development.

4.14.6 Platform for enhancing and expedite prevention campaigns

The findings of the study revealed that HIV/AIDS disclosure provided PLWHA with the opportunity of becoming role models whose footsteps the infected could follow. The participants highlighted that PLWHA have the prospect of inspiring seropositive individuals to disclose their status because the symbolic nature of prevention campaigns does not strike a chord with community members. The participants also highlighted that disclosure allows PLWHA to become ambassadors that address stigma and discrimination. The participants stated that dealing effectively with stigma and discrimination could improve the support systems for both the infected and affected. Some of the responses were as follows:

“I disclosed my status after silently living with HIV/AIDS for 10 years. I now teach others to follow suit and enhance their personal prevention endeavours. In order to reduce the stigma that HIV/AIDS is a death sentence... I encourage and counsel PLWHA to use condoms, take their medication and stay on their regimens. I also interact a lot with newly diagnosed youth who are broken and contemplating suicide and I advise them that the disease is not a hindrance if managed properly nowadays”

The aforementioned findings show that upon disclosure PLWHA can play a vital role in prevention campaigns. They not only put a human face to the disease, but they are a living proof that HIV/AIDS is a manageable illness that cannot stop people from living life to the fullest. However, partnerships with key stakeholders can help the infected to them take part in prevention campaigns that demystify and discuss issues surrounding the disease.

4.14.7 Financial opportunities associated with HIV/AIDS disclosure

The study findings revealed that some PLWHA benefit from employment in the HIV/AIDS industry, while a limited number survived on social grants. Participants also mentioned that PLWHA and their families have the mutual opportunity of gaining financial incentives from participating in research studies conducted by both private and public institutions. The following quotes illuminate this finding:

“As a peer educator, I raise HIV/AIDS awareness in my society. I teach people about safe sexual behaviour and the impact of sexually transmitted diseases. I also educate and advice the youth in schools to abstain from early sexual debut. I love what I do because it provides me with the opportunity to touch people’s lives but the job pays little... The government should surprise us with a permanent HIV/AIDS grant because they should remember that not all of us are in a position to get jobs that provide enough money to support our families and buy food that is needed to stay alive and healthy”.

The above statement confirms that the input of PLWHA can never be divorced from HIV/AIDS community work. The above statements also show that economic incentives for PLWHA enable them to purchase basic items such as food. This calls for non-governmental organizations to offer voluntary training to PLWHA so that they disclose their status and take up roles in the HIV/AIDS prevention campaigns.

4.14.8 Perfidy of HIV/AIDS disclosure

The research findings indicated that some PLWHA have the wrong motives for disclosing their status. Most of the participants in focus group discussions indicated that some PLWHA use the sympathy card to secure financial assistance or employment opportunities from non-governmental organisations or other key HIV/AIDS stakeholders. On the other hand, the focus group discussions revealed that PLWHA disclose their status to community members with the intention of selling their medication to drug dealers and substance abusers. The participants believed that some corrupt health officials were stockpiling the medication. The following are some of the participants' sentiments:

“Some PLWHA always try to capitalize on HIV/AIDS disclosure. When we are out there in the HIV/AIDS prevention campaigns, they come to you and reveal their status with the hope that you can give them some money, food parcels or jobs. They get so disappointed and angry with you when you do not offer them something.”

“Some PLWHA are full of tricks. They sell half an ARV for ZAR 25 and the full one for ZAR 50. This is a disservice because the money they gain from selling the drugs is normally used on alcohol. They seriously need to change their behaviour or get punished for abusing the privilege of getting free medication”.

These findings suggest that lack of integrity and moral character by some PLWHA has brought forth perfidious results that make disclosure a questionable act. This indicates that the perfidy of HIV/AIDS disclosure thrives because of corrupt tendencies by health workers. This calls for the government and the Ministry of Health to address the

malpractice perpetrated by some health officials and to establish economic empowerment programs that teach PLWHA to be self-reliant.

4.15 Factors that Drive Non-disclosure among PLWHA

4.15.1 Stigma as latent driver of HIV/AIDS non-disclosure

The research findings indicate that stigma in Alice has resulted in a low HIV/AIDS disclosure rate. The participants mentioned that people in Alice perceive HIV/AIDS to be a shameful subject that can result in the infected being shunned, mocked and labelled. Across the gender divide, the participants revealed that women are adversely affected by stigma as they are subjected to gossip that taints their character. The participants also mentioned that the fear of stigma causes some PLWHA to isolate themselves from mainstream society. Interestingly, the researcher learnt that PLWHA stigmatize one another within their inner circle. These are some of the responses shared by the study's participants:

“We have come a long way with the disease, but HIV/AIDS stigma is still a problem in Alice... you tell people that you are living with the disease and they think that you got infected through sleeping around or cheating in life. This is so discouraging and in the end, you end up deciding that it is much better to be silent because if you are open, the state of stigma directed towards you and your family can make it daunting for you to cope with this thing”.

“There’s a stigma attached to being a young woman living with HIV/AIDS... most people are taken aback when you reveal your status and they always want to know how you got infected so that they can maliciously spread the gossip about you”.

“a lot of times, older PLWHA are more judgmental and hostile towards each other.... This is especially true among those from Johannesburg and KwaZulu-Natal, where the disease is highly concentrated. They do not want to be involved with you because they say that you were prostituting and that you have a powerful strain of the virus”

The statements above indicate that perceived stigma has a detrimental effect on PLWHA, their families and the community at large. This implies that stigma works against the government's prevention campaigns because fear of stigma prevents many people from revealing their status and benefiting from the government's treatment program. This jeopardizes South Africa's chances of achieving the 90-90-90 UN targets. This calls for the government to intensify grassroots awareness campaigns that demystify the long-standing prejudices and stereotypes surrounding the disease.

4.15.2 Discrimination as a driver of HIV/AIDS non-disclosure

The research findings revealed that discrimination impeded HIV/AIDS disclosure. Most of the participants highlighted that HIV/AIDS disclosure has emotional repercussions because families and community members could ostracise them. Other participants in the focus group discussion claimed that disclosure to intimate partners could be socially taxing because it lead to divorce or domestic violence. Coupled with these factors, a few of the participants reported that discriminatory attitudes found in the employment arena could hinder PLWHA from securing employment. In essence, this means that discrimination has the propensity to destroy all aspects of PLWHA's lives. This indicates that socio-legal reform and tolerance is urgently required in Alice. These are some of the participants' sentiments.

“I remember my sister in law was taking care of our cousin who was HIV/AIDS positive. One day my cousin messed herself because she could not go to the toilet. My sister in law was disgusted to such an extent that she did not assist her. She went on to say that, it was my cousin’s fault that she got infected because she was foolish. Hearing this I said to myself I will never disclose my status to my family members lest they treat me like this.”

“I guess the infected are not keen on disclosing their status because people are wary of them. In community events where people see that the mouth of a seropositive individual is red, they give them their own small cups instead of the traditional calabash of beer that is passed around to everyone”.

“At work, PLWHA are unwilling to disclose their status because of the possibility of easily losing their credibility, and waged employment as some employers can stop them from preparing their food or handling their babies as a precaution against possible infection.”

These findings reveal how the perfidious ramifications of discrimination can dissuade PLWHA from disclosing their status.

4.15.3 Discrimination in health Institutions

The research findings showed that the fear of receiving differential treatment in hospitals and clinics inhibited PLWHA from disclosing their status. This was evidenced by the fact that almost all of the participants felt that PLWHA received medical services in their own special unit. They also used blue cards as opposed to the green ones used by other patients. The participants revealed that the discrimination they experienced made them feel like they belonged to the lower strata of patients, who

had to endure long queues, the breach of confidentiality and privacy by health care workers. Some of the responses were as follows:

“In the clinics and hospitals, HIV/AIDS positive people are handled differently from other patients. This makes us feel like we have a very bad disease that is dirty and if you are next to me, I can infect you. This separation is traumatic for the newly diagnosed individuals that are afraid that other patients will know that they are receiving treatment”. This is unfair because you spend close to 5 hours just waiting to receive medical care in an environment that you are not comfortable in”

“In the clinic, the nurses can be very judgmental and they talk about your status to other people... One becomes aware of this through whispers or people gazing in your direction”

In their defence, some health workers claimed that PLWHA's fear of institutional discrimination was driven by lack of knowledge. Other health workers also highlighted that PLWHA's fear of differential treatment was caused by the fact that some of them were attention seekers. These are some of the sentiments of the participants:

“The HIV/AIDS unit was designed in such a way that health care workers could counsel PLWHA and conduct all the necessary blood work under one roof. The discrimination that some of them think they experience is just the unintended consequences of the hospital design”

“PLWHA are sometimes attention seekers because they think that the nurses should do everything they want because they have disclosed their status. They easily forget that the clinics are understaffed because posts are frozen and we have been allocated a limited budget. This attention seeking behaviour is a

problem and it can also be seen by them going to the front of the line when we are being given food parcels in the campaigns”

The study's findings indicate that the fear of discriminatory attitudes and behaviours by healthcare workers can fuel mistrust, conflict and non-disclosure by PLWHA. However, to address the fear of discrimination, PLWHA might have to move from apathy to engagement with health workers. This can help health workers address PLWHA's perceptions about the indifferent treatment they receive at health care facilities. Coupled with this, the government might have to increase material and human resources in health care facilities. This is because the long queues and breach of confidentiality experienced by PLWHA can be a sign that the rural clinics do not have the capacity to attend to the large volume of patients, especially when the health workers lack the necessary motivation and supervision needed to render quality services.

4.15.4 Socio cultural factors stifling disclosure among PLWHA

The research findings indicated that culture stifles the process of HIV/AIDS status disclosure. The participants in the focus group discussion revealed that there is a long-standing belief in the AmaXhosa culture that chronic illness such as HIV/AIDS are caused by spirits. The participants claimed that this cultural myth can result in PLWHA being blamed for having evil spirits that kill wives, husbands and children. The participants mentioned that such accusations and cultural taboos prevent some PLWHA from disclosing their status. These are some of the participants' statements:

“When my father died from HIV/AIDS, his relatives started calling my mother a witch because they believed that bad things such as death are associated with a woman that is cursed or possessed by evil spirits. This horrendous experience has discouraged me from disclosing my status because I thought

that if my father's relatives could treat my mother like this, they would do the same to me."

"Disclosing my HIV/AIDS status is difficult on the basis that most people in our societies and schools have the misconception that it is a cultural taboo to talk about sexually related behaviour in the public".

The findings above reveal that from a socio-cultural perspective, HIV/AIDS is still an enigma. This indicates that for people in Alice to accept HIV/AIDS disclosure and its benefits, cultural custodians and other key stakeholders need to be educated about the scientific ontology and epistemology of the disease. This enlightenment could perhaps mitigate the risks and vulnerabilities the infected and affected face after disclosing their status.

4.16 Ramifications Experienced by PLWHA in Alice, Eastern Cape

4.16.1 Internal stigma and its ramifications

The findings of the study revealed that HIV/AIDS non-disclosure resulted in some PLWHA falling prey to internal stigma that caused them to experience mental health challenges such as anger, anxiety, stress and depression. The study's participants highlighted that PLWHA's exposure to internal stigma impaired their psychological wellbeing and it led them to experience various ramifications such as abusing substances like alcohol, carelessly sleeping around and avoiding medical check-ups etc. The problem with PLWHA withdrawing from local clinics is that some of them are forced to go to private facilities where they have to use their medical aid funds or pay from their own pockets. These are some of the participants' sentiments:

"Internal stigma makes it cumbersome for PLWHA to take advantage of the opportunity to access free health care services and prescribed medications.

The psychological turmoil inflicted by internal stigma changes their pleasant demeanour in such a way that they become withdrawn and consumed by anger, which causes them to burn bridges with family members that could offer them support and a shoulder to learn on”

The findings of the study showed that internal stigma is an inner force that marginalizes PLWHA and markedly diminishes their happiness and chances of achieving their full potential in life. This means that HIV/AIDS non-disclosure is a disservice to PLWHA, their families and the community at large. This indicates the need for educational campaigns and progressive policies that are able to instil confidence and encourage people to disclose their status.

4.16.2 HIV/AIDS non-disclosure and conflict in relationships

The study's findings revealed that some PLWHA use devious mechanisms and lies to hide their diagnosis from their partners, friends and community members. The participants highlighted that the ramifying effects of these devious mechanisms in intimate relationships was that they created conflict that resulted in divorce and domestic violence. Perhaps this is because PLWHA's partners could not fathom that their partners might have knowingly exposed them to the virus. The participants also revealed that non-disclosure by PLWHA disturbed the harmony in most families because of broken trust and cohesion. The following verbatim statements support the finding:

“My husband was working in East London and he would come back home on month ends and end of year holidays. I began to suspect that he was seeing other women and I asked him to use a condom. He said that “Are you a prostitute? ... Remember you are wife and I paid lobola. If you feel like you want to use condoms you can go back to your family.” Because of my husband's

response, we did not use condoms with him even though he knew that he was infected”

“I used to go and collect my medication at the hospital where my father works. In order to avoid him, I would use the longest route to get to my consultations... I would also walk close to a person and whisper that ‘that man we are approaching is my father, please tell him we are friends and I am accompanying you for your healthy check-ups. However, when I became hospitalized my father discovered my status. He felt so betrayed and said if I could hide serious things like being infected, what more could be known about me.”

The statements above reveal that HIV/AIDS non-disclosure can be counterproductive. They also show that PLWHA’s right to privacy can undermine other people’s right to health and wellbeing. This conflict of rights can be mitigated if HIV/AIDS disclosure was done in a timely fashion.

4.16.3 The association between non-disclosure and shattered lives

The findings of the study revealed that HIV/AIDS non-disclosure led some PLWHA to be constantly absent from work and school. The participants revealed that absenteeism, inter alia, negatively affected their academic achievement and employment potential. As a result, some PLWHA had to change their careers and suspend their studies, thereby lessening their chances of escaping the vicious cycle of poverty. These are some of the participants’ sentiments:

“I had to leave my job as a paramedic because the ARVS I was taking were making me feel dizzy and I could not attend my night shifts. I could not call in and say I can’t come in because I have to take self-limiting pills. In fact, they would say, what pills and I would not be able to explain to them that I have been

secretly living with HIV/AIDS. Can you imagine just telling them all at once, that I have got HIV/AIDS?"

"When I was diagnosed with HIV/AIDS, I was devastated to such an extent that I had to spend most of my time at the clinic receiving counselling. This would take all of my afternoons and I would miss some of my classes. This made me perform badly in my tests and asking for support from my lectures was not an option because they are terrible at keeping secrets. I later on decided that I would repeat my courses the following year since I could not cope with my diagnosis"

The above findings reveal that PLWHA require time out of their work and educational schedules to attend to their medical needs. However, if PLWHA do not disclose their status, their employers and educators can interpret this as low job or educational motivation. This can result in unemployment or educational suspension that can negatively affect the trajectory of one's life. The government should therefore ensure that educational and employment institutions have policies that not only encourage disclosure but also provide support services for HIV/AIDS challenges.

4.17 Coping Strategies for the Ramifications of Non-disclosure

4.17.1 Negative coping strategies

The findings of the study revealed that some PLWHA cope with the ramifications of internal stigma by blaming themselves and the people around them for their diagnosis. The participants mentioned that denial was another negative coping strategy adopted by PLWHA. Unfortunately, this coping strategy drove some PLWHA to consult traditional healers. The participants in the focus group discussions lamented on how consulting traditional healers diminished PLWHA's financial resources and caused ill

feeling between them and their neighbours. These are some of the participants' sentiments:

“PLWHA are can be oversensitive for nothing. They always get angry for nothing; one has to continuously walk on eggshells with them”.

“PLWHA make a mess of things when they start consulting traditional healers in search of external forces behind their illness. Many find themselves in huge debts because of purchasing some useless concoctions prescribed by bogus healers; while others make enemies with neighbours that they believe are bewitching them. This is unfortunate because their families will need help from their neighbours, especially when it comes to fetching water for caregiving purposes”

The research findings highlight that negative coping strategies can negatively affect the health and relationships of PLWHA. This shows that there is need for social workers to teach PLWHA about adopting positive coping strategies that address the ramifications of HIV/AIDS non-disclosure.

4.17.2 Positive Coping Strategies

4.17.2.1 Self-acceptance

The research findings illustrated that a common coping strategy adopted by PLWHA was accepting their HIV/AIDS status and making the best of it. The participants revealed that self-acceptance led some PLWHA to take an active role in adopting behavioural and nutritional interventions. The findings also showed that some PLWHA took advantage of social media and its ability to connect them to different platforms of support. These are some of the participants' sentiments:

“I am not ready to share my HIV status to other persons [sic], whether to any of my family members or work colleagues. So I have made sure that I use treatment in the right way, eat healthy food and exercise”.

“I used the internet to create different ghost accounts that would provide me with information about how PLWHA were managing their illness. Using these different accounts, I managed to get instant feedback on how I could address the medical, relationship and legal issues that arise from not disclosing my status”

The above findings led the researcher to deduce that self-acceptance enables PLWHA to take independent steps to deal with the ramifications of HIV/AIDS non-disclosure. The study also shows that technology is changing the world rapidly and if PLWHA take advantage of this tool, they will have the opportunity to find solutions to their own problems

4.17.2.2 Mediation and family therapy

The research findings revealed that PLWHA coped with the ramifications of HIV/AIDS non-disclosure through mediation and attending family therapy. Some participants highlighted that PLWHA, particularly the married ones, used revered family members as mediators that helped them disclose their status. The participants also mentioned that family therapy was crucial in reducing conflict and ensuring the smooth transition of relationships. These are some of the participant's sentiments:

“I called for a family meeting and with the help of my aunt I disclosed my status and I asked my wife for forgiveness. At first, my wife did not take it very kindly, but my aunt explained to her that pointing fingers would not help the situation. She told her that it was important for both of us to be each other's support

system. It has not been easy for the both us, but our tragedy seems to have drawn us closer to each other. We pray together and we always use protection so that we do not re-infect each other”

“Family therapy has provided us with a home remedy on how to use open communication and become each other’s emotional backbone”.

In reference to mediation, the study’s findings indicate that coping with the ramifications of HIV/AIDS non-disclosure is not a one-man show as family members can be a great asset in addressing conflict. Family therapy can be useful in promoting stability and integrating PLWHA back into their familial relationships.

4.17.2.3 Engaging with faith-based organisations and NGOs

The research findings showed that PLWHA and their families utilised religious and civil organisations in dealing with the ramifications of HIV/AIDS non-disclosure. In reference to faith-based organisations, the participants revealed that PLWHA sought refuge in religion as it allowed them to reinvent themselves and seek God’s divine guidance in remedying the ramifications of HIV/AIDS disclosure. These are the participant’s sentiments:

“People living with HIV/AIDS should be encouraged to go to church. I use prayer as a platform to ask God for strength when I feel depressed and to touch the hearts of the people I have wronged by not disclosing my status”

Interestingly, a few of the participants had mixed feelings about the church as they felt that church members harboured stigmatising attitudes. These are the participants’ sentiments:

“The problems with church members is that they think they are righteous and their words can’t hurt you. It was hard for me to go to church the first days because in choir practice if you are singing badly, they say you are singing as if you are sick with HIV/AIDS. It is more disgusting when you have a cold and you cough. They say that you cough as if you have TB. This joke is not even funny because you can’t joke about an illness”

Lastly, the findings showed that some participants sought assistance from non-governmental organizations in Alice. The participants cited that these organizations provided them with the socio-legal education and skills required to reveal their status. These were some of the respondent’s sentiments:

“Receiving education from non-governmental organisations provided me with the platform to disclose my status so that I would not give people the power to gossip about me or stigmatize me. It just dawned on me that the more you share your status, the more you regain the power to provide ignorant people with correct information about the disease”

With reference to faith-based organisations, the above finding shows that spiritual support can improve the physical and mental wellbeing of PLWHA, thus reducing the adverse effects of internal stigma. However, the church might have to adopt the human rights framework that educates its members about treating PLWHA with dignity and respect. Concerning non-governmental organisations, the study’s findings revealed that PLWHA gain technical and expert knowledge from them. The use of faith-based and non-governmental organisations by PLWHA is an indication that a holistic approach is crucial in addressing the ramifications of HIV/AIDS non-disclosure.

4.18 Conclusion

In this chapter, the researcher presented the study findings. These findings produced different themes that were supported by the participant's quotations. In the next chapter, the different themes will be contextualised and confirmed by a literature control. This will be complemented by the conclusions and recommendations pertaining to the research process and findings.

CHAPTER FIVE

FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The previous chapter presented the study's findings. This chapter discussed the study's findings by pitting them against other related literature. Apart from discussing the study's findings, this chapter will provide the study's conclusions and recommendations.

5.2. Demographic Information of the Participants

The demographic information of the study participants, from PLWHA, their families and key informants is discussed below. The researcher focused on biographical traits such as gender, age, educational level, marital status and the occupational status of the participants.

5.3 Age and Gender of the Participants

The demographic information in Chapter 4 indicated that PLWHA's ages ranged between 18 and 55 years, with a preponderance of those affected being between 18 and 30 years. The research finding on PLWHA's age heralds that the bulk of the country's workforce might be falling prey to the disease. This is problematic because the sting of internal or external stigma can exclude some PLWHA from participating in the country's vision of transforming the economy and creating better lives for communities at large. This tragedy is likely to affect the country's Gross Domestic Product (GDP) negatively. Shisana et al. (2014) hold that the continued high incidence of the disease among females between the ages of 20 and 34 years and males aged from 25 to 49 years is a serious call for the government to design and apply targeted

interventions for these groups, over and above the comprehensive interventions for the population at large.

The high incidence of the disease, particularly among females, is a sign that the government is overwhelmed in its attempt to curb the spread of the disease. The scenario discussed above necessitates that biomedical interventions should work in tandem with Social and Behavioural Change Campaigns (SBCC) (Shisana et al., 2014). For instance, the SBCC campaigns can dissuade the public from engaging in immoral behaviour that makes it difficult for HIV/AIDS disclosure and adherence to treatment.

The research findings indicated that the age of PLWHA's family members ranged from 18 to 64 years and the majority were female. In Africa, this is not unique considering that most caregivers are women. This has contributed to HIV/AIDS being viewed as a disease of women more than men, hence the concept of the 'feminization' of HIV/AIDS (Kang'ethe and Chikono, 2014). Literature reveals that the indirect impact of HIV/AIDS on family members is evident from children becoming caregivers for their parents and grandparents becoming "silent saviours" for HIV/AIDS orphans (Chenga and Cronje, 2007; Roux and Strydom, 2011, p. 323). Nevertheless, the fact that PLWHA's family members are mostly women is a disadvantage because care-giving responsibilities can provide men with information about the benefits and opportunities of HIV/AIDS disclosure.

This information is important because men in African societies tend to have low HIV/AIDS testing rates and lower CD4 cell counts when accessing treatment as opposed to women (WHO, 2013). This means that they will have a limited chance of having their health restored by ARVs. With regard to the age of the key informants,

the findings in Chapter 4 indicated that they were between the ages of 40 and 55 years and the majority of them were females.

The age of the key informants showed that they had the personal wisdom and understanding of HIV/AIDS and the associated ramifications of non-disclosure. The fact that most of the key informants were female indicated that women, more than their male counterparts, volunteered to participate in the developmental challenges of HIV/AIDS. Perhaps this environment has informed the stereotype that HIV/AIDS is a woman's disease. This stereotype is a problem in that it acts as a barrier for men to be active partners in prevention campaigns.

5.4 Participants' Educational and Employment Status

The findings indicated that PLWHA's low educational status was linked to their low employment status. The low educational status of PLWHA is worrisome because they might lack the opportunity to acquire disclosure skills and the mental strength needed to manage their illness. Low educational status does not guarantee that PLWHA will be able to seek legal and social remedies against individuals that stigmatise and discriminate against them (GNP, 2011). This is evident in a study conducted by the Human Rights Council in the Eastern Cape, where the PLWHA faced heinous human rights violations in their communities. Unfortunately, the study highlighted that the atrocities were a common phenomenon, mainly because PLWHA did not report their perpetrators to state authorities and they were not aware of the legal infringement of their rights (GNP, 2011). To this end, human rights education is a useful tool that should be utilised to seek social justice and change for abused PLWHA.

The fact that the majority of PLWHA's family members had low educational standards is a cause for concern, as they were unemployed and depended on state grants due

to their impoverished circumstances. The distressing part of a poor socio-economic background is that it forms fertile ground for viral proliferation and it appears to affect women more than men (Hargreaves et al., 2007).

In light of this, addressing social determinants such as social inequality and lack of economic opportunities can go a long way towards mitigating HIV/AIDS and the poor support given to those that disclose their seropositive status. The research findings revealed that the key informants had obtained tertiary education and were formally employed. The educational level of the key informants was an indication that they had the knowledge and skills needed to understand the different dimensions of disclosure. These skills created a climate in which they could debate on the different interventions that could enhance HIV/AIDS disclosure. The educational attainment of the key informants, particularly the health workers, created a platform in which the researcher could ascertain if their work was in alignment with the ethos of their profession. This is crucial in ensuring that service providers do not exacerbate the ramifications of HIV/AIDS non-disclosure. .

5.5 Participants Religious and Tribal affiliations

This study found that PLWHA and their families had religious affiliations with Christianity and the African Traditional Religion. This signified that both religions have the capacity to provide PLWHA with spiritual healing. According to Barney and Buckingham (2012), Christianity in improvised rural areas like Alice, can provide both the infected and affected with hope and sympathy needed to deal with debilitating illnesses. Besides this, religion can decry HIV/AIDS injustices and it can help with the reintegration of people who are alienated because of their status (NBTS TV Uganda, 2017). In as much as this study underscores that religion can help the infected with

disclosure, it is important to highlight that spiritual healing is controversial as some pastors and traditional healers claim that they can cure the disease permanently.

Unfortunately, due to lack of knowledge and low literacy levels among the rural folk some PLWHA can end up abandoning their medication for spiritual interventions. This is antithetical for the struggle against the pandemic and it indicates that some religious leaders do not understand the issues surrounding the prevention of HIV/AIDS. Therefore, it is imperative that collective dialogue between health care workers and faith-based leaders be used to establish policies that change harmful norms and religious dogma that prevents the infected from accessing preventative services and treatment.

Collaborations between health workers and religious leaders is imperative because it is estimated that 80% of African people rely on traditional medicine and spiritual healers for their primary health care needs (Njosing, Edin, San Sabastian, and Hurting, 2011). This suggests that if traditional leaders are supplied with relevant knowledge, they can encourage PLWHA to access the health care system. The findings in Chapter 4 revealed that PLWHA and their families were from the Xhosa and Zulu ethnic tribes. The difference in the participants' tribal affiliations is a sign of cultural diversity. It was comforting to note that these ethnic tribes were bathed by the Ubuntu philosophy (Osei-Hwedi, 2007). The fact that this philosophy instils solidarity and communal bonds is important because it created opportunities for some family and community members to offer social, material and physical support to people who disclosed their status. In essence, the findings suggest that the mainstreaming of religious values and positive ethnic values can promote HIV/AIDS disclosure and the wellbeing of both the infected and affected.

5.6 The Marital Status of the Participants

This study showed that the minority of PLWHA were married. This is disappointing because a survey commissioned by the Human Science and Research Council revealed that married couples had a lower HIV/AIDS incidence (0.6%) than those that were cohabiting (3.7%) and single (3.4%) (Shisana et al., 2014). Although marriage is not a panacea to prevent HIV/AIDS infections, it is interesting to note that PLWHA in this traditional union are more likely to disclose their status (Shisana et al., 2014). A case in point is a mixed method study that was conducted in Burkina Faso, Kenya, Malawi and Uganda. In this study, the authors found that people in marriages disclose their status because they need to mitigate the transmission of the disease and uphold the integrity of their relationships (Hardon et al., 2013).

Given that PLWHA in this study were cohabiting, they might be less motivated to disclose their status because they do not have the guarantee that they will receive support from their partners. The guarantee of support is questionable for cohabiting couples, as they do not have a legally binding contract that can force them to stay in a relationship that is fraught with challenges such as infidelity and illness. In this light, it is unfortunate that cohabitation is on the rise in South Africa due to commercialisation of lobola and the high costs associated with marriage. This perhaps signifies that there is a need for the South African National AIDS Council (SANAC), to encourage monogamous relationships or consistent condom use amongst intimate partners (Shisana et al., 2014).

SANAC could also consider reinventing the Abstinence, Be faithful and Use condoms (ABC) approach to HIV/AIDS. The reinvention of this approach to suit the South African context can help reduce the patriarchal norms that encourage men to have multiple partners as a sign of masculinity and sexual prowess (Chalk, 2014). The fact

that all the key informants were married was important as it suggests that they can understand that HIV/AIDS disclosure can have a positive or negative impact on couples.

5.7 The Panacea of HIV/AIDS Disclosure

5.7.1 Access to medication

The study established that HIV/AIDS disclosure opened the door for PLWHA to access treatment that gave them a second chance in life. This is supported by previous research from six treatment programs in the Western Cape, Gauteng and KwaZulu-Natal Provinces. This research documented that HIV/AIDS positive adults could have a near normal life expectancy of about 80% if they initiate ART before their CD4 count has dropped below 200 cells (Johnson, Mossong and Dorrington et al., 2013). In line with international research, this study revealed that the near-normal life expectancy of PLWHA on ARVs in high-income countries could be a living reality in low and middle-income countries (Johnson, Mossong and Dorrington et al., 2013). In South Africa, Bor (2012) and WHO (2013) noted that PLWHA enrolled on ART were likely to be employed 4 years after starting treatment. This shows that ART can increase labour productivity and the future prospects for PLWHA.

5.7.2 The psychological benefits of HIV/AIDS non-disclosure

The research findings indicated that HIV/AIDS disclosure improved the psychological wellbeing of some PLWHA. Qioa, Xiaoming and Zhao (2012) and Hult, Wrubel and Branstrom (2012) affirm that open communication with others about an illness is not only cathartic, but it provides individuals with the opportunity to receive emotional support, coping strategies and helping hands needed to manage one's illness.

Emotional support, particularly by family members, has a profound impact on PLWHA's psychological wellbeing because the disease tends to expose human beings to their terrible human vulnerabilities and it brings fear to the fore (Cameron, 2016). Kyaddondo, Wanyenze, Kinsman and Hardon (2013) hold that while open communication about HIV/AIDS is ideal for the management of the illness; disclosure to family members can be fraught with challenges. Research conducted in the Oliver Tambo (OR) District of the Eastern Cape Province revealed that HIV/AIDS disclosure to family members was a challenge, as they were the main culprits in labelling the infected as prostitutes, stupid and reckless for contracting the disease.

Typically, this creates feelings of humiliation and stress, which undermine PLWHA's immune system (Chida and Vedhara, 2009). However, disgraced PLWHA can take solace from the fact that HIV/AIDS disclosure provides them with the opportunity to access support structures that offer them psychological support (Stutterheim, Bos, Pryor, Brands, Leibregts and Schaalma, 2011). Asante (2012) holds that the susceptibility of PLWHA to psychological stress requires a significant improvement in the provision of mental health services for the infected.

5.7.3 Access to support structures

The research findings indicated that HIV/AIDS disclosure is beneficial for PLWHA because they can access community-based support structures such as the VCT and support groups. In reference to the VCT, the UNAIDS Gap Report (2014) and Cameron (2016) concede that disclosure increases HIV/AIDS testing, which is the gateway to knowledge, power, understanding and action. Card et al. (2008) also noted that HIV/AIDS testing and its accompanying counselling can help seropositive individuals to initiate behavioural changes that will reduce their chances of being infected by a different strain of the virus or passing it to others.

The WHO (2012) report noted that the reconciliatory nature of counsellors in the VCT centres is beneficial for PLWHA because it facilitates disclosure in couples and it helps them to identify seropositive children. Despite these preventative benefits, men in South Africa, the youth and key populations in most countries continue to face barriers in the uptake of voluntary counselling and testing services (UNAIDS, 2016). The barriers to accessing the VCT include fear of stigma, discrimination, unfriendly services and potential criminalization. In South Africa, the existence of these barriers does not require quick fix solution by the government but, state partnerships with the corporate world and civil society might provide innovative strategies that encourage HIV/AIDS testing.

Shisana et al. (2014) holds that the scaling up of testing in the workplace can propel men to test for HIV/AIDS. State partnerships with other stakeholders can also channel resources towards the creation of comprehensive care packages that have different services such as psychological counselling, HIV/AIDS education and water based lubricants for the LGBT group (UNAIDS, 2014; Kang'ethe and Mutopa, 2014). The provision of these comprehensive care services and increased testing is beneficial for South Africa because studies show that researchers are poised to understand the epidemiology of the disease, its associated behaviours and determinants when the hard to reach population is tested (Card, 2008). With this in mind, this research seeks to advance the idea that addressing the barriers to HIV/AIDS testing is key in unlocking the personal and public health benefits of HIV/AIDS disclosure.

5.7.4 Support groups

The research findings indicated that HIV/AIDS disclosure was beneficial for PLWHA because it enabled them to access support groups, which were a fitting vehicle for forming social networks and sharing experiences. This finding appears to be in accordance with Rohleder et al. (2010), who theorised that support groups extend the social network for PLWHA and they provide them with educational resources that help them reformulate their senses, their lives and social roles. A study conducted in Thailand confirmed that support groups enabled PLWHA, particularly women, to access emotional strength and collective power needed to address stigma and discrimination in their communities (Liangputtong, Haritavorn and Kiatying-Angsulee, 2009).

In affirmation of the barriers to accessing support groups, Liangputtong (2016) posited that modern communication and social media could go a long way in making support groups accessible to rural populations that have poor roads and bad infrastructure. Kekana (2011) also holds that a small size, mixed gender group composed of similar aged cohorts and a trained facilitator can increase the involvement of PLWHA in support groups. In Alice, which is this study's domain, this can reduce the shame some old aged PLWHA experience when they share sensitive information about their experiences and diagnosis.

5.7.5 Education for the youth and other sexually active individuals

Research findings indicated that HIV/AIDS disclosure provides PLWHA with the opportunity to educate the youth and other sexually active individuals about sexual health issues. This educational opportunity has been documented in Togo, Botswana and Tanzania where authors revealed that HIV/AIDS disclosure was key to improving paediatric ART adherence, family relationships and encouraging seropositive youth to

protect themselves and others against onward transmission (Polisset et al., 2009; Midtbo et al., 2012). Rochat et al. (2013) and Kyaddondo et al. (2013) hold that HIV/AIDS status disclosure can create a win- win situation in which seropositive parents take their medication with their children, thus increasing their adherence levels and family cohesion. To this end, empowering the young people and other sexually active individuals with sex education can lay the foundation for the creation of an HIV/AIDS competent generation (NBS TV Uganda, 2017).

This generation will be equipped with knowledge on how to modify their behaviour. This modification can add impetus to South Africa's goal of ending the pandemic by 2030 and maintaining that status quo for the generations to come (NBS TV Uganda, 2017). Psychologists and social workers in Alice could perhaps be of assistance to parents who use HIV/AIDS disclosure as a conversation starter. These professionals could create pamphlets that provide sex and HIV/AIDS information that is concise, understandable and sensitive to the target population's culture. This study's findings indicate that disclosure and open discussions about the disease can be an antidote to the shame that inhibits people from disclosing their stigmatised identity.

The study's finding also revealed that HIV/AIDS disclosure provides PLWHA with the opportunity to become role models that expedite prevention campaigns in their communities. Kang'ethe (2015) holds that PLWHA can add mileage to prevention campaigns. For example, role models like Judge Edwin Cameron have used their status disclosure to break the cycle of denial and stigma. Allem et al. (2017) posits that disclosure by PLWHA can reinvigorate people's response to the pandemic and encourage those who do not know their status to go for testing. To this end, advocating for tolerance towards people that disclose their status is crucial for revamping prevention campaigns.

This study aimed to highlight that NGOs in Alice should play a central role in mentoring PLWHA to be role models that inspire both the infected and affected to become active citizens that turn the tide of new HIV infections. The development of active citizens in Alice could lay the foundation for robust grassroots campaigns. Using the lenses of the labelling theory, this study's findings shows that the HIV/AIDS label can cause some people to gain status in society. This indicates that labels can have both positive and negative outcomes.

5.8 Perfidy of HIV/AIDS Disclosure

The research findings revealed that some PLWHA disclose their status with the intention of benefiting from their diagnosis. This finding resonates with Levi-Minzi and Surrat (2014) and Tsuyuki et al. (2015) who revealed that in America, some PLWHA sell their ARVs on the black market because of financial hardships or the need to sustain their substance addictions. In South Africa, reports of ARVs being sold on the black market have been documented in KwaZulu-Natal (AIDS Health Care Foundation, 2009). Some authors have highlighted that the selling of ARVs by PLWHA can be attributed to lack of medication literacy, poor socio-economic conditions and the spirit of dependency (Tladi, 2006; Govender, Fried, Birch, Chimbindi and Cleary, 2015). Although, the South African government has done its part in providing people with free treatment, it's time for social workers to be proactive in educating the infected about the legal and social consequences of selling ARVs. Besides this, corruption in the health care system needs to be addressed because it is necessary that ARVs go to the right people (Schulz-Herzenberg, 2007).

5.9 Stigma as a Latent Driver of HIV/AIDS Non-Disclosure

The research findings indicated that PLWHA are inhibited from disclosing their status because they fear that HIV/AIDS stigma can cause them to be isolated, shunned and

labelled. This finding is consistent with African and Asian studies that indicate that stigma has blanketed the disclosure processes in fear and consequently some PLWHA would rather keep their status to themselves (Izugbara and Wekesa, 2011; ZNNP, 2014; Li et al., 2009; Sublette, 2008). Some authors also posit that stigma, accompanied by discrimination, is an anathema in the fight against the epidemic (ZNNP, 2014). This is because the HIV/AIDS campaign can lose on two fronts, as people fear testing and accessing treatment that could label them as seropositive (UNAIDS, 2016). This study's finding is consistent with the studies theory because the fear of having a stigmatised identity and status loss can prevent HIV/AIDS disclosure. This is because HIV/AIDS disclosure can result in an individual losing their bona fides as a person of good faith (New America, 2017).

5.9.1 Discrimination as a driver of HIV/AIDS non-disclosure

The study's findings indicated that discrimination and its perfidious ramifications dissuades PLWHA from disclosing their status. The Stigma Index Survey in Western and Central Africa also highlighted this finding. This survey found that "PLWHA experience verbal violence, in the form of insults, harassment and threats (UNAIDS, 2016). Additionally, previous studies have highlighted that discrimination is one of the reasons behind PLWHA experiencing unemployment rates that are 3 times more than the normal national rates (UNAIDS, 2014). The economic castration experienced by PLWHA suggests that the right to equality and work is not yet a reality for some people (Cameron, 2016).

In consonance with this study's findings, some authors have highlighted that health care workers breach patient's right to confidentiality and they provide PLWHA with "different quality of treatment" (Gilbert, 2009; UNAIDS, 2014; UNAIDS, 2016;

Kang'ethe and Mutopa, 2014). This means that the human rights framework should be used to transform the health care system

5.9.2 Sociocultural factors that Influence HIV/AIDS non-disclosure

The research findings revealed that sociocultural factors and harmful traditional beliefs are a barrier to HIV/AIDS disclosure. This finding corroborates with studies, that state that “HIV/AIDS is associated with witchcraft and curses, making ostracism and stigmatization seem legitimate, in addition to causing people to be singled out for condemnation within their own community” (UNAIDS, 2000; Leclerc-Madlala et al., 2009; Kopelman, 2002 cited in Tsebe, 2016). The following authors Van Dyk (2010) and Ullah and Huque (2014) also theorised that PLWHA in the African and Asian contexts may be discouraged from disclosing their status because they fear that intimate revelations of their personal and social problems can bring shame and disgrace to their family. This finding suggests that culture should be re-examination so that PLWHA can have the freedom to disclose their status without fear of condemnation.

5.10 The Ramifications of HIV/AIDS Non-Disclosure

5.10.1 Internal stigma and its ramifications

The studies finding showed that HIV/AIDS non-disclosure caused internal stigma that led to social isolation and substance abuse. This finding was supported by the following authors: ZNNP (2014); Ullah and Huque (2014) and Daniel and Parker (1990), who observed that, “stigmatization can result in an individual experiencing social death”.

Cameron (2016) attributes this sad state of affairs to the fact that internal stigma is located deeply within self-blame, shame and self-loathing thoughts that ultimately

impair an individual's self-esteem. In this regard, internal stigma is shamefully expensive for South Africa because PLWHA tend to mask their pain in alcohol, which has the negative spinoff of "facilitating casual unprotected sex" (Gerbi, 2009). In this regard, this study's finding is in line with the labelling theory. This is because the abuse of alcohol and sexual recklessness by PLWHA can be viewed as self-fulfilling prophesy of the negative aspects of the HIV/AIDS label. This demonstrates why it is important for PLWHA to disclose their status so that they can be equipped with knowledge on how to deal with internal stigma.

5.10.2 Non-disclosure and conflict in relationships

The study findings revealed that HIV/AIDS non-disclosure created a fertile ground for conflict, domestic violence and possible criminalization. The following authors Paiva et al., (2011), Mamogobo et al., (2013) and Rwemisisi, (2008) also revealed that non-disclosure perpetuates secrecy and mistrust, which more often than not creates conflicts in families and spousal relationships. For instance, the initiation of condoms without disclosure can lead to intimate partner violence due to cultural beliefs that perceive this device to be unnatural (King et al., 2008; Patel, 2012; Leclerc-Madlala, 2009). This expands the epidemic because failure to discuss or practice safe sex means that seropositive people are likely to infect their partners. This studies finding is consistent with the stigma theory because it shows that condoms, are victims of secondary stigmatization. For this stigma to be addressed HIV/AIDS campaigners should rebrand condoms and equip PLWHA with skills on how to disclose their status before conflicts arises.

5.10.3 Non-disclosure and shattered lives

The findings of this study indicated that HIV/AIDS non-disclosure increased absenteeism among PLWHA. This lowered PLWHA's academic achievement and

employment potential, resulting in them leaving their jobs and suspending their studies. Consequently, this drew PLWHA into the vicious cycle of poverty. Bridgette, Pugh and Kleintjes (2007) and ZNNP (2014) noted that unemployment not only affects the “bread winner’s identity, but it increases family poverty, resulting in higher levels of stress, risky behaviour, psychological problems and even family breakdown”. The benefits of staff development and educational skills are laid to waste when PLWHA leave their education and employment (ZNNP, 2014). This perpetuates the stigma that investing resources in PLWHA is a waste of time because they are irresponsible. This calls for policies that enable PLWHA to disclose their status in both the work and education sphere.

5.11 Coping Strategies for the Ramifications of HIV/AIDS Non-Disclosure

5.11.1 Negative coping strategies

The outcome of this study revealed that some PLWHA coped with the ramifications of HIV/AIDS non-disclosure by blaming themselves and their families for their diagnosis. Khakha and Kapoor (2015) also stated that this coping mechanism is maladaptive because self-blame decreases PLWHA’s physical and mental wellbeing, their independence, social relationships and quality of life. Additionally, this study finding revealed that denial lead PLWHA to consult traditional healers for spiritual healing. Kheswa (2014) and Izugbura, Chimaraoke and Wekesa (2011) revealed that PLWHA who consulted traditional healers jeopardised their health and finances as they underwent expensive cleansing ceremonies and drank concoctions that had a negative impact on their immune system.

Chenga and Cronje (2007) also state that PLWHA can jeopardise their finances when they seek services from traditional healers that are not fully assimilated into the health

care system. The fact that denial and blame can set people on a path of self-destruction indicates that PLWHA should be taught on how to live a positive lifestyle.

5.11.2 Positive coping strategies adopted by PLWHA and their families

5.11.2.1 Self-acceptance

The study's findings showed that PLWHA coped with the ramifications of HIV/AIDS non-disclosure through self-acceptance. PLWHA who accept the reality of their diagnosis have a better quality of life because they are prepared to take steps in managing their illness (Khakha and Kapoor, 2015; Gahagan, 2013). The following author's Van Uden-Kraan, Drossaert, Taal, Seydel, and van de Laar, (2009) and Kalichman, Weinhardt, Austin, Luke, and Cherry (2003) confirmed that access to social media enabled PLWHA to be well informed and optimistic about their treatment.

5.11.2 2 Mediation and family therapy

The research findings revealed that PLWHA coped with ramifications of HIV/AIDS non-disclosure through mediation and family therapy. Kyaddondo et al. (2013) stated that family intermediaries such as uncles and aunts help people with HIV/AIDS disclosure. The upside of using family intermediaries in dealing with HIV/AIDS conflict is that they are perceived as trustworthy and they offer ongoing emotional and instrumental support. The research findings also found that family therapy was a coping strategy for dealing with the ramifications of HIV/AIDS non-disclosure. Van Dyk (2010) and Kyaddondo et al. (2013) confirmed that family therapy provides PLWHA with a neutral person that empowered them with knowledge on how to address HIV/AIDS trauma and family conflict. This study finding is a subtle reminder that PLWHA can have renewed friendships and family ties. This suggests that HIV/AIDS disclosure, when facilitated by professionals and intermediaries can perhaps water down the ramifications of HIV/AIDS non-disclosure.

5.11.2.3 Engaging with faith based and non-governmental organizations

The research findings indicated that civil and faith based organisations played an instrumental role in helping PLWHA deal with the ramifications of HIV/AIDS non-disclosure. Pinho (2017) noted that prayers and faith in god helped to reduce self-blaming attitudes amongst PLWHA. However, Pinho (2017) holds that the downside with the church is that some members are perpetrators of HIV/AIDS stigma and discrimination. Lastly, this study revealed that some PLWHA sought advice on how to cope with the ramifications of HIV/AIDS non-disclosure from non-governmental organizations. Evans and Becker (2009) noted that NGOs in the United Kingdom provide PLWHA with emotional support and workshops that equip them with practical skills on how to disclose their status to their families. Van Dyke (2010) also holds that NGOs provide PLWHA with educational and legal knowledge about their rights.

5.12 Study Conclusions

This section seeks to establish the extent to which the study achieved the aim and objectives that were set in the beginning of the study.

5.13 Discussion on the Study's Aim and Specific Objectives

The aim of the study was to explore the ramifications of HIV/AIDS non-disclosure among the PLWHA in Alice, Eastern Cape Province. The research achieved this aim because all the research categories, which included PLWHA, their families and key informants, revealed their attitudes, perceptions and notions about HIV/AIDS non-disclosure. However, to assess the extent at which the study's objectives have been meet, the following section will compare the empirical findings with the specific objectives.

5.13.1 To explore the opportunities and benefits of HIV/AIDS disclosure

The research met the demands of this objective by showing that the benefits of HIV/AIDS disclosure included, inter alia, access to medication, improved psychological wellbeing and access to support structures such as the VCT and support groups. Access to medication is recognized as the most important benefit of HIV/AIDS disclosure. This is because ARVs improve PLWHA's health and they enable them to become productive citizens. The research also revealed that HIV/AIDS disclosure not only brought financial benefits, but it also created a platform for the infected to educate the youth about the disease. In retrospect, educating the youth about the disease was the most important opportunity derived from HIV/AIDS disclosure as it could prevent the future generations from being trapped in the revolving door of new HIV/AIDS infections.

5.13.2 To examine factors discouraging HIV/AIDS disclosure in Alice

The study achieved this objective by showing that stigma, discrimination and socio-cultural factors are latent drivers of HIV/AIDS non-disclosure. Fear of stigma and discrimination is a hurdle that prevention campaigns need to overcome. This is because some infected people fear that disclosing their status will lead them to be treated as pariahs that are labelled and shunned. At an individual level, the fear of external stigma marginalizes both the infected and affected from accessing social support that can make positive living less burdensome.

5.13.3 To ascertain the ramifications of HIV/AIDS non-disclosure in Alice

The study fulfilled this objective by showing that the non-disclosure of one's HIV/AIDS status perpetuated internal stigma, conflict in relationships and diminished career and

educational achievement. The study established that internal stigma had the most effect on PLWHA because it compromised their opportunity to take their medication openly as well as adopt protective devices and behavioural changes needed to live a positive lifestyle (ZNNP, 2014; Cameron, 2016). Another effect of non-disclosure is that it causes PLWHA's lives to take a 180-degree turn. This is evident in the fact that some PLWHA isolate themselves from social circles and they sacrifice their educational and career pursuits. Such a situation is counterproductive as it could lead to substance abuse or suicide due to a feeling of hopelessness.

5.13.4 To describe coping strategies for the ramifications of non-disclosure

The study's findings put this objective to rest by revealing that PLWHA and their families can either adopt positive or negative mechanisms in coping with the consequences of HIV/AIDS non-disclosure. Some negative coping strategies are self-blame and denial while positive coping strategies are self-acceptance, mediation, and engagement with both faith-based and non-governmental organizations. With regard to the negative coping strategies, the researcher contends that self-blame is the worst coping strategy because some PLWHA sound horrendous and they create an unpleasant atmosphere for their loved ones. In contrast, positive coping strategies such as self-acceptance and engaging with faith-based organizations enabled PLWHA to acquire knowledge, spiritual peace and the skills needed to minimize the negative consequences of non-disclosure.

5.14 The Validation of the Studies' Assumptions

Qualitative researchers use research assumptions, which are defined as plausible statements that help develop, implement and justify a given study (Leedy and Ormrod, 2010). In order to shape the course of this study the researcher formulated three

assumptions that contributed to the research process. The discussion below authenticates the extent to which the validity of these assumptions were achieved.

5.14.1 Stigma and discrimination are a deterrent to disclosure

This study revealed that PLWHA are discouraged from disclosing their status because they fear that they will lose their moral standing, face differential treatment and societal humiliation. The WHO (2012) revealed that some people fear HIV/AIDS testing or collecting their results because their seropositive status will rob them of their dignity and self-worth. Although this gives credence to the assumption that stigma and discrimination deter HIV/AIDS disclosure, it is interesting to note that some of the study's participants were motivated to disclose their status because they wanted to use education to expel social stigma and discrimination. This indicates the complexity of HIV/AIDS stigma and discrimination.

5.14.2 Socio-cultural factors are a latent driver to non-disclosure

In the current study, most participants feared that disclosing their status would unleash socio-cultural forces that would render them vulnerable to verbal and physical abuse. A number of studies have shown that many African and Caribbean women diagnosed with the disease feared disclosing their status to their partners because HIV/AIDS is linked to promiscuity. Thus, disclosure may 'lead to physical harm and rejection by partners, who may in turn prevent the seropositive individual from seeking health services for fear of reprisal from community members' (Beauregard and Solomon, 2005; Gahagan, 2013). Studies have also shown that diseases such as HIV/AIDS are feminised and the so-called "culture of silence" inhibits disclosure by those who do not represent the conventional identities surrounding sexuality (UNAIDS, 2016). This supports the assumption that culture is a latent driver of HIV/AIDS non-disclosure.

5.14.3 Financial support and opportunities can facilitate disclosure

This research revealed that most PLWHA were motivated to disclose their status because they accessed grants, food parcels and employment opportunities. To this end, WHO (2012) and UNAIDS (2014), document that increased access to HIV/AIDS social grants and employment opportunities improve the quality of life for PLWHA. The majority of the participants stated that access to social grants and employment opportunities cushioned them from poverty. This implies that without any financial incentives to cater for PLWHA's nutritional and family needs, they might not see the need to disclose their status. This lends credence to the researcher's assumption that financial support and opportunities can facilitate HIV/AIDS disclosure.

5.15 Recommendations

This section of the study contains the research recommendations drawn from the perceptions of the research categories, empirical studies and the literature review.

5.15.1 The need for anti-stigma and discrimination campaigns

It is of paramount importance that the South African National AIDS Council (SANAC) engages in culturally sensitive stigma and discrimination campaigns in Alice. These campaigns should create an open space where PLWHA of different ages and sexual orientation share their experiences of living with the diagnosis. This will optimistically empower and educate individuals about HIV/AIDS disclosure and tolerance. The testimonies of people who offer support can go a long way in showing that PLWHA can receive positive feedback when they share their status. Secondary schools and universities such as Fort Hare can form partnerships with other key stakeholders who conduct stigma and discrimination campaigns such as Drama in Aids.

5.15.2 Research on internal stigma

Various researchers agree that there is a need for research to be conducted on internal stigma. Perhaps a longitudinal study with a large sample of PLWHA could find sustainable ways of dealing with this phenomenon.

5.15.3 Make support structures youth friendly

There is a need to develop innovative, youth-friendly services that are sensitive enough to cater for issues concerning sex education, testing and disclosure. Health care workers should ensure that youth-friendly services are available. However, if there are barriers to accessing services, they should come up with strategies to overcome these barriers. For example, introducing the youth to online platforms and self-testing kits could be one way of overcoming the barriers they face in disclosing their status. Most importantly, for all this to come to fruition, it is pertinent that refresher courses sensitize health workers on the legal and ethical considerations of maintaining the confidentiality and privacy of their patients.

5.15.4 The use of volunteers in health care Institutions

The Department of Health should encourage unemployed nurses and social workers to volunteer their services in understaffed clinics and hospitals in Alice. This could be a short-term measure to alleviate the long queues and the fatalistic attitudes held by both the infected and affected. However, as a long-term measure, the government could increase the intake of student interns or look for donor funding that will allow them to increase their human and material resources in health care facilities.

5.15.5 An inclusive approach in health care sector

The Department of Health must make health care institutions inclusive. This means that the design of a clinic should not have visible boundaries that separate PLWHA

from other patients. The medico-social worker or public relations officer should have an open communication channel that allows them to hear PLWHA's concerns and address them as espoused by their 'vision and mission' statements.

5.15.6 Partnerships between the government and religious leaders

Optimistically, the government has to create grass roots workshops or "*indabas*" to encourage health workers, religious and traditional leaders to work hand in hand in fulfilling their calling of helping both the affected and infected. The "*indabas*" could create dialogue with regard to the legal statutes that ought to be followed by professionals dealing with HIV/AIDS and the penalties they attract for not working within their stipulated limitations. Dialogue between these different stakeholders should result in complementary services being offered to the infected and affected. A united front by these different stakeholders could make it easier to identify those faith and religious leaders that use unethical means to prevent HIV/AIDS prevention and disclosure.

5.15.7 Grants to encourage the establishment of NGOs in rural areas

It is of paramount importance that the government provides special grants to motivate more NGOs to settle in rural areas like Alice. In a village characterised by low literacy and high dependency on state grants, NGOs can provide PLWHA with vernacularized communication materials and information about their legal rights so that they have recourse in times of crisis. NGOs can help PLWHA and their families to establish income-generating projects such as market gardening so that they can contribute towards household security and lessen their dependency on the state.

Social workers attached to the NGOs could develop a rapport with cultural and religious leaders to educate them on how to align their values and norms with the

human rights framework. The NGOs could conduct research into possible interventions to rehabilitate individuals affected by the ramifications of HIV/AIDS and non-disclosure and reintegrate them into their community.

5.16 Conclusion

HIV/AIDS status disclosure is fundamental for seropositive people to benefit from free treatment in South Africa. However, the disease is enshrouded in shame, which prevents some individuals from taking advantage of this medical benefit. Equally important is the fact that those who are resilient enough to access treatment encounter negative forces such as stigma, discrimination and socio-cultural factors that make it uncomfortable for them to disclose their status and benefit from community structures that are meant to better their lives. Unfortunately, these forces are a catalyst for HIV/AIDS non-disclosure and they have the cruel effect of imprisoning some PLWHA in the walls of internal stigma. Consequently, this increases conflict in relationships and it shatters the lives of both the infected and affected.

Unequivocally, the state of non-disclosure is ramifying and it can contribute to low adherence levels and new infections. This means that South Africa's goal of ending the disease by 2030 and creating an HIV/AIDS free generation could be derailed if a paradigm shift is not adopted to strengthen the campaign for HIV/AIDS disclosure. This is why the government, the corporate world and faith-based organisations have to work together to create an environment in which HIV/AIDS is viewed as a normal chronic illness that warrants disclosure to intimate partners, family and community members.

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APPENDENCES

Appendix 1: Application letter to conduct research



Dear Sir or Madam

REF: APPLICATION LETTER TO CONDUCT RESEARCH

My name is Ayisha Dadiso Mavhunga and I am a second year student at the University of Fort Hare department of Social Work and Social Development. In partial fulfilment of the masters of Social Work degree, I am conducting a qualitative case study on the Ramifications of status non-disclosure by people living with HIV/AIDS (PLWHA) in Alice, Eastern Cape. This letter seeks to ask for permission to conduct the highlighted study in the community of Alice. Given the sensitive nature of the study, the researcher will uphold the ethical standards of empirical research. Lastly, if you have any questions about this research you may contact me at 200808124@ufh.ac.za.

Yours Sincerely

Ayisha Dadiso Mavhunga

Appendix 2: Participants informed consent



University of Fort Hare
Together in Excellence

CONSENT FORM

Project Title: Ramifications of status non-disclosure by people living with HIV/AIDS (PLWHA) in Alice, Eastern Cape

Dear Participant,

My name is Ayisha Dadiso Mavhunga. I am currently studying towards my master's degree in Social Work at the University of Fort Hare. In partial fulfilment of the degree, I am conducting a research study that mainly explores the ramifications of status non-disclosure by PLWHA in Alice, Eastern Cape. Therefore, you are being asked to participate in this study because of the knowledge you possess about this research topic.

The researcher would like to inform you of the following issues pertaining to your participation in the study. Firstly, participation is voluntary and membership can be terminated at any time without affecting your relationship with the researcher and the University of Fort Hare. Secondly, the procedure that will be used to collect data will be one-on-one in-depth interviews and a focus group discussion. Thirdly, the data collection instrument will be a semi-structured interview schedule and the responses from this instrument will either be audio recorded or hand written. The interviews will be conducted at one point in time and the individuals who will be involved in the interviews will be the researcher, PLWHA, their caregivers, their families and key informants.

In this study, the confidentiality of participants will be insured through the use of pseudo names. Additionally, in the data analysis process any identifying information will be removed from written reports. However, this study might bring emotional discomfort associated with recalling the negative ramifications of non-disclosure.

Therefore, participants who require counselling services will be referred to a social worker who will assist them in coping with their emotions.

The benefit associated with this study is that the recommendations and publication of this study can sanguinely lead to the development of campaigns and educational programs that will advocate for comprehensive legislative and institutional reforms that can mitigate the ramifications of HIV/AIDS non-disclosure. Furthermore, the personal benefit of this study is that PLWHA will be able to debrief and help community members understand the realities they face in disclosing their status. Lastly, please feel free to ask any questions regarding your participation in this study. I can be reached at 200808124@ufh.ac.za. If you have any questions about your rights as a participant in this study, please contact the University of Fort Hare Research Ethics Committees (UREC) at + 27 40602 2440 or access their website at <http://www.ufhgmrdc.ac.za>. In summation, please sign your consent form with the understanding that your signature means that you understand what is involved in this research.

Statement of Consent: I have read the above information, and received answers to any questions I asked. I consent to take part in the study.

Name of Participant:

Date:

Signature of Participant:

Signature of the Researcher:

Appendix 3: Semi-structured interview schedule

UNIVERSITY OF FORT HARE
FACULTY OF HUMANITIES AND SOCIAL SCIENCES
DEPARTMENT OF SOCIAL WORK

SEMI-STRUCTURED INTERVIEW SCHEDULE

SECTION A: GENERAL INFORMATION

Date.....

Location of Interview.....

Interviewer.....

Interviewee.....

Time taken for the interview.....

SECTION B: BIOGRAPHICAL INFORMATION

1.What is your gender	Male	Female
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2.What is your age	
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3.What is your race	Black	White	Indian	Other
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4.What is your ethnic tribe	Xhosa	Zulu	Venda	Other
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5.What is your home language	Isixhosa	Islu	Venda	Other
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6. What is your marital status	Married	Divorced	Cohabiting	Single
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7.What is your Level of education	Non Formal education	Primary school	Secondary school	Tertiary education
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8. What is your employment status	Formally employed	Informally employed	Unemployed	Other
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Section C

Open ended questions for one- on- one interviews

1. Please may you share with me your thoughts on HIV/AIDS disclosure?
2. Could you also share with me your thoughts on the opportunities or benefits one can derive from HIV/AIDS disclosure?
3. In your own experience of HIV/AIDS disclosure have you reaped any benefits or opportunities?
4. If you have not reaped anything from HIV/AIDS disclosure, may you please share with me what you think might have stopped you from reaping the benefits or opportunities of disclosing your status?
5. Could you share with me your thoughts on the ramifications of HIV/AIDS non-disclosure?
6. In your own opinion, how do you think PLWHA and their families cope with the ramifications of HIV/AIDS non-disclosure?
7. Could you share with me what you think can be done to mitigate the ramifications of HIV/AIDS non-disclosure?
8. Lastly, do have any information that you feel is relevant towards the topic we have discussed?

Thank you for participating in the study, the researcher wishes to assure you that all the information that was discussed in this study will be kept with outmost confidentiality.

Section D

Open ended questions for the focus group discussions

1. May you share with me your comments on HIV/AIDS disclosure?
2. Do you think HIV/AIDS disclosure has any benefits or opportunities for Alice PLWHA?
3. In the event that there are no benefits and opportunities associated with HIV/AIDS disclosure, what do you think causes this to happen?
4. Do you think that there are any ramifications to HIV/AIDS non-disclosure by Alice PLWHA?
5. In the event that there are any ramifications, how do you think PLWHA and their families cope the ramifying effects of HIV/AIDS non-disclosure?
6. In your own opinions, what do think that could be done to mitigate the ramifications of HIV/AIDS non-disclosure?
7. Lastly do you have any information that you feel is relevant towards the topic we have discussed?

Thank you for participating in this study, the researcher wishes to assure you that all the information that was discussed in this study will be kept with outmost confidentiality.

Appendix 4: Ethical clearance



University of Fort Hare
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ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: KAN061SMAV01

Project title: **Spin offs associated with disclosure amongst people living with HIV/AIDS in Alice, Eastern Cape, South Africa.**

Nature of Project: Masters

Principal Researcher: Ayisha Mavhunga

Supervisor: Prof S Kang'ethe

Co-supervisor: N/A

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Druethical conduct of the research

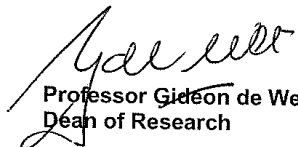
The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
 - Any unethical principal or practices are revealed or suspected
 - Relevant information has been withheld or misrepresented
 - Regulatory changes of whatsoever nature so require
 - The conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.
- In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office

The Ethics Committee wished you well in your research.

Yours sincerely



Professor Gideon de Wet
Dean of Research

21 April 2016