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Self-Disclosure of Human Immunodeficiency Virus Status in Personal Relationships: Perceptions of South Africans Living with Human Immunodeficiency Virus

Delile Gertrude Langeni
Walden University

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Walden University

College of Health Sciences

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Delile Gertrude Langeni

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Dr. Michael Schwab, Committee Chairperson, Public Health Faculty
Dr. Richard Jimenez, Committee Member, Public Health Faculty
Dr. Sriya Krishnamoorthy, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2018

Abstract

Self-Disclosure of Human Immunodeficiency Virus Status in Personal Relationships:

Perceptions of South Africans Living with Human Immunodeficiency Virus

by

Delile Gertrude Langeni

MA, Michigan State University, 2002

BSN, Nazareth College, 1990

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health: Community Health Education and Promotion

Walden University

February 2018

Abstract

Despite enormous research on the experience of living with HIV, many questions remain regarding self-disclosure of HIV status to sexual partners by people living with HIV (PLWHIV), which is essential to reducing further infection. In this study, a phenomenological approach captured the experience of self-disclosure among South Africans living with HIV in Louwsburg, South Africa. The health belief model served as a theoretical framework and in-depth interviews were conducted with 12 PLWHIV (8 women, 4 men) who self-disclosed their HIV status to their sexual partners. Their experiences were explored, discovering their illness, motives for self-disclosure, feelings regarding disclosing, responses of their sexual partners, their emotional reaction, and about their medical care. The themes rose from interviews showed that (a) many PLWHIV are reluctant to self-disclose until they actively experienced health issues; (b) motives for disclosure include the wish to ensure fairness; support and to empower other PLWHIV to prevent further infection; (c) feelings of disclosure are primarily relief and liberation, even though risks remain, especially for families separated by labor migration laws; (d) the response of sexual partners to disclosure varies widely; some are motivated to get tested and use condoms, decline and respond only with anger, blame, even abandonment; and (e) after accessing medical care, most PLWHIV reported support and appearing less sick, which reduces social stigma. The women were more open, forthcoming, and transparent about disclosing than men participants. Findings will assist with the creation of future health education programs aimed at creating safe environments to disclose HIV status, which may reduce community risk of contracting the virus.

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Dedication

I dedicate my work and give a unique gratitude to my late parents; they risked cultural beliefs that frowned on educating a female child. Secondly, they risked eviction from the farmer. A special appreciation to late Mr. Masuku and Mrs. Masuku who came to my rescue whose trust and love of nurturing raised and provided me the holistic education--mind, body, and spiritual--and I became what I am today. Their children who embraced me with love as their adopted eldest sister. I also dedicate this dissertation to my siblings who always showed their love and support for their many years of hard labor for the farmer. I will still appreciate all that they have done to bail me out of that hard work. To my children and grandchildren, you are the pillars of my strength. I also thank my husband who occasionally assisted proofreading my IsiZulu documents translation. I faithfully dedicate this to my community who suffered the scars of Apartheid.

Above all, I dedicate this work to Almighty God who sustained, motivated, and helped me to hold on; and He is the author and the finisher of all. "... Hold fast what you have, that no one may take your crown." Revelation 3:11.

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Above all, I thank with honor the participants for allowing me to interview them. I admire their humble spirit, determination, and empowerment amongst themselves. May God bless you all.

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Chapter 1: Introduction to the Study

Introduction

People living with human immunodeficiency are now confident that they can live longer since the therapy introduced. People can live longer as the disease became more of chronic. Some people are now determined to disclose their HIV status to their sexual partner to reduce transmission of the virus (Deribe et al., 2008). Self-disclosure of one's HIV status to the intimate partner can leave negative health implications such as the adverse outcome of disclosure. An individual who is positive for the HIV will have significant challenges to communicate their HIV status to sexual partners. A process that can lead to extreme rejection, a risk for violence, fear for blame, stigma, and discrimination (Dunkle 2004; Klopper, Stellenberg, & van der Merwe, 2014; Saki, Khemashahi, Mohammadi, & Mohrez, 2015; Surugue, 2017). Despite the importance of disclosure as the basis for HIV transmission prevention for both partners (Ssali et al., 2010), there are still challenges that will impede disclosure. It is crucial to alleviate the challenges by empowering, educating, and advocating for people living with HIV infection to disclose. The positive social change is for the community to understand various issues related to people living with HIV. The purpose is to explore experiences of self-disclosure for people living with HIV to the sexual partners in Louwsburg, KwaZulu-Natal, South Africa.

Background

AIDS is a deadly disease that has decimated numerous populations and caused huge distress among those affected. For an individual who is diagnosed as positive for the HIV, which causes AIDS, one of the greatest challenges is to communicate their HIV status to an intimate partner, a process that can lead to extreme rejection (Surugue, 2017). In this study, I examined men and women's experience facing this challenge in the Republic of South Africa. Over time, HIV destroys the body's immune system, leaving it vulnerable to many infections (Mulaudzi, 2009). Few people living with HIV are symptom-free, and most have significant health problems that are visible to the entire community (Surugue, 2017).

In many communities, especially where AIDS education is sparse, a diagnosis of HIV infection results in social rejection, and this has been the case in South Africa, where people living with HIV/AIDS (PLWHIV) are regarded as promiscuous (Cloete et al., 2010; Kalichman et al., 2008), which often causes infected individuals to try and hide their diagnosis. The disclosure of an individual's infection is an important step in the prevention of further infection, but disclosure, or *self-disclosure* as it is known, can distance or separate the infected person from society, causing stigmatization and discrimination (Nachege et al., 2012; Norman et al., 2005). This stigmatization may be induced by the HIV-infected person or by family or the community (Yebel, 2008). A study conducted by Sowell et al. (2003), on how women make decisions to disclose their infection, found that most women see the importance of disclosure and risk possible

negative consequences associated with self-disclosure; however, they require support for the potential stress related to stigma and discrimination, in which they find themselves abandoned and isolated. Similar findings have been reported by Norman, Chopra, and Kadiyala (2005), who pointed out that PLWHIV need self-efficacy and confidence as they weigh the threat of HIV against the benefits of disclosure, and they need social support that empowers them about how, when, and with whom to disclose without being stigmatized.

HIV-related stigma refers to the prejudice, discounting, discrediting, and discrimination against PLWHIV and the individuals, groups, and community associated with PLWHIV (Simbayi et al., 2007). Also, stigma is often accompanied by the internalization of negative attitudes a person experiences or anticipates in the community (Herek, Gillis, & Cogan, 2009), and this self-stigmatization debilitates individuals to a point where they tend to develop low self-esteem and extreme self-pity (see Lee et al., 2002). A study conducted in Tanzania found that participants perceived PLWHIV to be weak and a burden on the community (Wolfe, 2008). HIV-related stigma can lead to discrimination, with those infected subject to adverse treatment and denied opportunities based on their HIV status (Makoae et al., 2009); fear of being rejected and ostracized (Cloete et al., 2010); and isolation (Greeff et al., 2008). Discrimination is a stereotyping response to negatively perceived characteristics of a person (Simbayi et al., 2007), and discriminatory practices can alienate and exclude people living with HIV, reinforcing the stigma surrounding HIV and AIDS (Nachega et al., 2012).

Disease-related stigmatization and discrimination are often acts of ignorance about the disease and hyperbolic fears of physical contagion (Kalicman & Simbayi, 2009). Lack of knowledge and misconceptions about HIV increase the risk of infection (see Campbell et al., 2007; Simbayi et al., 2007; Ulasi et al., 2009). People in Southern Africa have heard about the disease; nevertheless, the participants in this study were from a rural area and many of them had low levels of education and lacked relevant information on HIV and an awareness of the risks. However, there were very few data on community knowledge regarding accurate information on HIV in KwaZulu-Natal, South Africa. This community had minimal support to alleviate the stigma and discrimination suffered by PLWHIV due to lack of knowledge about the disease.

Problem Statement

Educating the community about the dangers of HIV and AIDS is known to reduce transmission and reinfection, and self-disclosure of HIV status between sexual partners is an important element of this education Joint United Nations Program on HIV and AIDS (UNAIDS, 2007). Some studies have emphasized the importance of women's role in promoting self-disclosure in heterosexual relationships (Kerchen, Armistead, & Cook, 2009; Mill & Anarfi, 2002; Pettifor et al., 2004; Wodi, 2005). However, in many cultures, women's ability to negotiate condom use is hampered by long-established patterns of gender power (Long, 2009) and by the stigma and discrimination associated with HIV/AIDS (Nachega et al., 2012). In this study conducted in the rural area of KwaZulu-Natal, I explored PLWHIV's experiences of self-disclosure to their sexual partner. The research was needed to explore the role of stigmatization and discrimination

in self-disclosure experienced by PLWHIV and how to overcome it to strengthen education for PLWHIV and the general public.

Purpose of the Study

In this study, I focused on the self-disclosure of HIV status between sexual partners, with particular reference to the role of stigma and discrimination, and the strategies that empower PLWHIV to set their sexual health agenda. The purpose was to explore the lived experiences, the process, and the impact of self-disclosure to find ways to facilitate disclosure safely. This study was unique because it was conducted at the community level using a phenomenological approach to describe people's lived experiences of the problems associated with disclosure of HIV status (see Balls, 2009). At the community level, this approach gives high priority to local knowledge and empowers community members as agents of social change (Engler & Winskell, 2009). The primary purpose of this study was to explore the lived experiences of PLWHIV disclosing their HIV status to their sexual partners. Through dissemination of the findings, I hope to see an increase and allow more educational programs. The results can assist building the morale of people living with HIV the purpose to provide a sense of purpose. It can also open doors to include community's involvement in support infected individuals and their families without preconception.

Research Questions

The primary research question I developed to guide this study was:

What are the experiences of South African people living with HIV (PLWHIV) with respect to self-disclosure of their infection to their intimate partner?

Research sub questions were:

1. What are the experiences of PLWHIV with respect to discovering their HIV status?
2. What are the motives of PLWHIV with respect to self-disclosure?
3. What are the feelings of PLWHIV with respect to self-disclosure?
4. What are the methods used by PLWHIV to self-disclose?
5. What are the responses of intimate partners to self-disclosure by PLWHIV?
6. What is the emotional effect of self-disclosure on PLWHIV?
7. What is the experience of PLWHIV with respect to accessing medical care?

Conceptual Framework

I used the health belief model (HBM) in this study. The HBM affirms that behavior depends upon knowledge and attitudes (Rosenstock, Stretcher, & Becker, 1994). The HBM is one of the most frequently used theories in health behavior research (McKenzie et al., 2009). It was developed in the 1950s by psychologists to help explain why people would or would not use health services (Rosenstock, 1950) and has been used to help solve a variety of health behaviors (Becker, 1974; Janz & Becker, 1984). In the 1980s, the element of self-efficacy, the perceived ability of an individual to effect change, was added to the model (Strecher & Rosenstck, 1997). There are six elements of the HBM applied to behavior change about a disease: (a) perceived susceptibility to the disease, (b) perceived severity of the illness, (c) perceived threat of developing the disease, (d) perceived benefits of behavior change, (e) perceived barriers to behavior change, and (f) perceived self-efficacy in being able to change. In this study, I explored

the perceptions of PLWHIV about their susceptibility to HIV infection, the severity of the disease, the benefits and barriers of adopting safer behaviors, and their self-efficacy in disclosing their HIV status.

Nature of the Study

In this study, I used a qualitative approach to develop an in-depth understanding of the experiences of PLWHIV in disclosing their HIV status to an intimate partner with a view to developing guidance on safe methods for self-disclosure without being discriminated against or stigmatized. I used a phenomenological design to accurately describe participant's lived experience (see Balls, 2009). The data were collected through in-depth interviews. The results of this study will help to pinpoint the challenges that impede self-disclosure and could form the basis of a new model for eradicating the fear of disclosure.

I recruited a purposive sample of 12 participants (six women and six men) at a local clinic in Louwsburg, KwaZulu-Natal, a rural area in South Africa. Inclusion criteria for participants were: (a) they resided locally; (b) aged 20-49 years; (c) had a steady sexual partner (spouse, live-in sexual partner); and (d) had been diagnosed with an HIV infection. I recruited participants from a local clinic after both the Walden University and the South African Institutional Review Boards (IRB) granted permission.

Definition of Terms

AIDS: The diagnosis for a group of related symptoms and conditions, caused by HIV infection that destroys the immune system (Mulaudzi, 2009).

Concordant: Concordant sexual partners are where both couples are infected with

HIV and one is HIV negative (Malamba et al., 2005).

Cluster differentiation 4 (CD4): CD4 cells are white blood cells that are most important in the immune system that protect from viral infections. They coordinate with other cells to fight bacterial and fungal infections Center for Center for Disease Control and Prevention (CDC, 2013).

Discordant: Where one is HIV positive and the other is negative (Ravikumar & Balkrishna (2013).

Enzyme-linked immunosorbent assay (ELISA): A set of blood tests used to diagnose chronic infection with HIV. ELISA alone cannot be used to diagnose HIV even if the test suggests that there is high probability that antibody to HIV is present (Kinman, 2012).

HIV: A virus that attacks the immune system and can therefore destroy the body's ability to fight off infection. It can lead to life-threatening illnesses called opportunistic infections, and ultimately to death (UNAIDS, 2010). The virus can be transmitted via blood transfusion, drug injection, or sexual intercourse (UNAIDS, 2011).

People living with HIV (PLWHIV): Persons who have tested positive for HIV, are diagnosed with AIDS, and are still alive. They include every living person who has ever received an AIDS diagnosis regardless of their current state of health (National HIV Surveillance Report, 2010).

Sexual partner: Consensual sexual relations, is generally a person with whom an individual is engaging in a sexual activity (Greenberg, Bruess, & Oswaldt, 2016).

The Group Areas Act (1954): Three acts of the South African Parliament, enacted under Apartheid that assigned racial groups to different residential and business sections in urban areas (Christopher, 1994).

Western Blot: A test always used following a positive ELISA test to confirm HIV infection (Kinman, 2012).

Assumptions

There were two assumptions related to the nature of this study. I assumed that the participants were honest in providing and answering all the questions they were presented with. I also assumed that participants understood the questions as they were asked.

Limitations

There were a couple of limitations in this study. The results will only describe the lived experiences of the participants in this particular rural area. Given this limitation, the results of this study will still provide valuable insights on the lived experiences of PLWHIV and added to the understanding of the self-disclosure process and its impacts.

Delimitations

To avoid ethical concerns regarding interviewing minors, the participants in this study were over the age of 20. I excluded people aged 15-19, even if they were living with HIV, so the results do not represent the whole population living with HIV in this area of South Africa. The group was not represented for ethical reasons.

Significance of the Study

In this study, I identified safe and efficient ways to facilitate self-disclosure of HIV status between sexual partners, which could significantly enhance HIV prevention. HIV is a life-long process that needs primary and secondary prevention efforts (UNAIDS, 2010). The study was unique as I focused on the experiences and perceptions of PLWHIV with the phenomenon of self-disclosure of HIV status among intimate sexual partners through in-depth interviews with the participants (see Lester, 2007). My long-term goal was to reduce further HIV infection among PLWHIV, increase secondary prevention, and assist in the reduction of new infections in the community (primary prevention). The findings of this phenomenological study will help to understand ways in which the community may facilitate safe self-disclosure of HIV infection to sexual partners and how to act as critical enablers to bring about positive social change. This study was intended to bring positive social change by educating the community as a whole about the disease and assist PLWHIV to have confidence in disclosing HIV infection to their sexual partners without fear.

Summary and Transition

In this chapter, I introduced the proposition that HIV-infected persons need to avoid transmitting their disease to others and that disclosing their status to sexual partners is key to preventing coinfection. I described how prevention interventions have focused on personal HIV infection reduction and support to reduce risky behaviors but that few researchers have explored the experience of self-disclosure of HIV to sexual partners and few have examined the experience of both women and men. The background, purpose,

and methods of the study were summarized, and I provided definitions of key terms used in the study. In Chapter 2, I will present an extensive literature review on the prevention of HIV, the impact of self-disclosure of HIV by PLWHIV, the HBM as a theoretical framework, and phenomenology as the chosen qualitative methodology.

Chapter 2: Literature Review

Introduction

HIV is a major public health crisis. The number of PLWHA at the end of 2016 was approximately 36.7 million (UNAIDS, 2016), and an estimated 2 million become infected every year (World Health Organization) (WHO), 2016). Sub-Saharan Africa is the most severely affected region with an estimated of 25.6 million PLWHIV in 2015 (UNAIDS, 2016), and South Africa has the largest population of people living with AIDS of any country in the world at 7.0 million people (UNAIDS, 2016). The HIV prevalence (rate of new infections) in 2010 was 29.4% in KwaZulu-Natal, 20% in Gauteng, and 13.8% in Eastern Cape, which are the country's most severely affected provinces (UNAIDS, 2016). This rate of could be reduced if PLWHIV both men and women, were to disclose their infection status to their intimate sexual partners (Paiva, Segurado, & Filipe, 2011). Disclosure may reflect PLWHIV's concerns to limit the risk of transmitting HIV infection to sexual partners or encourage for HIV testing and perhaps influence the use of a condom. According to Zola et al. (2014), the disclosure is necessary for preventing transmission of HIV and improving quality of life for PLWHIV. However, studies from Tanzania, South Africa, and Kenya showed that 3% -15% of women who disclose their HIV status reported negative reactions including blame, abandonment, anger, and violence (see Dahlul et al., 2015). Among those who do not disclose their status, fear of violence is the major barrier (Medley et al., 2004), while nondisclosure appears to have the devastating effect of non-adherence to medical treatment, specifically to antiretroviral (ARV) therapy (see Zola et al., 2014); those who do self-disclose have

higher rates of adherence than PLWHIV who do not reveal (Cornet, 2008).

The goal of this study was to provide a deeper understanding of the nature of self-disclosure for PLWHIV, including the nature of stigmatization and discrimination as a result of the disclosure, and to advance safe and purposeful disclosure through education in the community, especially to families and friends of PLWHIV. In this chapter, I will review the literature on HIV/AIDS in South Africa; the reasons for disclosure and nondisclosure of HIV status; the socio-cultural factors related to HIV/AIDS such as gender inequality, sexual violence, knowledge of HIV/AIDS, poverty and the political legacy of Apartheid; and the conceptual framework of this study.

Literature Search Strategy

For this literature review, I searched peer-reviewed journals and scholarly articles through the Walden University EBSCO database, Google Scholar, ProQuest, Academic Search Premier, local public libraries, SAGE, PubMed, Psych INFO Database, CNAHL, and Medline. I made various searches of health literature between the years 2006 to 2016, using various combinations of the following key words and phrases: *disclosure of HIV/AIDS status, reasons for disclosure, gender inequality, violence, and sexual HIV in South Africa including cultural beliefs*. I reviewed the sources digitally as well as through print versions of peer-reviewed journals. I also reviewed a few books to provide historical aspects of the research on HIV/AIDS self-disclosure. A list of terms I searched in preparation for this study included: *health belief model, disclosure of HIV status (spouse and steady) sexual partners, gender inequality, prevention of disease, HIV related stigma and discrimination, knowledge of disease, male circumcision, poverty and HIV infection,*

HIV tests, political transition/the legacy of Apartheid, and reason for disclosure/nondisclosure.

HIV/AIDS in South Africa

According to UNAIDS (2012), an estimated 5.6 million people were living with HIV/AIDS in South Africa in 2011. The age group with the highest prevalence--almost 40%--was among 15-49-year-olds. Globally, there were dramatic declines in new HIV infections and HIV/AIDS-related deaths between 2001 and 2011 as some countries had a 50% decline, with over half of this decline occurring within the last 2 years (UNAIDS, 2012). In South Africa, Burundi, Kenya, Namibia, Togo, and Zambia – there was a 40%-60% decline in some children with HIV (UNAIDS, 2012). However, the situation remains dire for those in Sub-Saharan Africa over the age of 15, who make up most of the 5.3 million HIV-infected people in South Africa (UNAIDS, 2012). HIV/AIDS is a public health issue that affects the whole of South Africa. It is a significant health problem in KwaZulu-Natal province where the incidence and prevalence of HIV/AIDS among pregnant women is highest at 37%, among female adults under the age of 40 (UNAIDS, 2011). National Commitments and Policies Instrument (NCPI) (2012) reported the number of PLWHIV was 6.1 million in South Africa.

According to the Desmond Tutu HIV Foundation (2011), the reasons for the disproportionately high HIV prevalence in South Africa are a lack of adequate services and several social and structural barriers including stigma and discrimination. The Actuary Society of South Africa (ASSA; 2011) has estimated that 16.9% of South Africans aged 15 and older are infected. The prevalence rate (number of new infections

every year) continues to exceed the number of AIDS-related deaths; currently, more than 1,000 people in South Africa are infected with HIV daily (UNAIDS, 2011).

South Africa has increased the number of people treated for HIV by 75% in the last 2 years (UNAIDS, 2012). The South African government also increased its domestic expenditure on AIDS to \$1.6 billion, but the problem remains severe and mortality figures remain high (UNAIDS). The overall annual number of deaths increased sharply between 1999 and 2006 and were mostly young adults (Thanapairin, 2013; UNAIDS, 2011). The disease also had a devastating effect on children because it heavily affected young reproductive adults (UNAIDS (2011). Also noted that premature deaths in 2010 related to HIV/AIDS had significantly risen from 39% to 75% over the last decade. One impact of this has been that grandmothers have increasingly become primary caregivers for children who lost both parents to AIDS (UNAIDS, 2011). The National Strategic Plan 2012–2016 aimed to lessen the impact of HIV on orphans, vulnerable children, and youth by increasing their access to the social services they need (UNAIDS, 2011).

The infection spread in different patterns across and within South African provinces. In South Africa as a whole, the proportion of people who had HIV reported being increased from 13.9% in 2005 to 41.6% in 2009 (UNAIDS, 2011). The primary goal for the country was to reduce HIV incidence rate by 50% by 2011 (UNAIDS, 2011).

HIV Prevention in South Africa

The South African National Strategy Plan includes HIV/AIDS awareness campaigns (UNAIDS, 2011). The strategy was to publicize the availability of free counseling, the use and distribution of condoms, and education about sex and HIV

(UNAIDS). A Life Orientation curriculum was implemented in the secondary school level curriculum in 2002 across South Africa, focusing on life skills and HIV/AIDS programs and the ability of the teachers to conveying accurate information (Mantel et al., 2011). Also, the implementation was to provide information to reduce transmission of HIV infections (Mantell et al., 2011). Govender & Edwards (2009) affirmed the overemphasis on HIV/AIDS information in the plan. Through their study they determined that the curricular implemented focused too much on HIV/AIDS prevention awareness. Other researchers pointed out the dire need to emphasize physical and mental health awareness (see Yi, Chhoub, Suong, Thin, Brody, & Tuot. (2015).

A government-led circumcision campaign was established by King Goodwill Zwelithini and MEC for Health and Premier of KwaZulu-Natal launched MC campaign to medically circumcise for all males in across the province (WHO, 2013). One goal of the campaign was to ensure that South African boys and young men (ages 10 and older) were circumcised by December 2013 (WHO, 2013). The circumcision was expected to prevent 1 million or 17% of all new adult infections (WHO, 2013). In South Africa, circumcision is traditionally performed on young men as part of initiation rites of passage among individual tribes, including the Venda, Pedi, Xhosa, and South Sotho (Connolly et al., 2008; Simbayi et al., 2007). Traditionally, tribes perform the procedure to young men post puberty, but this presented health hazards such as infections, hemorrhage, and dehydration, so South Africa is now working on medical guidelines for neonatal and young adult circumcision in line with WHO and UNAIDS recommendations (WHO, 2012). The National Strategic Plan for HIV/AIDS and sexually transmitted infections

(STIs) for 2007-2011 called for the prevention of mother-to-child transmission, identified as a critical area for improvement (Business Monitor International, 2012). In 2009-2011, over 900,000 pregnant women living with HIV/AIDS received ART prophylaxis for prevention of mother-to-child transmission, resulting in a drop in infection from 56,500 in 2009 to 29,100 in 2011 (WHO, 2012).

About 3.5 million South Africans are still not getting therapy or do not comply with the medications (Petesch, 2012). Granich et al. (2008) showed that testing adolescents and adults at least 15 years old once a year and starting individuals on ART as soon as they test positive will reduce HIV incidence, prevalence, and mortality to 1 case per 5,000 adolescents and adults per year. Starting therapy early when CD4+ is under 350 cells per cubic millimeter is recommended (Cohen et al., 2011).

The ART program may be the most promising prevention of further HIV infection in South Africa for people living with the virus. Colvin (2011) stated that South Africa has a broad range of access to treatment as the largest. The government has reduced the amount spent on research due to rising costs of its epidemiological response to HIV/AIDS to concentrate to treatment (Development Institute, 2010). The primary goal for the country was to reduce the national HIV incidence rate by 50% by 2011 (UNAIDS, 2012). It is evident that infected South African adults who received ART drugs early with their CD4 counts above 200cells/mm³ were expected to live a near normal life expectancy (WHO, 2012). Yaya et al. (2015) conducted a cross-sectional study at the regional hospital of Sokode, in Togo among PLWHIV on ART where 60% of the men and women had disclosed to their sexual partners. The authors reported relatively small

results and that documenting associated factors, such as adherence to ART, sexual partner awareness of HIV serostatus, and marital status, can, in turn, reduce the risk of further infection. However, nondisclosure remains a significant problem (Yebel, 2008). Maman et al. (2014) findings confirmed that disclosure to sexual partners was motivated by their willingness to reassure partners to test for HIV and learn their diagnosis.

Socio-Cultural Factors Related to HIV-Infection and Disclosure

Several socio-cultural factors have been identified as contributing to the spread of HIV infection. These factors are gender inequality, violence, political transition, poverty, lack of knowledge, and cultural beliefs (Dunkle et al., 2004). They will be discussed in the following sections.

Gender Inequality

The Director of UNAIDS in 2010 pointed out that gender equality is a primary issue in the spread of HIV/AIDS because it reduces women's ability to discuss or negotiate safer sex with their intimate sexual partners (Dunkle et al., 2004; Langeni, 2005; Moore et al., 2007). South African culture remains male-dominated in general, with women relegated to a lower status than men (Ankrah & Henry, 1994). Men remain controlling, while women are submissive and taught to over respect men and act submissively towards them (Ehrhardt et al., 2009; Moore et al., 2007). Inequality increases women's vulnerability to HIV infection; women's inferiority leaves them with no power to protect them by insisting on condom use (Dunkle et al., 2004). In KwaZulu-Natal, South Africa, women are generally still treated differently from men culturally and socially (Mantell et al., 2011). Men are more likely to be excused for any sexual behavior

than women (Ankrah & Henry, 1994). There is a need to address gender inequality to bring positive social change to the community's response to HIV infection.

Violence and Sexual Violence

In South Africa, men tend to have control over women, and when it comes to safer sex, some men become violent and refuse to use of a condom (Beagle, 2013). In many instances, women are raped and suffer sexual violence, which results in a very high risk of contracting HIV/AIDS (Colombini, James, Ndwiga, & Mayhew, 2016; Jewkes, Dunkle, Nduna, & Shai, 2010). A study in South Africa reported in 8 new infections in young women are due to intimate partner violence (Beagle, 2013). Women face significant risks of rejection, abandonment, verbal abuse, and assault as they continue living with controlling male partners who put them at risk for HIV infection (Colombini et al., 2016). Addressing sexual violence is needed to bring positive social change in KwaZulu-Natal to stop the trend. Certain cultures still have cultural belief and behavioral practice such as rites of marriage where a woman is expected to have sex with her deceased husband's brother (Mwenda, 2008). Although this is an acceptable cultural practice, this may be a risk factor of spreading HIV/AIDS because of multiple sexual partners. Sexual behavior is becoming less and less safe in Sub-Saharan African countries with an increase in the number of risky sexual partners and an increase in sexual violence, which includes refusal to use a condom (Dunkle et al., 2004). All of these factors put young women and girls at greater risk of HIV infection.

Political Transition and the Legacy of Apartheid

During the Apartheid era, labor migration was the main cause of sexual problems. The Group Areas Act prevented the workers from settling with families in areas where they were working in cities, which caused Blacks to commute long distances from their homes to secure employment (Laurie et al. 2003). There was separation in men and women in families for extended periods of time. The separation caused partners to seek sex outside their stable relationships and put them at greater risk of infection. Also, single-sex hostels encouraged migrant laborers to practice male-to-male sex.

Poverty

The characteristics of rural South Africa under the Apartheid regime was the low levels of education and literacy, and high levels of unemployment and poverty. In a culture that prohibits young women from negotiating for safer sex, there is money or gifts involved in exchange for sex (Langeni, 2007), and where most girls face financial problems, then these young women and girls were vulnerable. It is the situation in the community where I conducted my research. Although the government provides free medication, the population for my study has lived in poverty since the apartheid era under the farmers' oppression. The community still needs money for transportation to medical clinics and nutritious food. Good nutrition is cited by Weiser et al. (2007) as essential for healthy immune system and food insecurity's likelihood to increase people to become HIV infected.

Lack of Knowledge and Misconceptions

Stigma related to HIV/AIDS carries fears due to communities' shared perceptions on PLWHIV such as infectious, contagion, incurability, immorality and punishment for sinful acts (Campbell et al., 2007; Simbayi et al., 2007; Ulasi et al., 2009). One of the myths that people still have is the belief that having sex with a virgin helps to cure the disease. Also, in an average homestead lack of open communication, discussion and guidance on the subject cause young people to pick up misinformation from their peers. Moral judgment, therefore, has an active role in stigmatization and discrimination towards PLWHIV and this brings barriers to disclose their HIV infections.

Cultural Beliefs

The stigma associated with HIV/AIDS in Southern Africa prevents many South Africans from disclosing their HIV status if they are positive Deacon (2006); Kalichman et al. (2008). The community where the study will occur mainly perceives people who have HIV/AIDS as promiscuous. South African traditional opinion links AIDS with sexual promiscuity and often causes HIV positive individuals to be rejected by their communities and households (Cloete et al., 2010).

It is the belief that many people do not want to disclose their HIV status, and those who know will often keep it secret, some even from their sexual partners (Mbomvu et al., 2009). Fears of stigma and discrimination have deterred individuals from being tested for HIV and from disclosing their seropositivity status to sexual partners, family, and friends (Becker, 2004). The communities tend to perceive and assume that individuals have HIV when they are sicker and thinner than normal. A telephonic survey

conducted by the Center for Epidemiology and Biostatistics School of Public Health in a Chinese university find that at least 42% of respondents exhibited a discriminatory attitude. They would avoid physical contact with PLWHIV; 35% believed in dismissing all infected medical staff, and about 47% would agree with the law prohibiting PLWHIV from visiting Hong Kong (Lau et al., 2004). Also, a sizable number proportion of the respondents held negative attitude perceptions about PLWHIV being promiscuous and believe they were receiving the punishment they deserve for their behavior. Moral judgments play an influential role in stigmatization and discrimination against PLWHIV and create substantial barriers to disclose their HIV status.

Self-Disclosure of HIV Infection

The stigma associated with HIV/AIDS in Southern Africa prevents many South Africans from disclosing their HIV status if they are positive Deacon (2006); Kalichman et al. (2008). It is also the only country with a high HIV prevalence rate country in the world that has significantly contributed to AIDS research (De Lange, 2012). South Africa plays a significant role in research on HIV testing, counseling, and providing antiretroviral drugs. The community where the study will occur mainly perceives people who have HIV/AIDS as promiscuous. South African traditional opinion links AIDS with sexual promiscuity and often causes infected individuals to be rejected by their communities and households (Cloete et al., 2010).

Understanding self-disclosure in sexual relationships is important for intimate sexual partners to reduce HIV-infection. Altman and Taylor (1987) define self-disclosure as sharing information with others that they would not know or discover. Disclosure can

be a stressful process. Self-disclosure of HIV status and safer sex negotiations between intimate sexual partners will be an important strategy to curtail further spread of the disease. Some researchers have reported that disclosure of HIV status often leads to stigmatization and discrimination (Nachegea et al., 2012; Norman et al., 2005; Stutterheim et al., 2011; Visser, Neufeld, de Villiers, Makin, & Forsyth. (2008). Disclosure may lead to disruptions of intimate relationship and rejection. Sowell, Seals, Phillips, and Julious (2003) conducted a study on how women make decisions to disclose their infections. They found that most women in their sample saw the importance of disclosure, but were afraid to risk the possible negative consequences and required support in coping with stress related to potential stigma (Sowell et al., 2003). Norman, Chopra, & Kadiyala (2005) found the same need concerning the fear of rejection or abandonment. Regardless of the benefits of HIV self-disclosure, deciding to disclose may leave PLWHIV open to stigma and discrimination and put them at risk of abandonment and rejection (Deribe et al., 2008; Greeff et al., 2008).

Disclosure may be accompanied by regrets and isolation (Ssali et al., 2010). Ssali et al. (2010) conducted an exploratory study in Uganda to explore why PLWHA disclose their HIV status. They wanted to receive support, improve relationship ties, explain the change in behavior or appearance, promote HIV prevention or protect others from HIV infection (Yaya et al., 2015). It was also noted that self-disclosing had to do with the desire to encourage the sexual partner to test for HIV infection (Yaya et al., 2015). Disclosing opens individuals to stigma and discrimination in which they found

themselves abandoned and isolated which, is a 'perceived barrier.' (Kalichman et al., 2009).

PLWHIV confidence in disclosing their HIV status is therefore crucial. PLWHIV must weigh the threat of HIV/AIDS against the difference between benefits and barriers to disclosure. Because stigma and discrimination associated with disclosing, PLWHIV's ability to effectively cope may be jeopardized, especially in a relationship where PLWHIV may be at risk of stigmatization and discrimination. Disclosure of HIV status opens an opportunity to educate PLWHIV to protect their sexual partners from HIV reinfection. Disclosure of HIV status is an opportunity to reprioritize life (Greeff et al., 2008). It is necessary for individuals to be empowered how to when to, and to whom to disclose.

Culture and the community have focused on issues that undermine women, by making them responsible for HIV infection. In reality, when the condition is perceived unjustly, it increases challenges of living with that disease, in this case, HIV/AIDS. Most societies in Africa expect women to be monogamous but expect men to have extramarital affairs (Ankrah & Henry, 1994; Strebel et al., 2006). Therefore, women are more likely to be held responsible for HIV risk reduction than men (Strebel et al., 2006). Stigma and fear of being rejected by a spouse or other sexual partner increase PLWHA reluctance to disclose HIV positive status, (Cloete, Strebel, Simbayi, van Wyk, Henda, & Nqeketo 2010; especially among HIV-positive South Africans Deacon, 2006; Kalichman et al., 2008). The stigma may vary on the route of transmission. For example, in South Africa heterosexual sex is the primary route of HIV infection, which gives the community the

power to stigmatize and discriminate PLWHIV. Many people do not want to disclose their HIV status, and those who know will often keep it secret, some even from their sexual partners (Ssali et al., 2010). Fears of stigma and discrimination have deterred individuals from being tested for HIV and from disclosing their seropositivity status to sexual partners, family, and friends (Becker, 2004). The communities tend to perceive and assume that individuals have HIV when they are sicker and thinner than normal.

One study of PLWHA showed that discriminatory attitudes were prevalent towards PLWHA in Hong Kong and were strongly associated with other negative perceptions, such as promiscuity, and contagion (Lau et al., 2005). In this telephone survey of Hong Kong residents, age 18-50 years, 42% of respondents reported avoiding physical contact with PLWHA, 35% believed in dismissing all infected medical staff, and 47% agreed with the idea of a law prohibiting PLWHA from visiting Hong Kong (Lau et al., 2005). Also, a sizable proportion of the respondents held negative perceptions about PLWHA, for example, that they were promiscuous, and were receiving the punishment they deserved for their behavior. Similar reports of stigma such have been reported by Campbell et al. (2007); Simbayi et al. (2007); Ulasi et al. (2009). Moral judgments play an influential role in stigmatization and discrimination against PLWHIV and create barriers to PLWHIV disclosing their infection

Literature Related to Methodology

Through my literature review, I discovered that there are several studies related to self-disclosure of HIV status by PLWHIV and its consequences. Nakigozi et al. (2013) completed a qualitative study to explore barriers to entry into care for HIV care

providers. This theory in health belief model from psychological theory suggesting that health-seeking behavior determined on how people decided to avoid the disease and the belief that a particular cause of action will prevent or relieve sickness (Janz et al., 1984). The study relied on in-depth interviews with 48 HIV infected participants 15-45 years of age. The interviews started before started care during that 6 months. The findings revealed that barriers to use HIV care included fear of stigma. Also, women's lack of support from male partners, demanding work schedules, and high transportation costs (Nakigozi et al., 2013). This study supports the relevance of the current study to utilize a similar qualitative approach.

Chirwa et al. (2011) conducted an exploratory study that adopted a qualitative approach utilizing the phenomenological design to explore youths' experiences in disclosing their HIV positive status disclosing their HIV positive status. This study conducted in Likuni urban and Namumba areas in Lilongwe district, Malawi where 10 positive males and females between ages 19 - 25 years were purposely sampled half from each field. The researchers used a qualitative approach and collected data through in-depth face to face audiotaped face to face interviews. The researchers found that disclosure of HIV positive status among infected youths is difficult and remains a challenge. Chirwa (2009) found that all the major barriers and hindering factors in the disclosure of HIV status were stigma and discrimination.

Peter (2011) conducted a qualitative study interviewed 15 participants from five branches of Alpha Organizations in South Africa. The goal of the study was to allow individuals to express their daily experiences of living with HIV after disclosure in their

workplace. Participants perceived and experienced the level of support from managers differently and got support from all colleagues. They also expressed high support from wellness practitioners (employee wellness professionals) in their personal and family lives. At some point, stigmatization was experienced by both managers and colleagues with negative remarks stemming from their physical appearance to their work attendance. Their most experiences were fear of rejection, imminent death, and infecting others. It was evident that HIV status disclosure in the workplace had both negative and positive consequences (Peter, 2011). Researchers have demonstrated that disclosure of HIV status among people living with HIV/AIDS remains a challenge.

Mwini-Nyaledzigbor et al. (2013) conducted a study in sixteen Ghanaian women experienced dilemmas in disclosing HIV positive. Their findings indicated that women were reluctant to disclose their HIV/AIDS status. Adverse results of disclosure included eviction from homes and ostracism (Mwini-Nyaledzigbor et al., 2013). Many women decided not to tell. These reasons are consistent with previous research (Chandra et al., 2003; Deribe et al., 2008; Lau et al., 2005; Rice et al., 2009; Simbayi et al., 2006). Mwini-Nyaledzigbor et al., 2013) conducted a study in sixteen Ghanaian women experienced dilemmas in disclosing HIV positive. Their findings indicated that women were reluctant to disclose their HIV/AIDS status. Adverse results of disclosure included eviction from homes and ostracism (Mwini-Nyaledzigbor et al., 2013). Many women decided not to tell. These reasons are consistent with previous research Chandra et al.; Deribe et al.; Lau et al.; Rice et al.; Simbayi et al.).

Literature Relating to Differing Methodologies

In this study, the aim is also to provide information on self-disclosure of HIV status in PLWHA self-disclosure to sexual partners and experiences when they disclosed. Yonah et al. (2014) completed a study to provide information on HIV serostatus disclosure among PLWHA attended care and treatment clinic at Sekou-Toure hospital in Mwanza, Tanzania. A cross-sectional study was carried out with two hundred seventy adults living with HIV/AIDS attended Care and Treatment Clinic (CTC). The study emphasized the importance of disclosing HIV serostatus to prevent and health maintenance for PLWHA their spouses and the community. The study concluded that participants that delayed disclosure were a small portion of the participants. Among the participants who disclosed their status reported closeness to a person they revealed (Yona, et al., 2014). Two hundred amongst those disclosed had emotional support after disclosed. Thirty-four felt discriminated, and 12 were divorced. As with other studies, disclosure present both positive and adverse outcome.

Wagner et al. (2012) interviewed men who have sex with men (MSM), to explore psychosocial processes that influence risk behavior and HIV testing. Researchers divided men into two groups. Sixteen MSM age 18–25 were in one group, and 15 MSM age above 25 were in the other group. Some had at least some college education, and most were either employed or attending university and among them with known religious affiliation, Christian, and Muslim. The qualitative semi structured interviews were used in this study to explore various social factors on sexuality and HIV behavior of participants. The instrument covered in their study: (a) Comfort with the disclosure of

sexual orientation, (b) experience of support and stigma, (c) Sexual behavior including condom use, (d) HIV testing and (e) Discussion of HIV status, risk and condom use with sex partners. Partly reported used condoms regularly and one tested positive and some not with regular partners. Fear of infection motivated many to get tested and use condoms, but fear of disease and social stigma led others to avoid testing. The findings suggested that similar factors influence condom utilization and HIV testing of MSM in Beirut as those observed in studies elsewhere in the world.

Theoretical Framework

Rosenstock's health belief model (HBM) provides an appropriate behavior change perspective for examining self-disclosure of HIV status and potentially help individuals to avoid HIV reinfection (McKenzie et al., 2009). There are five constructs for health belief model. They are: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and self-efficacy. These are defined and applied about PLWHIV as follows.

Perceived susceptibility

The construct refers to a personal belief that an individual has about reaching an unsafe stage engaging in dangerous behavior (Rosenstock et al., 1984). For example, PLWHIV must recognize that they are at risk to re-infect their partners and may further be re-infected with the stronger strand of the virus (Janz et al., 1984). Individuals may differ in understanding how susceptible they are to any illness (Sharma & Ramos, 2009). PLWHIV may deny any possibility of infecting others with HIV infection whereas the other PLWHA may admit to the possibility of re-infecting their partners and believe that

it would not happen to them.

Perceived severity

This construct refers to the individual's personal belief and perception on the risk of harm that can result from acquiring a further infection (see Greeff et al., 2008). It also varies in different individuals' perception of the disease. For example, PLWHIV might perceive HIV reinfection from their health viewpoint, and therefore will be thinking about the fatality of illness, whereas others might be concerned about HIV implications on their family, especially the stigma and discrimination associated with contracting HIV. Rosenstock (1974) recommended that health educators should emphasize the consequences of engaging in harmful behaviors such as engaging in unprotected sex.

Perceived benefit

It refers to the belief of the advantages of methods recommended for reduction of the seriousness of the disease (see Janz et al., 1984). It means that the belief PLWHIV have the importance of self-disclosure of HIV status in protecting themselves against HIV reinfection would help them to have safer sex. Health educators need to specify what action to take as well as the result of the benefit of disclosing. For example, the health educators need to determine that PLWHIV should frequently and safely disclose their HIV status each time before they engage in sexual intercourse to reduce the risk of infection in one's sexual partner (Miller et al., 2008).

Perceived barriers

It is a psychological perception of social or financial costs of following a new behavior (Kalichman et al., 2009). For example, PLWHIV may believe that self-

disclosure is effective in reducing perceived susceptibility or perceived severity of being re-infected with HIV, but may consider self-disclosure of HIV status as uncomfortable. AIDS-related stigma remains one of the barriers to curtail the further spread of the disease amongst people who know their HIV-positive status (Pelter et al., 2004). If the individuals believe the barrier of disclosure outweighs the benefit of self-disclosure of HIV status, the individuals will not have the motivation to disclose. Health educators should assist in reducing barriers to encourage PLWHIV to use new and safer ways to reveal.

Self-efficacy

The term borrowed from Bandura's social cognitive theory (Bandura, 1978), refers to the confidence that one might have the capability to pursue any given behavior (Rosenstock et al., 1988). An example of self-efficacy would be PLWHIV's convictions that they can successfully disclose their HIV status to their partners. It displays one's beliefs to take the initiative to motivate him/herself. Self-efficacy beliefs determine how people feel, think, drive themselves and behave.

I used the health belief model to construct the research questions and to organize the findings of this study. However, there were inconsistencies between the themes that emerged from the data and the health belief model. The perceived threats might encourage avoidance to disclose HIV infection. Perceived severity and perceived susceptibility might not affect disclosure. Self-efficacy might assist PLWHIV's confidence in revealing their HIV status. I also organized the results by research question instead.

Summary

Self-disclosure of HIV status to intimate sexual partners is an important factor to for preventing new HIV infections. The HIV/AIDS incidence worldwide has recently decreased. However, there is signs and increase of risky behaviors in the number of sexual partners in several countries (UNAIDS, 2013). South Africa has the highest incidence rate among the Sub-Saharan countries, with significant increase in the number of sexual partners, and the challenges to addressing the problem are many: limited access to quality HIV, sexual and reproductive education and health services; an increase in sexual violence against young girls and women (UNAIDS, 2013).

In this chapter, I have described the literature on AIDS prevalence, the socio-cultural factors related to HIV infection and disclosure and my theoretical framework. The socio-cultural factors are described under the main headings of gender inequality, violence and sexual violence, and political transition and the legacy of Apartheid. The elements of the HBM were described as they apply to the lived experience of PLWHIV in the self-disclose of their HIV status. In Chapter 3, I will describe the methodology employed in this study, including the phenomenological research design, and data collection and analysis procedures.

Chapter 3: Research Method

Introduction

I conducted this qualitative study to explore the lived experience concerning self-disclosure of HIV infection to sexual partners by PLWHIV infection. This chapter will include a discussion of the research methodology in this study. The chapter will also include a description of the data collection as well as data analysis, a description of the appropriateness of the research design, the population, assumptions and limitations, ethical assurances, and the themes I identified from interviews.

In this study, I used the phenomenological design. I explored the perceptions of PLWHIV and focused on: (a) their susceptibility to HIV before infection, (b) the severity of the risk, (c) the benefit of disclosure, (d) the barriers to disclosing, and (e) their self-efficacy in relation self-disclosure of their infection. I used the descriptive phenomenological method attributed to Husserl (1963). My focus was on the experience from individuals' points of view, based on their knowledge, subjectivity, and interpretation (see Balls, 2009). Reporting the direct experience of a phenomenon eliminates assumptions and allows a researcher to identify the principal features and essence of a phenomenon (see Ball, 2009). The goal of using phenomenological design in this study was to describe a person's lived experience precisely. According to Ball (2009), the data or information are usually collected through individual interviews to yield stories related to their lived experiences; consequently, I used interviews in this study.

Research Design and Rationale

The primary research question I developed to guide this study was:

What are the experiences of South African PLWHIV with respect to self-disclosure of their infection to their intimate partner?

Sub questions included the following:

1. What are the experiences of PLWHIV with respect to discovering their HIV status?
2. What are the motives of PLWHIV with respect to self-disclosure?
3. What are the feelings of PLWHIV with respect to self-disclosure?
4. What are the methods used by PLWHIV to self-disclose?
5. What are the responses of intimate partners to self-disclosure by PLWHIV?
6. What is the emotional effect of self-disclosure on PLWHIV?
7. What is the experience of PLWHIV with respect to accessing medical care?

This study was exploratory, and I based it on in-depth, face-to-face interviews with a purposive sample of 12 PLWHIV. The interviews yielded rich, thick data on the phenomenon of self-disclosure of HIV infection. I used a phenomenological approach to examine the experiences to allow me to accurately identify what lived experiences PLWHIV have had (see Balls, 2009). The approach included interviews, stories, and participant observation. In this study, PLWHIV were able to make their voices heard regarding factors that affect safe self-disclosure of their HIV-positive status to their sexual partners.

I used descriptive phenomenology, which was developed by Husserl (1963; original work 1913). Descriptive phenomenology attempts to make phenomenology a rigorous science through the use of *bracketing* to maintain objectivity (Balls, 2009). I collected data only through semi structured interviews and storytelling (see Colizzi, 1978; Wimpey et al., 2000). I did not audio tape the interviews per all participants' requests. Participants expressed discomfort on recording their experiences. I wanted to make sure that the data collected revealed both men and women living with HIV experiences disclosing HIV status to their sexual partners. Creswell (2013) explained the six-step process to explore qualitative data. The first part of this process was to prepare and organize the data (Creswell, 2013). For this first section of the process, I took notes on the interviews for all of the participants. The second step involved reading the notes and categorizing them to explore possible themes. The third phase included coding the data. In the fourth stage, the coding system is used to organize potential themes that could be further examined (Creswell, 2013). The themes represent the significant findings of the study. The fifth step is the determination of the themes and the gathering of quotable narrative passages from the interviews (Creswell, 2013). In the final stage, I attempted an understanding of the data according to the themes; this step provided meaningful interpretation (see Creswell, 2013).

The Role of the Researcher

Before initiating the study, I obtained permission from the IRB at Walden University and the KwaZulu-Natal Health Clinic in South Africa to collect data. I designed the semi structured interview questions (see Appendix A).

I presented accepting and nonjudgmental attitude throughout this research to control bias in this study about what I was investigating (see Creswell, 2013).

During interviews, I listened carefully, took notes, paid attention to body language, and reviewed each participant's responses including my conclusion.

I continued to facilitate the study to help interviewees to talk freely. I read participants' responses more than once to gain familiarity with them as suggested by Terre Blanche and Kelly (1999). I reflected on my presupposition about the perceptions of participants' lived experiences disclosing their HIV infection status using bracketing. Bracketing eradicates any bias inherent in a researcher's beliefs and attitudes (Creswell, 2009; Marshall & Rossman, 2006). I set aside assumptions about what I already knew about this population's experiences and approached the data with no presumptions about the phenomenon (see Dowling, 2004; Lopez et al., 2004). Also, putting aside any preconceived ideas and attitudes allowed commonalities in experiences to be revealed and described (Ashworth, 1996).

As the researcher, I recognized the sensitivity of the topic and encouraged participants to talk freely. Although I had never worked in this clinic or area, I still served as a potential source of bias (see Hammersley & Gomm, 1997) due to my being part of the community under study. I adopted an outsider researcher role because of my lack of

knowledge on PLWHIV experiences disclosing their HIV status to their sexual partners. I did not encounter challenges to establishing and building trust with the participants I was interviewing.

My understanding and assumption of the safe disclosure are that an individual must be sure or confident that it was safe to disclose. Greater rates of self-disclosure could substantially reduce the rate of new infections in South Africa. Self-disclosure could involve issues of trust and can slow down the decision. Chung & Bemak (2014) cautioned about the slowness of confidence as resistance.

Also, my perception bias against cultural knowledge of women and sympathy toward women living with HIV might have misled participants' responses. I used bracketing to avoid my feelings. Bracketing allows the researcher to put aside personal beliefs to avoid bias to explore the phenomenon under study (Balls, 2009).

Methodology

For this qualitative study, I conducted a series of semi structured interviews using a purposive sample of PLWHIV disclosing their HIV status to sexual partners. A qualitative approach was appropriate for this study to explore lived experiences of participants disclosing their HIV status to their sexual partners. This study was phenomenological in nature as I aimed at focusing on the lived experiences of the participants (see Creswell, 2006). Therefore, the purpose of this study was to explore the personal experiences of the participants to gain an in-depth understanding of their perspectives.

Setting and Sample

I recruited a purposive sample of 12 participants at an HIV clinic in KwaZulu-Natal that male and female adults attended for their HIV treatment clinic. The sample was comprised of four men and six women who had been tested and diagnosed with the HIV infection. According to Moustakas (1994), only a small number of subjects are needed for prolonged engagement to develop patterns of relationships. The phenomenological approach usually includes a sample size of 12 (Creswell, 2013). I intended to interview 12 participants and I achieved saturation by reaching this number. I recruited the participants by word of mouth and through the help of the staff members.

I recruited potential study participants who met the preliminary inclusion criteria. I did not use flyers because of the distance between the stores and place of residences for potential participants (see Appendix B). Also, the sensitivity of the study could have attracted negative interests. There was no initial discussion related to this research with the subjects before the approval by Walden University IRB approval. To be included, the participants had to have attended grade school (at least Grades 9-12). People who were willing to participate confirmed their participation in the study during recruitment due to transportation, the long distances necessary to travel, and set appointments with the clinic appointments.

Eligibility Criteria

Participants were made up of men and women who had been diagnosed with HIV-positive serostatus and the HIV infection, in relationships for a long time, and had disclosed to their sexual partners. Individuals also had to be willing to share their

experiences self-disclosing their HIV status, aged 20–49 years old, married or in a long-term relationship, sexually active, and living with their partner. Three of the participants were older than the anticipated age, but I interviewed them because they fit the other criteria and were willing to participate. People aged 15-19 were excluded from the study due to ethical concerns that prohibited me from interviewing minors. The criteria were verified at the first initial contact with PLWHIV in person. I asked them questions that assisted to establish eligibility, for example, “Have you revealed to your sexual partner your HIV infection? If so, when and how did you approach your sexual partner?” The dynamics and experience of men and women tend to be different (Ashburn et al., 2008); therefore, in this study I included both men and women.

Data Collection Procedure

My recruitment of the participants took place after receiving approval from the Walden University IRB (Approval Number 0 1-19-16-0128232 renewed 01-10-2017) and the Health Research Sciences Council SA IRB HRKM363/16 KZ 2016RP52_659, KwaZulu-Natal in South Africa. I used the traditional face-to-face interview following the primary criterion recommended by Giorgi (2009), who said, “What one seeks from a research interview in phenomenological research is as complete a description as possible of the experience that a participant has lived through” (p. 122). The interviews took place in familiar surroundings, which had been negotiated with participants to decrease any anxiety. The semi structured interviews lasted between 45-60 minutes with each interview averaging closer to 55-60 minutes. The interviews incorporated probing questions to elicit detailed responses.

I collected the data at a time and place that suited the participants to maintain confidentiality. After introducing myself, I explained the use of the microphone, asked the permission to record the participants, and explained security and privacy issues such as protecting the participants. The participants opposed the use of tape recording, so I did not use tape recorder per participants' request. I took notes and captured their nonverbal responses. The notes generated from the interview were then typed and entered into a computer file, which was secured so that no other person would have access to the data. I did not need an interpreter or translator with the participants as I am a native, fluent in both English and IsiZulu, the local language. I conducted interviews in IsiZulu; all the participants were IsiZulu speaking. I provided a translation of interview questions in IsiZulu, which I then translated back to English. I was also in charge of handling the resulting data and setting up a filing system as indicated in Ulin et al. (2005). I made sure that all discussions were kept confidential by ensuring that any information I included in my report would not identify the participants. I did not use participants' names in the data. Participants were instead identified by assigned numbers to protect their confidentiality. I translated all responses in IsiZulu into English for analysis.

Data Analysis and Interpretation

I analyzed the data using Colaizzi's (1985) phenomenological approach. I used thematic analysis and coding using the participants' own words and phrases. Once all the data was recorded, I identified the main themes that occur and coded all the data accordingly. I consulted my chairperson at all stages of the research process to improve the validity of my findings. I analyzed data generated from interviews by hand in the

form of coding and mapping. I obtained detailed information from the participants regarding their experiences self-disclosing HIV status to their sexual partners. I reread the notes for each participant's response to the same individual question. I examined different and similar responses from each participant. I identified words, phrases, statements supplied by each participant. The goal was to incorporate the link the data collected and the research questions. The themes that were: discovering HIV status, the response of partners to disclosure, method of disclosure, motives for disclosure, feelings about disclosing, emotional effects of disclosure on PLWHIV, and accessing medical care.

Issues of Trustworthiness

I exercised member checking with caution throughout the interview for each participant. I repeated statements that I needed clarification to confirm only the content of their statements for validity. I reread the participants' interview summaries and then asked for input about whether their statements were accurate representation of their story (Lincoln & Guba, 1985). I did member check to establish validity of their answers by clarifying each statement that was not clear or needed more clarification showing summaries of their data to respondents for their comments and behavior during interviews as recommended by Trochim and Donnelly (2008). I did not use triangulation to check my research due to sensitivity of the population I interviewed. I employed member checking to verify their answers and saturation to validate the credibility.

In this model, there are four elements to trustworthiness; they are credibility, transferability, dependability, and conformability (Creswell, 2013; Ulin et al., 2005). Credibility referred to the truth value of the data and conducted in a manner by which the phenomenon the challenges experienced by PLWHIV in disclosing their status. Transferability means using and describing data collection methods so effectively that they can be utilized in the future research. Dependability means using reliable and replicable methods, and conformability means remaining neutral to achieve impartiality. Credibility was obtained by capturing the essence of PLWHIV's narrative lived stories with trust and acceptance (Isler et al., 2012). I provided trust and acceptance of participants to their lived experiences. I abused my ability to provide and implement member check for this study's credibility to assure transferability. Credibility can be obtained through PLWHIVs' life stories and investigator's rebuilding and representing of those stories (Greenstein, 2003); maintained the opportunity to understand and assess the participants' intended to say (Guba & Lincoln, 1989). Also, confirmability and dependability were satisfied through the process of data gathering and presenting the correct form of documentation (Greenstein, 2003). I achieved transferability through describing sampling, and member checking. Dependability and confirmability obtained through the process of gathering data, documentation and the presentation of the data.

Ethical Considerations/Protection of Participants

In protecting the participants in this study, I was vigilant in meeting all the standards of ethical research practices. I had completed the National Institutes of Health online course Protecting Human Research Participants, on 07/09/2015 and the South

Africa TRREE Training Certificate on 07/31/2016 (Appendix E). I also followed the Provisions of the Code of Health to research in South Africa.

According to ethical principles for health research in South Africa, a researcher should identify the required standard to protect the well-being of the participants in research (Department of Health Ethics, 2003). To further safeguard the confidentiality of participants, I had no assistant interviewing for me. I included the principles of privacy, informed consent, confidentiality, protection from harm and avoided deception for this study. I honored and respected the dignity, safety, and well-being of participants; their culture, language, beliefs, perceptions, and customs were considered and maintained. I kept awareness of the vulnerability of participants regarding their level of education and provided research details in a clear, simple and culturally appropriate manner. I maintained participants' confidentiality throughout the research to protect participants' identity as indicated in Nieswiadomy (2008). Participants had the rights to choose not to participate, and could terminate their participation at any time. All 12 recruited participants participated throughout the interviews. Ethics approval was obtained from Walden University Human Research Ethics Committee and South African Human Research Ethics before the commencement of this study for permission to collect data for the primary study. I informed participants about the risk and benefit of participating in the study and how to maintain their confidentiality.

I informed the participants participation in the study was voluntary and that they could terminate the interview at any time without giving the reason. I also told the participants that all material was confidential and would be used only for this study. I

collected and accessed the data. I arranged consultation with nursing staff before interviews in case the participants experience emotions to give appropriate counseling.

Summary

In this chapter, I outlined the methods used phenomenological approach. The chapter will include: setting up my research questions following Colizzi's phenomenological methodology and collecting data from approximately 12 participants (I was only able to interview four men and eight women) through a series of 45- 60 minutes face to-face-interviews. The purpose was to explore PLWHIV experiences disclosing their HIV status to their sexual partners. This chapter will also include procedures for maintaining high ethical standards and coming to trustworthy results. I will present the results in Chapter 4.

Chapter 4: Research Findings

Introduction

The primary purpose of this study was to explore lived experiences of PLWHIV disclosing their HIV status to their sexual partners in KwaZulu-Natal, South Africa.

Chapter 4 will include a discussion of the study findings.

The primary research question for this study was:

What are the experiences of South African PLWHIV with respect to self-disclosure of their infection to their intimate partner?

Sub questions were:

1. What are the experiences of PLWHIV with respect to discovering their HIV status?
2. What are the motives of PLWHIV with respect to self-disclosure?
3. What are the feelings of PLWHIV with respect to self-disclosure?
4. What are the methods used by PLWHIV to self-disclose?
5. What are the responses of intimate partners to self-disclosure by PLWHIV?
6. What is the emotional effect of self-disclosure on PLWHIV?
7. What is the experience of PLWHIV with respect to accessing medical care?

The implications for positive social change are that this resulting in-depth understanding of the lived experiences of PLWHIV about self-disclosing their HIV status to sexual partners might serve as the basis for the development and refinement of educational programs for the community to build understanding of the disease and reduce stigma towards PLWHIV.

Study Setting

I planned to recruit first and to interview in a safe place suggested by the participants. I recruited likely participants that were recommended by the clinic based on negotiations with the participants on their availability and convenience. Due to long distances traveled and clinic appointments, I interviewed those who were eligible and agreed to participate the same day. The location was a safe, private room suggested and determined by the sister-in-charge and the researcher for the health clinic, in the hope that participants would feel more comfortable in participating. All 12 participants were given a choice to interview on a different day or place where they might be free to take part. The participants received a stipend of R300 (\$25) for their participation and travel expenses.

Demographics

I numbered the study participants 1 through 12 to protect their identities. They included eight females and four males who had self-disclosed to their sexual partners. They all shared the same location, a health clinic in the KwaZulu-Natal region of South Africa and had been diagnosed with HIV infection, married or in a long-term relationship, sexually active, and lived with their partners. Ten were not married but had a child or children together within their long-time relationship. Two women had been married and were now widowed. One man participant reported that he had lost his partner. The mean age of participants was 40.6.

Table 1

Participants' Demographic Information

Participant	Age	Marital Status	Gender
1	27	Not married	Female
2	65	Widow	Female
3	33	Not married	Female
4	39	Not married	Female
5	27	Not married	Female
6	39	Married	Female
7	34	Not married	Female
8	39	Not married	Male
9	26	Not married	Male
10	59	Widow	Female
11	41	Not married	Male
12	59	Not married	Male

Participant 1 was a local resident and 27 years old. She had a 9 year-old child. She lived approximately a mile and half away from the local health clinic and had a long-term sexual partner. When asked what made her self-disclose to her sexual partner, she stated,

“It’s painful to put someone else to my situation especially when you know that you have tested positive.”

Participant 2 was a 65-year-old widow, who lived approximately 10 miles away from the clinic. She relied on taxi transportation to get her to and from healthcare clinic

appointments. She had grown up children. When asked what made her self-disclose to her sexual partner, she stated:

I had hoped that my husband would be encouraged to also disclose because I knew that he was taking medications and when I tested positive I advised him to get tested but he refused and constantly blamed high blood pressure as his illness.

Participant 3 had two young children and lived with her long-term sexual partner not far from local health clinic. She was 33 years old. When asked what made her self-disclose to her sexual partner, she stated:

“I wanted him to know that I tested positive so that he could go and be tested too because he might had too since I was positive.”

Participant 4 was a 39-year-old female with three children. She lived about one and half miles away from the clinic. She was a caregiver for her two sisters, both died of AIDS in 2010 and 2012. When asked what made her self-disclose to her sexual partner, she stated:

“I wanted him to know that I tested positive so that he knows that he is dealing with somebody positive. I do not want anybody go through what I am going through right now.”

Participant 5 was 27 years old. She lived with her long-term sexual partner and had 3-year-old child. She lived a mile and half away from the clinic. When asked what made her self-disclose to her sexual partner, she stated:

I was hoping that he would be faithful too about his HIV status because I know that he was taking the pills. I know those pills were for HIV. I did not want to be the one who brought it to him.

Participant 6 was married to a man 7 years older than her. She was 39 years old. She lived far away from the clinic, approximately 40-50 miles away. Transport is one of her major problems for appointments. When asked what made her self-disclose to her sexual partner, she stated:

“I was stressed even at night, my body felt like it was choking. I followed my mother’s advice who would encouraged us to report so that we can get help, avoid spreading the disease.”

Participant 7 was a 34 year old female who reported that she was raped. She now lives with her sexual partner, whom she met at the clinic 6 years ago. When asked what made her self-disclose to her sexual partner, she stated:

“I wanted to make sure he knows that I tested positive before I agreed to date him.”

Participant 8 was a 39-year-old widower who lost his partner before he was diagnosed with the HIV infection. His partner died of AIDS. He recently moved closer to the clinic. When asked what made him self-disclose to his sexual partner, he stated:

“I wanted to get some help and support as I was very sick. I tested positive and I had no strength; I couldn’t walk. I got help from my mother and my sister.”

Participant 9 had a long-term girlfriend and a child with her; they lived with his mother. He traveled approximately 19 to 25 miles to the clinic. When asked what made him self-disclose to his sexual partner, he stated:

“I wanted her to know because I felt bad that I am the one who had been behaving badly. I felt guilty that she tested positive before I find out.”

Participant 10 was a 59-year-old widow who lived close to the clinic. She had lost all her children due to the HIV infection. She was now in a relationship with her brother-in-law (which is culturally encouraged), who is married. When asked what made her self-disclose to her sexual partner, she stated:

I wanted him and his wife know that I am HIV positive. I believed that his wife needs to know so that she knows what she is dealing with. I did not want anyone to feel what I felt when my husband did not disclose to me about his HIV status.

Participant 11 was an unmarried 41-year-old man with a long-time sexual partner and children from different lovers. He had his own place about a mile and half away from the clinic. When asked what made him self-disclose to his sexual partner, he stated:

I wanted to disclose before she finds out herself. I had these many pills I am taking that I would have no way to hide them. I wanted her to get tested too so that we can help each other.

Participant 12 lived not far from the clinic. He had a live-in sexual partner and mentioned that they were not legally married. They had grown children. When asked what made him self-disclose to his sexual partner, he stated:

I know that she was taking pills but never told me what they were. I wanted her to know before she sees bunch of pills so that she knows even though she had cut off our sexual activities and reports that she was sick.

Data Collection

After reviewing each participant's statement on their lived experiences about self-disclosure of their HIV status to their sexual partners, I transcribed all of my notes from my interviews with each participant. The interviews were transcribed and translated into English for thematic analysis. I reread the transcripts several times to identify themes to obtain a general sense about the whole content. I then used Colaizzi's method for data analysis (see Creswell, 2013).

After I transcribed all the data, I created a list of the main themes that I identified by their words and statements on self-disclosure of HIV status to their sexual partners and grouped the themes together. I analyzed the data generated from interviews by hand and with a form of coding for interpretation that used the participants' own words and phrases. This allowed me to code all the information according to themes. With these ethical grounds in mind, I separated the resulting information into main categories. The categories addressed the PLWHIV's descriptive framework about issues that helped and affected them when self-disclosing their HIV status to their sexual partner and how they handled their experiences. A qualitative research process is an inductive approach that evolves from the telling and recording of a story in an effort to understand that story (Creswell, 2013). Participants addressed issues that helped and affected them when self-disclosed their infection status to their sexual partners and how they handled their

experiences. I believed the findings would develop inductively to provide the subsequent presentation of facts. I interviewed, collected data, and find themes addressed by the people living with HIV.

Data Analysis

I obtained detailed information from the participants regarding their experiences of self-disclosing their HIV status to their sexual partners. I reread the notes for each participant's response to the same individual question and noted different and similar responses. Through this process, I identified similar words, phrases, and statements supplied. The goal was to link the data collected and the research questions. The themes I found in my analysis were: discovering HIV status, the response of partners to disclosure, method of disclosure, motives for disclosure, feelings about disclosing, emotional effects of disclosure on PLWHIV, and accessing medical care.

Evidence of Trustworthiness

I established the reliability and credibility of the study using Lincoln's and Guba's model (1985). Qualitative research potentially involves human bias whereby the researcher or participants may introduce their assumptions during data collection or analysis (Carpenter, 2007). The researcher can display a degree of neutrality in the findings of the study if they follow the participants' responses and not their own interest or motivation as researcher (Sutton & Austin, 2015). I reread the interview transcripts several times to reduce the potential bias associated with one-time analysis. To ensure trustworthiness, I conducted in-depth interviews in the participants' local language,

IsiZulu; transcribed the interviews in English; and then reviewed for accuracy by reading each transcript several times.

I achieved and obtained credibility through interviews and my notes to develop the essence of people living with HIV narrative lived experiences (see Isler et al., 2012). I completed member checking, and each of the participants responded approving the validity interpretation of the interviews. In this study, I achieved transferability through describing the sampling and member checking process. I obtained dependability and confirmability through the process of gathering data, documenting my process, and presenting the data.

Results

The participants' responses to questions were analyzed into themes, which are presented below with statements made by participants. The primary research question that was asked to achieve the purpose of this study was: What were the experiences of people living with HIV, especially with respect to disclosure of their HIV infection? A semi-structured interview guide was used to incite responses that will enlighten the lived experience of PLWHIV KwaZulu-Natal in South Africa.

Experiences Discovering HIV Status (Sub question 1)

Out of the 12 participants, six discovered their HIV status when they felt sick and went to see a health professional, five find out it during prenatal visit, and one reported the rape occurred.

Theme 1: Most participants discovered their HIV status after falling sick and going to the clinic.

After my husband 2006, I just did not feel right, nothing was painful but my body was not right. I did not have symptoms. I went to the clinic and reported that I was not feeling good and my husband just died (P2).

I find out November, 2015 that I was positive. I was not feeling well, my body was not right and I went to the clinic to be checked (P6).

I got very sick, couldn't walk, and couldn't eat. I reported to a Social Worker at work and I was sent to the hospital to be checked. I tested positive for HIV infection in 2016 around October, My partner died January, 2016 (P8).

I was just sick, my body was not feeling good, and then I was found that I had TB and ted positive for HIV (P9).

It is about 11 years ago after the passing of my husband. I attempted suicide by taking a bunch of pills when I find out. I had that anger that he has been taking pills he never disclosed what were they for (P10).

I felt like I had flu. I went to the hospital and discovered that I had TB. I was given pills for that. I continued feeling sick and I was admitted to different hospital where I stayed six months. I was treated for both TB and HIV infection last year (referring to 2016). I was sick and started on TB pills but I tested positive for HIV infection in 2012. I was admitted to the hospital from 2014 to 2015 (P12).

Theme 2: Some discovered their HIV status when they got pregnant and went for a prenatal visit.

I find out when I went to clinic for my prenatal first visit. It is the routine that we get tested for HIV by the law here (P1).

I have three children but find out that I was positive for HIV during my second pregnancy for my routine prenatal visit in 2012. When pregnant, it is the law that you get tested for your first visit (P3).

I was a caregiver for my two sisters who were HIV positive who died 2010 and 2012. I first discovered that I was positive when I was pregnant with my third child here in the clinic. The clinic tested me and find out that my 'soldiers' (referring to CD4 counts) were low (P4).

I find out during my first prenatal clinic visit approximately three and half year ago, 2013 (P5).

Theme 3: One discovered her status after being raped then tested.

I was healthy with no signs and symptoms of HIV infection. I was raped, never felt sick before. I did not want to share my rape story with anyone. I was already positive when I lived in with my partner in 2010. (P7)

Five participants became sick and went to clinic and tested positive for HIV infection. All women mentioned that they find out during their prenatal first visit but one who was the victim of rape. She found out after she felt obligated to seek help testing. They reported that the government requires testing for the virus for any pregnant woman.

Motives of PLWHIV with Respect to Self-Disclosure (Sub question 2)

Theme 4: Some felt obligated to be fair and chose to disclose to their sexual partners.

I wanted to make sure that I announced that I was positive so that he knows my status, no need to hide like some people like to hide. I wanted to be fair. I thought about what I saw what my sisters went through dying of AIDS (P4).

“I accepted it because I know, it has happened; how far can I go? I wanted to be fair with other person” (P5)

Theme 5: Others felt that getting help empowered them to disclose.

“Many people has the disease, I told myself to get strong, get some help. I disclose so that my sexual partner can also check himself since I tested positive.” (P3).

When I tested positive, I thought we might help each other. My partner continued to refuse any sexual activity. I do ask other women and refused to sleep with me once I tell them my status but I see one, she knows my status (P12).

Theme 6: Some wanted to disclose to protect their partner from infection.

“My mother always encouraged us to check ourselves. She would told us the importance of knowing our status because many people has died of this disease. “I wanted to protect myself and others from spreading more infection.” (P6).

“I wanted her to be tested, I saw that it does not help to hide.” (P11).

Theme 7: One disclosed to avoid being blamed.

I disclosed and I wanted him too to disclose his status so that I don't get blamed that I brought the disease to him. I also reminded him that to stay away from drinking as it doesn't go along with the medications they take (P7).

Theme 8: One said he chose to disclose to prevent being left or abandoned.

“My partner died before I was diagnosed. I would tell my partner so that she does not run away or leave me for hiding my status. I would hope.” (P8)

Most participants expressed their specific situation led them to disclose as not to infect their sexual partners knowingly. Some wanted to be fair and others for the protection of each other. One emphasized the importance of being free from the blame of carrying the virus as the motive to disclose.

Feelings Before and During Disclosure (Sub question 3)

Theme 9: One expressed fear that women would not accept him should he disclose his HIV status.

“I find out that I was positive after the death of my partner. I would not disclose; (when was asked if can should he meets someone) I am afraid that they will run away from me.” (P8)

Theme 10: One felt guilty disclosing his HIV status to his sexual partner.

“She did not say anything, I am really guilty even though she did not disclose her infection. I had a lot of run around.” (9).

There were some fears that disclosure would have led to run away and guilty feelings due to risky behavior.

Method of Disclosure (Sub question 4)

Theme 11: Most participants waited to break the news about their HIV status to their sexual partners until they were face-to-face.

“I first told my mother then told my partner that I was HIV positive. I told him face-to-face and he disappeared, he left me with a child.” (P1).

“I told him that I was at the clinic and tested positive today; it was face-to-face.” (P6).

“I was upfront with him before I dated before we dated. I am positive for HIV. How can you date me while I have the disease?” (P7)

I told her face-to-face, that I tested positive but it took a week before I told her.” (P9).

“I talk to her face-to-face ... man, I have a problem that I need to tell you. I take pills” (taking pills is a symbolic way to say one is HIV positive). (P11)

I asked my partner to accompany me to clinic to get tested. She refused and asked me to ask my daughter-in-law to take me. She accompanied me and I tested positive. I got home and told my partner that I tested positive (P12).

It was evident in this study that participants had the preference of how, when and whom to disclose to suit their level of confidence. One participant decided to call he partner on the phone while she was at her parents' house.

Response of Partners to Disclosure (Sub question 5).

Participants had variety of responses of partner's disclosure of their infection. They include support, abstinence, and condom use, sense of shock, disappearance, fear, and guilt.

Theme 12: Some participants were supported by their sexual partner after disclosing their HIV status.

I did not have a chance to disclose to my husband because he died before I tested positive. I told my daughter that I tested positive. She supported me; she knew that I was always home. I was not that kind of person (P2).

“I was up front with him before with my status and he expressed that I can help him too; we can assist and support each other. He refuses the condom use.” (P7).

“I approached my partner face-to-face. She assured me that there are many people on pills. She gave me that positive support. He reminds me to take my pills and agreed to be tested too.” (P11).

Theme 13: Some partners declined further sexual intercourse after disclosure of their HIV status.

He did not talk; he called me the following day and said he did not want to discuss it over the phone. And he preferred to talk to me in person. The night he came, he did not want to engage to any sexual activity but supported me (P4).

She (his partner) continued with the claim that she is still sick which was her was her reasoning for her refusal before I even knew I was positive. When she started

these pills that I was not informed what were there for. She asked that to abstain from sexual intercourse (P12).

Theme 14: Some agreed to use condom during sexual intercourse after disclosure

“My partner said ‘oh child, let’s accept this,’ I asked him to get tested and he did. He cooperates with condom use” (P6)

I was diagnosed after my husband death whom I was not told that he was HIV positive but I suspicious of the pills he was taking. Due to cultural practices or values, I became my brother-in-law sexual partner who is married. We are using condom as I agreed (P10).

Theme 15: A few reported that their sexual partner was shocked when hearing her HIV status.

“I called him on the phone. He did not talk, kept quiet for a minute. He eventually talked assured me that I should get strong as many people have the disease” (P3).

“When I called him, he answered his phone, kept quiet with no response to what I was telling him.” (P5)

Theme 16: Disclosure of HIV status caused one sexual partner to leave.

“The man disappeared and left me with the child.” (P1)

Partners’ reactions included offering support, insisting on abstinence, agreeing to condom use, a sense of shock or fear, and abandonment or disappearance. These combination of responses brought different experiences to individuals affected.

Emotional Effect of Disclosure on PLWHIV (Sub question 6)

Theme 17: Four participants underwent pain as their specific situation led them to choose to disclose their sexual partners.

“It’s painful to put someone else to my situation especially when I know that I’m positive. I wanted support during my difficult time.” (P2)

I chose to tell her because I was the one who was unfaithful, had affair, and ran around with women. I knew she was taking medication because she told but did not disclose her status. I did not protect myself. It makes me feel bad and hurting. (P9).

I did not to spread the disease. I deceived by my husband lying about his infection, knowing that he had another woman at workplace. I did not want someone else experience same deception I went through with my late husband (P10).

Theme 18: Most participants felt freed when they disclosed their HIV status.

I had confidence in me and realized that it was the time to tell. I wanted to be free from hiding what I was going through while there is better way to deal with it. I am taking my medications without hiding (P1).

“I felt relieved and freed even though it was very difficult to tell my children that I have this disease. I have all the support I need” (P2).

“I felt like I was freed from the crime I didn’t commit” (P4)

“I felt relieved as I took initiative to disclose my HIV status before I commit to a sexual partner” (P7).

“I feel that relief; I am able to talk to others about importance of disclosing their status and checking themselves as the help is available at the clinic. I do follow up with my treatment with confidence” (P10).

“I am able to take my medicine freely because I would have not able to hide them from my sexual partner; they are so many” (P11)

“I was able to get treatment and I am taking my pills free. I don’t have to lie about them even though we have not been able to continue with our sexual relationship” (P12).

Theme 19. Some felt that choosing to disclose their HIV status brought support.

“Even though, I was diagnosed with HIV after the death of my sexual partner, I felt that full support from my mother and my sister” (P8).

“I feel better now that we both know each other’s status. I like the sense that we support each other to take our medications” (P9)

Theme 20: Some felt reduced stress after choosing to disclose.

“Death of my two sisters I took care of was the touchiest moment that I felt support would help me to go through as they did” (P4).

Theme 21: Some experience an increase in confidence after disclosing their status.

“I felt assured that I can make this happen. My partner gave that assurance when he told me that there are other people with this same disease and I should get strong” (P6).

Participants' emotions ranged from painful, guilt, and denial to situations. Self-blame was related to unsafe sex to other women. One way or another their emotions were mostly affected.

Experience after Accessing Medical Care (Sub question 7)

The themes that emerged in response to this sub question were: increased medication compliance, increased support and confidence, and improved judgment.

Theme 22: Most reported improved medication compliance and health status.

Our government helps a lot by giving us medications, the number of pills are a lot less than before. I continue taking my pills per instructions. My baby tested negative and actually we give birth to healthy babies now. I always tell my partner that the pills do not do well with liquor (P1).

I knew that my husband was taking the pills that he did not disclose it was for his HIV infection. He was faithful taking them but he would say it was for blood pressure. Nobody could tell that he had HIV infection just by looking at him. I feel confident being among other people because nobody can tell anymore. (P2)
 "I am taking my medicine every day; I took them when I was pregnant and my baby was not positive when I gave birth. My CD4 counts were low. These pills has improved my look" (P5).

My major concerns is my partner who does not want to use the condoms. We are both good in taking our pills as instructed; we remind each other on daily basis. I remind him about drinking liquor and take pills that is not good (P7).

“I know that I was very sick, I could not walk. I am now feeling better now that I am taking the pills” (P8).

I was diagnosed with TB, my mother insisted that I get tested. I tested positive for HIV infection. I am taking my pills faithfully; I am here today because of them. I am just here today to get some that ran out (9).

I take my medicine as I was advised. We have stopped our sexual activities with my sexual partner before I even tested positive. She was taking the pills that I did not know what were they for. She did tell me that we should not engage in sexual activity because she was sick. I do sometimes see other women without using condom. I am not comfortable using them; she knows my status (P12).

Theme 23: The local clinic gave appropriate support during their treatment.

“We get help from the clinic; we get pills and great support from the staff. We support each other in both taking pills and condom use” P6).

I attended support group where I where I led the group. We discussed issues related to our treatment, concerns about the disease, coping with the community perceptions about us, and how to stay alive and active (P10).

I am on both TB and HIV pills. We take pills together (at the same time) with my partner; we remind each other every day. We call each other. Disclosing my status was the best thing I did because I can take my pills without fear and I do not have to hide them (P11).

Theme 24: Participants felt they would live longer with treatment and medication.

“I am confident that people now live longer than before after tested positive because of the medication and treatment that is available to us. This is the reason I wanted my partner to get tested too” (P3).

Theme 25: Medication and treatment were felt to remove stigma towards PLWHIV.

I saw my two sisters dying, their bodies wasting off. They were immediately identified by their look by the community before they were diagnosed. Once you lose weight, you were judged as promiscuous and your appearance predicts that you are HIV positive (P4).

The government and the clinic staff were their positive factors to medication compliance. The reduction number of pills were mentioned being helpful in their medication. The clinic team was supportive discussing their treatment. Their level of confidence grew as their body appearance improved.

Seven participants expressed the increase medication compliance was helpful due to the number of pills they now take. The medications were improved and also helped with their body appearance. Three of those stated that the support they received from the clinic has been helpful. One felt said that she was confident with their treatment and one expressed that there was less judging from the community due to their body appearance.

Summary

I reported the results of my 12 interviews, organized by research question. The findings suggest that PLWHIV who disclose their HIV status to their sexual partner have different experiences. In this sample, some found out their diagnosis when they got sick, and others when pregnant, or raped and they then visited the clinic. Reactions on the part of their intimate partners varied from support and condom use negotiation to declining further sexual intercourse, shock, guilt, and disappearance.

Some chose to tell their partners face-to-face, some while away, first sharing with relatives instead. Some participants chose to disclose because of the pain produced by hiding their HIV status; others did so in order to get help or protection, or because they did not want to get blamed for infection and wanted to avoid abandonment by their sexual partners. Most participants felt free after they chose to disclose their HIV status to their sexual partner. Some got support, stress reduction, and assurance from their sexual partner. This sample also expressed that medication and treatment improved their physical appearance to the community, and had reduced the stigma of the thin body associated with HIV infection; they expressed their appreciation for the great support they received from the clinic and sexual partners and family.

In Chapter 5, I discussed interpretation, findings, limitations, recommendations of the future research, implications for positive social change and conclusions. I also concluded the analysis and discussions of the themes, limitations of this study, conclusions, and recommendations for the future research. The chapter presented the findings based on the responses obtained from the participants

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of the study was to explore the lived experiences of PLWHIV disclosing their HIV status to their sexual partners in KwaZulu-Natal, South Africa and their perspectives on the disclosure of their HIV status to their sexual partners. In this chapter, I provided my interpretation of the findings of this phenomenological study.

The purpose of the findings, presented in this chapter review the use of the study and interpretations of the results compared to those in chapter 2 the presentation of the conclusions of phenomenological context (Creswell, 2013)

Finally, I addressed the recommendations for further research and implications for positive social change for PLWHIV in the community and possible educational programs. The study was designed to explore the lived experiences of 12 participants from the KwaZulu-Natal region in their local native language, and I then translated the responses into English for analysis. The data analysis indicated that the experience of self-disclosure differs for different people. I have reported the findings of the study as 24 themes in response to the following seven research sub-questions:

1. What are the experiences of PLWHIV with respect to discovering their HIV status? Most participants discovered their HIV status after falling sick and going to the clinic. Some discovered their HIV status when they got pregnant and went for a prenatal visit. One participant discovered her status after she was raped.

2. What are the motives of PLWHIV with respect to self-disclosure? Four participants underwent pain as their specific situation led them to choose to disclose.

Some felt obligated to be fair and chose to disclose to their sexual partners. Others felt that getting help empowered them to disclose. Two wanted to disclose to protect their partner from infection. One disclosed to avoid being blamed, and one said he chose to disclose to prevent being left or abandoned.

3. What are the feelings of PLWHIV with respect to self-disclosure? Most participants felt freed when they disclosed their HIV status. Some participants felt that choosing to disclose their HIV status brought support. Reduced stress was felt by some participants choosing to disclose. Participants felt reassured and relieved that they expressed their feelings and got the feedback from their sexual partners. Even though some outcomes were contrary, they were able to deal with the issue.

4. What are the methods used by PLWHIV to self-disclose? Most participants waited to break the news about their HIV status to their sexual partners when they were face-to-face. Three participants preferred disclosing their HIV status to their sexual partners over the phone. Three participants were widows when tested positive for HIV and told their relatives in person.

5. What are the responses of sexual partners to self-disclosure by PLWHIV? Some participants were supported by their sexual partner after disclosing their HIV status. Some had partners decline further sexual intercourse after disclosure of their HIV status. Some agreed to use condoms during sexual intercourse after disclosing their HIV status. A few reported that their sexual partner was shocked when hearing her HIV status. One participant's disclosure of HIV status caused her sexual partner's disappearance.

One expressed fear that women would not accept him should he disclose his HIV status.

One felt guilty after disclosing his HIV status to his sexual partner.

6. What is the emotional effect of self-disclosure on PLWHIV?

Four participants underwent pain as their specific situation led them to choose to disclose to their sexual partners. The pain involved emotions and physical wellness and guilt of infidelity with unprotected sex.

7. What is the experience of PLWHIV with respect to accessing medical care?

Most participants reported that the local clinic gave them appropriate support during their treatment, which resulted in medication compliance and improved health status. They viewed medication and treatment as removing the stigma towards PLWHIV. The primary goal for the country was to reduce the national HIV incidence rate by 2011 (UNAIDS, 2012). According to the WHO (2012), infected South African adults who received ART drugs early while their CD4 counts were above 200 cells/mm³ are expected to live near-normal life expectancy. One participant reflected on her low CD4 found when tested. She reported that her CD4 were not too low as she got treatment early enough. The medications she was on had improved her look.

Interpretation of Findings

All 12 participants were willing to express their experiences regardless of the sensitivity of the nature of the study. I conducted interviews in their native language, IsiZulu. Some of the themes that emerged from this study resonated with the findings of the literature I reviewed in Chapter 2 and some represents new findings. My interpretation will follow the categories of themes I reported in Chapter 4. These are:

circumstance of discovering HIV status, motives for disclosure, feelings before and during disclosure, method of disclosures, and response of partners regarding disclosure, the emotional effect of disclosure on PLWHIV, and their experience after accessing medical care.

Circumstance of Discovering HIV Status

Most participants were experiencing health issues or ailments and went to clinic when they discovered that they were infected. South Africans who have HIV/AIDS tend to be regarded as promiscuous (Cloete et al., 2010; Kalichman et al., 2008) which often causes infected individuals to wait longer to seek medical help. Some participants reported sickness from not feeling right to feeling suicidal. Seven of the participants considered that feeling sick was happening in their life at the time of their diagnosis. P12 reported that his sexual partner did not officially disclose her status but was on medication and decided to abandon their sexual intercourse. She stated that she was sick. Many people do not want to disclose their HIV status. Those who know often make sure to keep it secret from their sexual partner (Ssali et al., 2010). Gender inequality remains an issue that reduces the ability of women to discuss or negotiate safe sex with their sexual partner (Dunkle et al., 2004; Langeni, 2005; Moore et al., 2007). These findings confirm the research conducted by Mwini-Nyaledzigbor et al. (2013) that participants were reluctant to disclose their HIV infection status. Some studies reported that many women decided not tell their partner about their HIV status (Chandra et al., 2003; Deribe et al., 2008; Lau et al., 2005; Rice et al., 2009; Simbayi et al., 2006).

Four participants discovered that they tested positive during their prenatal visitation to their local health clinic. All participants cited that their government required every pregnant woman to test for HIV infection. One participant reported the incidence of rape and had no sign of sickness when she tested positive for HIV. In many instances, women are raped and suffer sexual violence and this results in a high risk of contracting HIV (see Dunkle et al., 2004). A study in South Africa reported 1 in 8 new infections occurred in young women due to intimate partner violence (Beagle, 2013). Women face significant risks of rejection and assault as they continue living with controlling male partners, which also puts them at a higher risk for HIV infection (Weiser et al., 2007). Participant 7 reported that she was raped and was already tested HIV positive when she met with her current live-in sexual partner. Maman et al. (2014) confirmed that disclosure to sexual partners was the motivation and a desire to encourage partners to test for HIV and learn their diagnosis.

Motives for Disclosure

The motive behind the participants' self-disclosing was to ensure that fairness and acceptance was exercised with their sexual partner. Some expressed the need for empowering each other to get strong and helping each other to prevent further infection. One participant reported that she was motivated to disclose to avoid blame that led her to disclose that she infected the man with an attempt to encourage him to disclose too (P7). Her disclosure reflected concerns to limit the risk of infecting and the blame. She also reminded her partner that medication does not go along with alcohol.

Feelings of Disclosure

Some participants expressed that they felt free, confident, relieved, and were getting support from their sexual partners when they chose to disclose their HIV status. They appreciated the value of disclosure as well as sharing experiences freely with other affected individuals. Participant 5 stated that she felt like she was free from the crime she did not commit. Participant 10 expressed his guilt as he shared about his infidelity.

There are still some cultural beliefs and behavioral practices in this community in South Africa, such as rites of marriage. A woman is expected to have sexual activities with her deceased husband's brother. Although this is an acceptable cultural practice, this may be a risk factor of spreading HIV/AIDS because of multiple sexual partners. Sexual behavior became less and less safe in Sub-Saharan African countries with an increase in the number of risky sexual partners and an increase in sexual violence, which includes refusal to use a condom (Dunkle et al., 2004). All this puts women and girls at higher risk of HIV infection (see UNAIDS, 2013).

During the Apartheid era, labor migration was the leading cause of sexual problems (Laurie et al., 2003). The Group Areas Act prevented laborers from settling with families in areas where they were working in cities, which caused Blacks to commute long distances from their homes to secure employment (Laurie et al., 2003). This separated men and women in families for extended periods of time. The situation caused partners to seek sex outside their stable relationships and put them at higher risk of infection as was the case with P10. The disclosure of HIV status to their partner helped other participants to have open communication and made them feel free to move on with

their lives. One thing cited by the participants was that disclosing relieved and reduced their stress.

Method of Disclosure

The participants perceived the severity of their disease and weighed out the specific or best way to disclose it to their sexual partner. They also chose the best, most suitable, and safe way to express their susceptibility to spreading the disease to their sexual partner. They assessed their ability on how, when, and when to disclose their status. Half of the participants waited to tell their sexual partner when they were face-to-face. In reality, speaking face-to-face gives that ability to observe the body language/posture and the facial expression of the person you are communicating with. They wanted their sexual partner to participate in the disclosure. Others decided to call their partner over the phone for different reasons such as fear of the unknown, fear of rejection, and so their partners could be with relatives for support. Some disclosed to a family member whom they were close to since their spouse or sexual partner deceased before the participant was diagnosed with HIV. The family was often their source of support, which led them to their decision to disclose in person.

Response of Partners to Disclosure

The emotional responses experienced by some participants varied. Participant 7 received support from her sexual partner; he expressed mutual support but declined condom use. Participant 12 reported that he sees another woman privately whom knew that he was infected, and they do not use the condom. Wagner et al. (2012) conducted a study interviewing 31 MSM living in Beirut as part of mixed methods research to explore

psychosocial processes that influence risk behavior and HIV testing. The researcher examined various social factors on sexuality and the HIV behavior of participants. Half reported not using condoms consistently, and one tested and some not with regular partners. Fear of infection motivated many to get tested and use condoms, but fear of disease and social stigma led others to avoid testing. Wagner et al.'s findings suggested that similar factors influence condom utilization and the HIV testing of MSM in Beirut as those observed in studies elsewhere in the world.

The support that P11 reported from his partner assured and encouraged him with medication compliance. As with other studies, disclosure presents both positive and adverse outcomes. A cross-sectional study by Yonah et al. (2014) aimed to provide information on self-disclosure of HIV status in PLWHIV to sexual partners and their experiences when they disclosed. Those who disclosed their status reported closeness to that person, emotional support after disclosure, and being discriminated against (Yonah et al., 2014). In this study, P1 reported that her sexual partner disappeared after she disclosed her HIV status. Participant 6 said her sexual partner cooperated with condom use after she disclosed her HIV status.

Emotional Effect of Disclosure on PLWHIV

Four participants underwent pain as their particular situation led them to choose to disclose (P1, P2, P9, and P10). Others cited a variety emotional status such as feeling confident and relieved to talk about their medicine and treatment freely. They expressed that their stress was reduced and gained assurance from their sexual partners. In reality, PLWHIV is afraid of risking possible adverse consequences, and they require support in

coping with stress (see Sowell et al., 2003). According to Mbomvu et al. (2009), people do not want to disclose their HIV status, and they will keep it secret even to their sexual partners. Findings in this study regarding motives for PLWHIV disclosing HIV status confirm findings by Ssali et al. (2010). These include financial, material, moral, and emotional support from their sexual partners.

Experience After Accessing Medical Care

According to Surugue (2017), a study shows that people who are on ART life expectancy have increased by ten years since introduced about two decades ago. It is my interpretation that the participant has gained more knowledge on the importance of treatment compliance. All the participants gave high recognition to the clinic staff with their support and the effort they have made related pills reduction. All participants indicated that they had confidence in the therapy they were receiving from the clinic. Some participants mentioned that medication and treatment had removed the stigma towards PLWHIV. PLWHIV in South Africa has a broad range of access to treatment (Colvin et al., 2012).

Symbolic Representations of Taking Medications (Pills)

All the participants addressed their disease by using the term ‘taking pills. Both participants and the community address taking pills as a symbolic representation of HIV infected. The community perceives and identifies them as HIV positive. Participants addressed their disease as “I am taking medicine” (referring to HIV positive). The primary goal for the country was to reduce the national HIV incidence rate by 2011 (UNAIDS, 2012). It is evident that HIV positive South African adults who received ART

drugs early with their CD4 counts above 200cells/mm³ would live near normal life expectancy (see WHO, 2012).

Limitations

There were some limitations noted in this study. It was a convenience sampling. Convenience sampling cannot be generalized, but I might have had some hidden bias due to participants' vulnerability. Another limitation was related to audio-taping that I did not use per participants' requests. I relied only on my notes that could impede my ability to get full information. It might have some limitation on the accuracy and validity of the findings. Another limitation was that I collected and analyzed the data alone might have some limited accuracy and validity of my findings. I continued with consistency to maintain my impartiality as suggested by Lincoln and Guba (1985).

I interviewed all 12 participants and I reached the saturation. The lack of an equal number of men and women limits the generalization of this study. Given the limitations, the study may provide valuable insights into the lived experiences of PLWHIV and the understanding of the self-disclosure process and its impact. Also, it is fair to include that I was the novice and the self-developed interviewing questions could affect the accuracy and validity of the data (Creswell, 2013).

Recommendations

I gathered some differing concerns from men and women participants that might need some particular and immediate attention related on how to disclose efficiently and faithfully to their sexual partners. Most male participants express their concerns that sometimes they experienced abandoned from sexual intercourse from the sexual partners

and they engaged in unsafe sex with other women without disclosing their HIV status. On the other part, women participants shared their concerns that men are noncompliant with condom use. Also, one female participant expressed the need for educating men to educate men on the dangers of drinking alcohol while on medication. More education on the importance of safe sex is needed. Special programs to inform the community about the disease that it is like all other disease and should get treated the same other medical disorders.

Recommendations for Future Research

The literature review showed that most studies conducted in big cities mostly among women. It is recommended that more research will benefit the community that will include both men and women in rural area in South Africa. There is a need to educate men too in relation to reduce HIV infection. It is highly recommended that future research to recruit or encourage more men to share their experiences self-disclosing their HIV status to their sexual partners.

Implications for Social Change

The findings of this study could bring positive social change when the results shared with the facility where the research interviews took place to educate the community. Also, the results of this study could serve as a tool for educational programs for the community at large about the nature of the disease. The findings suggest that there is a need to educate both PLWHIV and the community about the signs. Disease-related stigmatization and discrimination are often acts of ignorance about the disease, and hyperbolic fears of physical contagion (Kalichman & Simbayi, 2009). Lack of knowledge

and misconceptions about HIV increases the risk of infection. There is a need to encourage PLWHIV to identify HIV status by its name rather than referring it to taking pills. For example, Participant 10 felt that her husband betrayed her “he did not tell me he was eating pills.” P12 also commented that his sexual partner suspended sexual intercourse stated she was sick. He then presumed that tablets administration is an indication of being infected. The findings of this study can support PLWHIV to disclose without fear, provide health education to the community, and promote more awareness concerning the disease and reduction of new infection.

According to the Government of South Africa (2010), there was an increase in the annual rate of HIV infection, 29.4% in KwaZulu-Natal, 20% in Gauteng, and 13.8% in Eastern Cape, which are the country’s most severely affected provinces. According to the Desmond Tutu HIV Foundation (2011), the reasons for the disproportionately high HIV prevalence in South Africa were the lack of adequate services and several social and structural barriers including stigma and discrimination. The findings can also assist the community learn more about the importance of disclosing and the condoms use.

Conclusion

PLWHIV have differing motivations for disclosing their HIV positive status to their partners. Among the most cited were: illnesses, support, acceptance, and decrease stress. In this study, some participants reported their motivations as emotional and physical support, acceptance from their sexual partners, and decreased anxiety. Peter (2011) stated that disclosing had both positive and negative consequences. Barriers to disclosure included: Fear of rejection, abandonment, stigma, and discrimination. A study

conducted by Chirwa et al. (2009) noted that significant barriers and hindering factors in disclosing HIV status were stigma and discrimination. Providing a supportive environment for those who have already disclosed will help to continue providing the ongoing emotional support and openly discuss fears, benefits, and positive outcome of disclosure to their sexual partners. Removing these barriers can help develop a specific disclosure plan. The development of support groups for PLWIV for infected men can provide an avenue for the support that may help them through their disclosure of HIV status. Involving more men living with HIV infection in disclosing their status may help to avoid barriers associated with disclosure and may also assist in sustaining new infection. I did not find any literature confirming evidence of increase or decrease of self-disclosure of HIV status among PLWHIV to their sexual partners. Community-based programs to reduce stigma and discrimination might help individuals in overcoming barriers to improve self-efficacy. Incorporating this information into existing or new educational programs may increase safe self-disclosure of HIV status for PLWHIV to their sexual partners.

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Appendix A: Interview Script (English)

Before we start talking about your experience disclosing your HIV status, I would like to ask you some general questions about your health status. Remember now, if there is anything you do not want to discuss, we can move on to another question.

1) Could you tell me when were you diagnosed with HIV?

2) Can you tell me about your experiences with telling your sexual partner that you are HIV positive?

(Probe: How long ago? Months, year or more? How did you find out? How soon did you tell someone about anyone?)

3) Can you please tell me about a specific situation where you disclosed to someone that you were HIV positive?

4) What was going through your mind before making the disclosure?

5) Can you tell me, how did you break the news?

6) Can you tell me how the person you told reacted to the news?

7) Tell me what went through your mind after you disclosed you were HIV positive.

Appendix B: Interview Script (Translation)

Inkulumo Yocwaningo

Ngaphambi kokuba siqale ukuxoxa ngokozwelo lwakho ngenxa yokuveza isifo songulazi, ngithanda ukuthi ngikukhumbuze ukuthi unelungelo lokuba ungaqhubeki nalokho ongathandi ukuba kuxoxwe ngakho. Umbuzo olula nje: Ungase ungitshela ukuthi wathola nini ukuthi unegciwane. Kunesikhathi esingakanani wazi ukuthi unengculazi? Wazi kanjani? Kwathatha isikhathi esingakanani ukuthi kubekhona omazisayo?

- 1) Ungase ungitshela wezwa nini ukuthi unesifo ingculaza?
- 2) Wazizwa unjani ngaphambi kokuziveza ngalesisifo na?
- 3) Yini owawuyicabanga ngaphambi kokuziveza ngalesisimo?
- 4) Ungangitshela ukuthi wenzenjani ukuyihulula lemfibinga?
- 5) Ungasho ukuthi lomuntu owamtshela ngaloludaba wenzenjani?
- 6) Shono ukuthi wena wazizwa unjani ngenkathi uziveza ngaloludaba.
- 7) Ngitshela ukuthi yini owawuyicabanga emuva kokuziveza.
- 8) Yini owawunayo engqondweni uma ukhetha ukungamvezeli isimo sakho?

Appendix C: Recruitment Letter (English)

I am a graduate student with Walden University Public Health in Baltimore, MD and I am conducting an interview study of men and women living with HIV/AIDS who lives with sexual partners, married and has/or has long term stable sexual relationship.

If you fit the criteria of being a man or woman 20 years or older, have been living with HIV/AIDS and have at least disclosed to your sexual partner your HIV status, I want to hear your story. Participation in the study consists of participating in a private one-to-one taped interview lasting between 45 and 60 minutes. You will be compensated with a small token for compensation in respect of your time and effort in the form of \$25.00 to assist in transportation. All responses will be kept completely confidential.

Please call me at (082) ### - ##### for more information or to become a participant. Thank you so much. I am eager for your input.

Sincerely,

Delile Langeni

Appendix D: Recruitment Letter (Translation)

Incwadi Yesimemo

Ngingumfundi weqhuzu eliphakeme lezifundo zempilo eWalden University, eMelika.

Nghlelele imibuzo yophenyo ngabesilisa nabesifazane abaphila benesifo sengculaza, abashadile noma-nje bephila noma senihlalisene isikhathi.

Uma ukulesisimo ungowesilisa noma ungowesifazane oneminyaka e-20 noma ngaphezulu unelungelo lokuphendula. Uma wena nowakwakho beniphila nalesisifo waze wamvezela owakwakho ukuthi unalesisifo, ngithanda ukuzwa kabanzi okuthile kuwena.

Kuloluphenyo-ke uzobuzwa imibuzo ezofakwa emshinini. Isikhathi salokhu kungaba imizuzu-nje e-45 noma ihora elilodwa.

Uzokhokhelwa-ke ngesikhathi sakho isipho esingango R250-00 ukulekelela ezintweni zokuhamba. Zonke izimpendulo ziyogcinwa zifihlekile kwabanye abantu. Siza-ke ungishayeke kulenombolo **(082) ###-####** ukuze uthole imininingwane noma ufuna ukuthatha inxaxheba. Ngiyabonga kakhulu. Sengiyolindela ukuzwa ngawe kulomkhankaso.

Ozithobayo

Delile Langeni.

Appendix E: Recruitment Flyer (English)

Self-Disclosure Experiences HIV/AIDS to Sexual Partners for People Living with HIV/AIDS

STUDY ADVERTISEMENT

People Living with HIV- Men and Women Needed!!!

I am looking for men and women who are living with HIV/AIDS to participate in a 45 minutes to 1 hour taped interview concerning their experiences of living with HIV/AIDS men and women.

Confidentiality is my first priority.

I am a student in Public Health at Walden University in USA conducting graduate research on people living with HIV/AIDS and related experiences of men and women with HIV/AIDS

I want to hear your story!

Who can Participate?

Men and women 20 – 49 years old who are living with HIV/AIDS and married or long living-in sexual partner who can participate in a 45 minutes to 1 hour audio recorded private interview.

Every participant will receive a \$25 monetary for participating in the study.

Private interview location is secured or I can come to you.

For more information or to become a participant, please call Delile Langeni at 082-

###-####

Deadline to enroll is March 14, 2016.

Make your voice heard!

Research is conducted through Walden University-Baltimore Walden University IRB

Approval #

Appendix F: Recruitment Flyer (Translation)

Ifulaya Yesimemo

Indima yokuziveza ngengculaza kulabo abahlalisene noma abashadile benesifo ingculaza.

Ukukhangisa Loluphenyo

Abantu abaphila benesifo sengculaza, besilisa nabesifazani bayadingeka ukuba bazophendula kuloluphenyo. Makube yilabo abaphila nesifo sengculaza.

Loludaba alusoze luvele obala nakancane kwabanye abantu

Ngingumfundi wezempilo eNyuvesi yaseWalden, eBaltimore, Maryland eMelika. Ngenza uphenyo oluqondene nabantu besilisa nabesifazane abaphila nesifo lesi sengculaza. Ngithanda ukuzwa indaba ngokuphila kwakho.

Labo abanelungelo lokuphendula

Abesilisa nabesifazane abaneminyaka e-20 kuze kufike ku-49 abaphila nalesisifo lesi igculaza. Ungaba umuntu oshadile noma ube nomasihlalisane isikhathi eside. Ngicela nje isikhathi sakho esingamaminithi a-45 kuze kube-nje ihora elilodwa, uzophendula emshinini akekho ozokwazi ngaloludaba. Wonke umuntu ophendulayo uzonikwa umthobanhliziyo ongu R250.00 Indawo yemibuzo yindawo ekhuselekile, noma-ke mina ngizoza kwakho uma ufisa lokho.

Uma ufuna imininingwane noma uthanda ukuthatha inxaxheba siza ushaye uDelile Langeni kulenombolo (082) ###-####. Usuku lokugcina lokwamukela izicelo kuzoba 14 March, 2016.

Zwakalisa izwi lakho

Loluphenyo lwenziwa ngokuxhumana ne-Walden University eBaltimore, Maryland eMelika. Imvume yalomshikashika yi IRB # -----



Appendix I: Certificate of Completion

Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Delile Langeni** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 07/09/2015

Certification Number: 1796770
