

**Challenges in the process of HIV/AIDS disclosure:
Perspectives of HIV positive students
in a South African university.**

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This dissertation is submitted in partial fulfilment of the requirements for the degree of Master of Social Science in Counselling Psychology in the Discipline of Psychology, School of Applied Human Sciences, College of Humanities, University of KwaZulu-Natal, Pietermaritzburg.

Declaration

I, **Gellinda Pillay**, hereby declare that the information reported in this dissertation is my own work submitted to: The Discipline of Psychology, School of Applied Human Sciences, University of KwaZulu-Natal. I know that plagiarism is wrong. Plagiarism is to use another's work and pretend that it is my own.

I have used the APA 6th edition conventions for citations and referencing. Each significant contribution to and quotation in this research project from the work, or works, of other people has been acknowledged through citations and references.

This research treatise is my own work and it has not previously been submitted for assessment or completion of any postgraduate qualification to another university or for another qualification.

I have not allowed, and will not allow, anyone to copy my work with the intention of passing it off as their own work.

I take responsibility for all editorial, grammatical and structural errors which appear in this text.

A handwritten signature in black ink, appearing to read 'Gellinda Pillay', written over a horizontal line.

Gellinda Pillay

February 2020

Date

Acknowledgements

I would like to dedicate this thesis to my Lord and Saviour Jesus Christ, through whom all things are possible and from whom I receive my strength and sustenance.

“Sustain me as You promised, that I may live; let me not be ashamed of my hope.”

Psalm 119:116

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Abstract

From the moment individuals are diagnosed as human immunodeficiency virus (HIV) positive, they are overwhelmed with various emotions. People living with HIV who have recently been diagnosed will usually search for comfort as they adapt to this unsettling life change. In addition, HIV-positive students may feel alienated because they live away from their source of support. This study explored HIV-positive students' lived experiences of HIV disclosure. University students fall within the age group of South African youths who are most likely affected by HIV. Because of the social dynamics of university life, such as living away from home, it is of interest to study the disclosure patterns of these students. The objective of this study was to understand HIV-positive students' process of disclosure, focusing on both the challenges and the facilitators of disclosure. A qualitative study was conducted at the University of KwaZulu-Natal, Pietermaritzburg, South Africa. In-depth individual interviews were conducted with five participants – two men and three women – who were on antiretroviral (ARV) treatment and who were recruited through the campus health clinic. The data were analysed using thematic analysis. The findings showed that the negative consequences of disclosure were that the participants were subjected to judgemental responses after disclosing; a positive consequence of disclosure was having access to support. The participants were afraid to disclose to friends and roommates at university because they feared the judgemental attitudes and stigma. However, the participants chose to disclose to close family members, owing to the support they would receive from them. The university was also seen as having a good support system for HIV-positive students. In this regard, the participants suggested that interventions geared at social support and the dissemination of information should be employed at the university.

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Chapter One: Introduction

1.1 Background to the research problem

South Africa, as is the case with many other countries, continues to battle the scourge of the human immunodeficiency virus (HIV). The HIV infection rates continue to increase daily according to Statistics South Africa (2016). South Africa struggles with the increase in new HIV infections yearly, despite the various behaviour modification strategies put into place, according to Johnson, Dorrington and Moolla (2017). The HIV prevalence for South Africa is currently estimated at 12.6 per cent, according to Statistics South Africa (Stats SA, 2016). Furthermore, the estimated prevalence for the age band of 15 to 24 years was 5.6 per cent in 2016, which accounted for 7.03 million South Africans (Stats SA, 2016). However, Stats SA (2016) indicated that the prevalence rate among youths aged 15 to 24 years decreased steadily from 7.6 per cent in 2002 to 5.6 per cent in 2016. Dellar, Dlamini and Abdool Karim (2015) reiterate that women (15–24 years) have a higher infection rate in comparison to their male counterparts. The above is attributed to the disparate age–sex relationship resulting from females dating older men.

Despite the increase in HIV incidence, the HIV-related death rate has decreased significantly, as reported by (WHO,2017). This is attributed to the lifestyle changes of HIV positive individuals as well as their enrolment in antiretroviral (ARV) treatment programmes (WHO, 2017). Moorhouse et al. (2019) state that close to 3.4 million HIV-infected individuals are currently on the ARV treatment programme. This places South Africa in the position of having the largest ARV treatment programme in the world.

There is an increase in the rate of HIV infection among those who are in the age range of 18–24 years. The Higher Education and Training HIV/AIDS Programme (HEAIDS 2009) study conducted at a few universities, including the University of KwaZulu-Natal (UKZN), expresses concern at the unacceptably high HIV-prevalence rate that translates into 1 in every 40 students being HIV-positive. This is despite programmes at higher-education institutions (HEI) to combat HIV, according to a study conducted by HEAIDS (2009) across South Africa's HEIs. However, the study conducted by HEAIDS (2009) argued that the HIV-prevalence rate among UKZN students was marginally lower than the student prevalence nationally: the overall prevalence among staff and students at UKZN was 2.8%, whereas the prevalence nationally

was 3.4%, according to HEAIDS (2009). There appears to be no new research done at the UKZN to ascertain the current prevalence rate.

1.2 HIV disclosure

As the burden of HIV infection increases, so does the need to disclose one's status. HIV disclosure refers to openly sharing one's HIV-positive diagnosis with someone else, according to Atuyambe et al. (2014). Driskell, Salomon, Mayer, Capistrant and Safren (2008) assert that the use of ARVs has slowed down the HIV progression rate and placed the burden of disclosure on the person infected with HIV. Driskell et al. (2008) comment that, previously, those who were HIV positive disclosed only as a response to disease progression and the deterioration of their body. They further argue that as a result of ARVs slowing the progression of HIV in their bodies, people who are HIV positive have to make a conscious decision about whether or not it is beneficial for them to reveal their status. Disclosing an HIV positive status is therefore accompanied by many outcomes, some positive and others negative, according to Maman, Van Rooyen and Grooves (2014).

HIV-positive individuals may experience emotional turmoil preceding their disclosure (Ssali et al., 2010). This is because, once individuals have disclosed, they might suffer rejection, judgemental attitudes and abuse, which may create reluctance to disclose to the next person, according to Murugan (2009). However, Murugan (2009) also found that some individuals received positive support after disclosing. Atuyambe et al. (2014) state that HIV disclosure should be encouraged as it can bring about a change in people's perspectives on HIV and also afford People Living with HIV/AIDS (PLWHA) the necessary support. Murugan (2009) states that some individuals prefer to disclose to close family members such as sisters and mothers because of the support they believe they will receive. However, Murugan (2009) emphasised that most individuals hardly ever disclose to partners as they are afraid of rejection, blame being placed on them, or even abuse.

Diedricks, Myburgh and Poggenpoel (2018) comment that people living with HIV are faced with many challenges and that these challenges are especially hard for HIV-positive students to face. According to Diedricks et al. (2018), this in turn causes mental-health problems for the students living with HIV. These mental-health issues may be triggered by the lack of support HIV students feel and also a feeling of alienation (Diedricks et al., 2018). They argue that HIV-positive students find it difficult to adapt to living with HIV and this is exacerbated by the

stigmatisation they encounter. Diedricks et al. (2018) added that HIV-positive students are highly stigmatised by their sexual partners. They argue for the introduction of a comprehensive programme at institutions as being necessary to provide support for HIV-positive students.

This study focuses on the lived experiences of HIV-positive students who have subscribed to ARV treatment regimens. The objective of this study is to understand the benefits/barriers and/or challenges to disclosure that HIV-positive students face. This study also seeks to understand the facilitators of HIV disclosure among HIV-positive students. It is also important for this study to investigate the effect disclosure has on adherence to ARV treatment. A study of this kind is important because the majority of the HIV-positive population lies in the range of 15–25 years, which is the same age range as the majority of higher-education students. Also, the literature relating to the study of HIV disclosure among students is limited and this study accordingly seeks to contribute to the literature in this field.

1.3 Structure of the study

In order to understand fully the lived experiences of PLWHA, a comprehensive literature review will be presented in Chapter Two. This chapter encompasses the process of HIV disclosure, the barriers to and the facilitators of HIV disclosure, the consequences of non-disclosure as well as HIV-disclosure theories. Chapter Three presents the methodology used in the study. Chapter Four presents the findings of the study and Chapter Five discusses what the findings mean in relation to prior research on the issue. Chapter Six provides some conclusions arising from the study and discusses its strengths and limitations, and also offers recommendations for practice and further research.

Chapter Two: Literature review

2.1 Introduction

This chapter discusses the literature and theories related to HIV disclosure. It begins by presenting a background of HIV/AIDS globally and then focuses on the South African context. The chapter then considers a discussion on HIV disclosure, its relatedness to treatment adherence, and behaviour modifications such as safe-sex practices. This is followed by a discussion of the process of HIV disclosure, the facilitators of disclosure, barriers to HIV disclosure and the consequences of non-disclosure. Finally, the chapter discusses the different theories related to HIV disclosure and their relevance in current times, especially to the student population.

2.2 HIV and AIDS

The HIV/AIDS pandemic continues to spread despite various behaviour-modification interventions put to place by the South African government (Johnson, Dorrington & Moola, 2017). The pandemic has been researched extensively throughout the world with the aim of understanding it, acquiring new treatment modalities and inculcating modifications in behaviour in order to curb the HIV infection rate (Johnson et al., 2017). Although many may argue that research in the field of HIV/AIDS should by now have been exhausted, looking at the statistics of new infections daily and the effect the pandemic has on individuals, this is not the case and much more needs to be studied. Fick (2014) states that an estimated 1.3 million adolescents worldwide died in 2012. Of these deaths, HIV was said to be the second leading cause of death worldwide (Fick, 2014). Bradshaw et al. (2016) further state that in 2015–2016 the leading cause of death was HIV, followed by tuberculosis (TB) and then lower-respiratory infections. The southern African region is significantly affected by the pandemic (Halperin & Epstein, 2007), highlighting the need for research and the implementation of structured behaviour-modification interventions in this region.

It is estimated that South Africa has the most PLWHA globally (Cloete et al., 2010). This is evident in the latest Stats SA (2018) report where it is recorded that those living with HIV in South Africa were close to 7.06 million in 2017 as compared to the 4.27 million in 2002. This indicates an increase of HIV infections. However, the new infection rate (or incidence) in South Africa appears to have declined over time from 1.9 per cent in 2002 to 0.9 per cent in 2017

(Stats SA, 2018). The population most highly infected with HIV is working-class youths aged 15 to 24. This is the age group likely to be attending school and university and which would potentially in the future contribute to the country's economy were they to remain alive and sufficiently healthy to be economically active in their area of specialisation. According to Stats SA (2018), the HIV prevalence rate among youths aged 15 to 24 declined over time from 7.3 per cent in 2002 to 4.6 per cent in 2017.

HIV/AIDS and poverty have also been shown to be linked. Tladi's (2005) research on HIV/AIDS and poverty in the South African context showed that the coexistence of poverty and HIV/AIDS infection in a community has undesirable effects. Tladi's (2005) study, based on women in the age group 15 to 49, found that women coming from low-income backgrounds were at a higher risk of contracting HIV compared to those of economically stronger backgrounds. Tladi attributes this to poverty-related characteristics that affect the poorer communities and to limited knowledge of the means of avoiding HIV infection. A study conducted by HEAIDS (2009) in 2008 across the five UKZN campuses found that there were approximately 675 students living with HIV out of a sample of 1 593 students, an infection rate of 42% in this group. A study conducted by Dellar, et al. (2015) stated that young women aged 15 to 24 are uniquely susceptible to contracting HIV and that one of the leading causes could be engagement in age-disparate or transactional relationships. These relationships place young women at risk because there is an imbalance of power between the male and the female, and in most cases the women are highly dependent financially on the men (Dellar et al., 2015). It is therefore difficult for women to negotiate the use of condoms and safe sex practices for them to protect themselves against infection with HIV.

2.3 HIV/AIDS disclosure

HIV disclosure, as defined by Obermeyer, Baijal and Pegurri (2011), is a process by which an individual's status (i.e. HIV), whether positive or negative, is revealed; an infected person would voluntarily disclose their status. HIV disclosure is not a once-off decision, but a continual process. The study conducted in South Africa by Norman, Chopra and Kadiyala (2007) also mentioned that disclosure is a process and is therefore not essentially linear, chronological and /or one that has an inevitable outcome. This process may take years to complete or could be delayed until PLWHA are in the stage of the full-blown acquired immune deficiency syndrome (AIDS). However, the process of disclosure is not only one of relief: it may also cause a lot of discomfort. Maman, et al. (2014) conducted a study at two South

African sites – Soweto and Vulindlela – with the aim of exploring the disclosure narratives of PLWHA between the ages 18 and 32 years. They found that HIV disclosure should be encouraged as it leads to positive outcomes such as social support for PLWHA. However, PLWHA who disclose should also be wary of the negative impact associated with disclosure, such as stigmatisation, discrimination and violence. These are reasons why many PLWHA may delay disclosing their status.

This then leaves people with a higher burden of keeping the “secret” or of deciding whether to disclose or not. HIV disclosure has recently become a conscious decision on the part of the PLWHA owing to their having to take ARV medication. Abdool Karim et al. (2015) state that HIV disclosure informs both treatment and prevention. Moreover, Abdool Karim et al. (2015) maintain that HIV-positive individuals who have disclosed their status are more likely to have delayed disease progression and therefore the likelihood of infecting their partners is less. This highlights the need for a greater engagement with education and research about HIV disclosure.

The HIV/AIDS literature has addressed the processes of and the challenges to disclosure of one’s HIV/AIDS status. Norman et al. (2007) and Maman et al. (2014) have stated that the disclosure of HIV is an important part of behaviour modification and therefore also an important factor in maintaining adherence to treatment for PLWHA. Furthermore, Klitzman et al. (2004) and Serovich (2001) have commented that the disclosure of one’s HIV status could be an essential factor in the reduction of behaviours that continue to spread HIV, and therefore disclosure should be seen as a prerequisite for acquiring social support. Following this reasoning, if an individual discloses their status, it is believed that they will be more careful in not transmitting the disease to others. Therefore, disclosure enables behaviour modification in individuals regardless of the infection status of their sexual partners. Norman et al. (2007) have reiterated that the disclosure of an individual’s HIV status has become an essential part of behaviour modification and of access, as well as adherence, to treatment among people infected with HIV. Driskell et al. (2008) argue that the results from their study on men having sex with men (MSM) have shown that decreasing the spread of HIV is an important public-health matter. Therefore, Driskell et al. (2008) maintain that there is a need to develop effective prevention methods, through the understanding of the multiple dynamics associated with HIV disclosure. Moreover, Norman et al. (2007) argue that understanding HIV/AIDS disclosure and the environments that enable such disclosure in the individual and at the community level could foster the development of effective public policy. For example, research on HIV/AIDS

disclosure could help with developing policies related to HIV testing and counselling (HCT) and making testing more accessible to the public. Serovich (2001) argues that disclosure therefore becomes an important process in public health maintenance and policy formation. Driskell et al. (2008) states that due to highly active antiretroviral therapy (HAART), HIV is no longer a deadly disease, but it is now easily treatable.

Receiving ARVs has increased the life expectancy of individuals, which in turn influences their decision to disclose. Klitzman et al. (2004) have stated that disclosure could affect adherence to treatment and that the uptake of ARVs could also affect an individual's decision to disclose. The findings of Klitzman et al. (2004) about HIV disclosure showed that HAART interacts with and also affects disclosure. This could also be related to the theory of disease progression. As the disease progresses to a stage where an individual requires medication, he or she decides to disclose their HIV status.

2.4 The process of HIV disclosure

Individuals living with HIV, especially adolescents and young adults, are faced with having to learn about their own diagnosis and having to disclose their status to family, friends and sexual partners. A study conducted by Murugan (2009) on HIV-positive ex-offenders in KwaZulu-Natal found that disclosure was a process that occurred on a continuum. She found that people do not simply choose to disclose their HIV status, but rather that they process their diagnosis first and then disclose their status to others. Processing one's diagnosis could be called "disclosing to self" in that before one even begins to disclose to any other individual, one needs to find it in oneself to accept one's diagnosis. The end-point of disclosing one's HIV status, according to Murugan (2009), is not clear and it is sometimes non-existent, because the participants had to weigh the enabling factors against the barriers before disclosing. As discussed above, the process of disclosure has been found to be intrinsically linked to adherence to treatment: failure to disclose may affect the way in which individuals take their medication.

In Murugan's (2009) study the process of disclosure never seemed to end, because infected individuals continually had to disclose to someone at some point or other in their life. As individuals became accustomed to their diagnosis and also initiated new romantic relationships, they began to disclose more. Murugan (2009) argued that the process of HIV disclosure unfolds when the benefits of disclosing outweigh the costs, when situations are perceived as favourable

or when individuals have control over their HIV-disclosure decision-making. The benefits of disclosure include social support and economic support, all of which would increase the infected individual's adherence to treatment. The costs could be situations where individuals are rejected, neglected, stigmatised or even abused.

PLWHA undertake a number of steps during their process of HIV disclosure. A study conducted by Norman et al. (2007) on the different factors relating to HIV/AIDS disclosure outlines the possible steps in the process of disclosure; they state that "after discovering their HIV-positive status, PLWHA undergo a cost-benefit analysis" (2007, p. 1777). The PLWHA will then weigh up whether or not it is worthwhile disclosing their status. According to Norman et al. (2007, p 1777), "the second step is the sounding out of potential reactions to disclosure from family members or significant others". In this case, individuals may make up a hypothetical situation to pose to another person. For example: "If you were to find out a close friend or relative were HIV-positive, how would you react?" If the reaction is negative, they may say they were joking; but if the reaction is positive, this may be an opening for them to disclose their HIV-positive status properly. Norman et al. (2007, p. 1777) state, further, that

the third step is a full disclosure to closest friends and family. This step is executed once the individual has received a positive reaction from the sounding out step.

Therefore, by this stage the individual living with HIV is much more comfortable in disclosing their status.

The fourth step is a full but passive public disclosure. In this step the infected individual admits their HIV-positive status to those individuals who ask. Norman et al. (2007 p .1777)

Norman et al. (2007, p.1777) also mention that "the final step is the step of active disclosure. This step forms part of activism and a way in which to support others". Through this step the individual is also able to give psycho-educational talks and help with interventions geared towards combating the spread of HIV. In the last step proposed by Norman et al. (2007), PLWHA start campaigning for social change.

Although Norman et al. (2007) might outline these steps, the intricacies of disclosure, in the sense of to whom it occurs and how, warrant further discussion.

It is quite a tough choice to disclose one's HIV status, because of a number of factors. Hence HIV-infected individuals might choose to disclose first to someone they trust and with whom they have a good relationship. PLWHA are quite particular about whom they initially disclose to, and it seems that the individual they earmark should be trustworthy and someone who is significant in their life. According to Abdool Karim et al. (2015, p. 2) "there are various factors to disclosure regardless of context". These determinants, or the consequences the PLWHA anticipate, may shape the setting of disclosure.

The research findings of the study conducted by Murugan (2009) on South African ex-offenders indicated that participants were most likely to disclose to significant others such as close family members. A study by Ssali et al. (2010) conducted in Kampala, Uganda, found that a large number of the participants disclosed to family members. This may be due to the closeness of the relationship and those individuals creating an enabling environment for PLWHA to disclose. Murugan (2009) stated that other studies conducted on HIV-positive African men indicated that individuals disclosed mainly to mothers or sisters first before disclosing to other members of the family. The study by Serovich, Esbensen and Mason (2005) conducted in the United States on MSM argued that it was easier to disclose to mothers and sisters as they provided a source of support and were less likely to stigmatise or reject the infected individual.

HIV disclosure is seemingly difficult for both males and females; however, it appears to be much more difficult for males to disclose their HIV-positive status. Abdool Karim et al. (2015) found that female participants were more likely than male participants to disclose to family members. This was regardless of their ART initiation status. This may be due to the constructions related to being a "man" in most patriarchal societies. It may be seen as a weakness for a man to disclose that he is HIV-positive, especially to his family members, as he might lose his status in the family. This is supported by Cloete et al. (2010), who state that men who were diagnosed HIV positive were reluctant to get treatment because they were afraid of the stigma. The above behaviour according to Cloete et al. (2010) has been attributed to the belief that men are strong and are not easily sick, also that HIV was a female thing.

In contrast to the South African research, studies conducted in Europe have argued that individuals prefer disclosing to friends rather than families (Serovich et al., 2005). According to Serovich et al. (2005), this may be because a number of individuals from European countries relate most closely to friends rather than to their immediate family structure.

In order to understand to whom PLWHA disclose it is necessary to understand the context and nature of that disclosure. Maman et al. (2014, p.5) state that one of the participants found it difficult to disclose, and when she did, she only disclosed to her sister. It was easier for the woman to disclose to her sister because of the relationship of trust they shared, she further stated that her sister will not discriminate because of her status (Maman et al., 2014). Moreover, findings by Maman et al. (2014) suggested that a portion of the respondents felt comfortable disclosing to family members, whereas the rest disclosed to sexual partners, for varied reasons.

Some of the PLWHA may have difficulties telling their sexual partners about their HIV status. Klitzman, et al. (2004) noted that a number of PLWHA do not disclose to their sexual partners, because they are afraid of being blamed and their partners abusing them, or their partners leaving them for somebody else. Disclosure specifically to sexual partners in a study with HIV-positive adults enrolled in the Vulindlela CAPRISA AIDS Treatment (CAT) programme in KwaZulu-Natal was found to be somewhat unusual (34.1%), more importantly in woman (29.8%) (Abdool Karim et al., 2015). Moreover, female participants in Abdool Karim et al. (2015) study were found disclose more to their sexual partners in comparison to the male participants.

This may be related to the stigma attached to female contraction of HIV, as already previously noted. However, rates of disclosure overall appeared to be quite low as fewer than one-third of the participants in the study by Abdool Karim et al. (2015) initially reported that they had disclosed their HIV-positive status to someone they sexually engaged with.

Klitzman et al. (2004) also reported that many PLWHA do not report to parents and siblings because of various concerns they have about their health and family: for instance, PLWHA were afraid to disclose as the family might become worried about their health. Moreover, family dynamics might change once the infected individual discloses their positive status, and they may not obtain the necessary support. The family dynamics may also change in such a way that the family is so caring, and may treat the infected individual as such a “special case”, that they actually lose their autonomy and decision-making power.

Whereas some PLWHA decide to disclose to other adults such as family, friends, spouses or sexual partners, others may choose to disclose to their children, as was the case with participants in the study conducted by DeMatteo, Wells, Goldie and King (2002). The study was conducted in Canada on HIV-positive mothers. The study by Driskell et al. (2008) on Men

who have Sex with Men reported that MSM find it difficult to disclose to their sex partners; they also found that the type of sexual partner carried a lot of weight in the disclosure process. According to Driskell et al. (2008, p.6), participants felt that if they did not have a relationship with the person they had sexual engagement with and if were once off, there was no need to disclose their status.

2.4.1 Inadvertent disclosure for people living with HIV/AIDS

Studies conducted by Klitzman et al. (2004), Murugan (2009) and Norman et al. (2007), reported findings indicating that PLWHA did not disclose their status directly. In the study conducted by Klitzman et al. (2004), the participants reported inadvertently disclosing their status. In this study the participants reported instances where friends, family or other individuals had seen their ARV medication and the participant then had to disclose their status. In such instances the individuals felt compelled to disclose their status because not disclosing might have caused them not to adhere to their treatment.

In Murugan's (2009) study on ex-offenders, the findings suggested that PLWHA inadvertently disclosed their HIV-positive status in the setting in which they found themselves. While the ex-offenders were in prison, they would go to the clinic in the prison to receive treatment and the nurses and other offenders would get to know about their HIV-positive status in that way.

The participant in the Murugan (2009) study did not want to disclose her status on her own to her partner and preferred the nurse at the clinic to do so. This may have been because of the fear she had about disclosing to her partner. In a study by Azia, Mukumbang and Van Wyk (2016) some participants believed that standing in long queues at the clinic could inadvertently disclose your status, as people just assume that you were HIV-positive. Other PLWHA may use different means to disclose, such as writing a letter. Murugan's (2009) study also found that while the ex-offenders were still inmates they would write a letter to their family telling them that they had contracted HIV – in that sense it was a form of disclosing. This helped the PLWHA not to face the family and their negative reactions face to face and they had the peace of mind of knowing that their family knew about their illness.

2.4.2 Time from diagnosis to disclosure

Not much literature seems to exist relating to the time it takes for an infected person first to disclose after first being diagnosed with HIV. Comparative studies conducted on HIV status disclosure to sexual partners prior to Highly Active Antiretroviral Therapy (HAART) (e.g. Marks, Richardson & Maldonado, 1991) and post-HAART (Hays et al., 1993) indicated that PLWHA are most likely to disclose once they begin HAART. The reason why many PLWHA may wait until they have been initiated onto HAART before disclosing is that it would be difficult to hide their status once they are on treatment. As previously stated, it becomes much easier for PLWHA to disclose once they are on treatment.

ART-initiation appears to be a catalyst to HIV disclosure: it affects an individual's decision to disclose. This effect will most probably be positive in that it motivates an individual to disclose. This may be due to the fact that individuals perceive themselves as compromised and in a situation in which they are "forced" to disclose.

Murugan's (2009) study on ex-offenders found that the timeline for disclosure differed among participants: it ranged from one to seven years after diagnosis. This time period, according to Murugan (2009), depended on whether the individuals felt they were prepared to disclose and also on whether they found a safe and containing space to disclose where they felt they were not being judged for contracting the infection.

Norman et al. (2007) conducted a study in Umzimkulu in KwaZulu-Natal, and in Mbekweni, in the Western Cape, following a cohort study that focused on pregnant women in the national prevention of mother-to-child transmission (PMTCT) project. This study initially focused exclusively on pregnant women and then also looked into the experiences of other individuals in the community. Norman et al. (2007) found that almost all of the respondents had found much difficulty in disclosure, some took years to disclose their status.

Maman et al. (2014) conducted a multi-country study on an individual's disclosure to their family for social support. Their study was conducted in Tanzania, Thailand, Zimbabwe and in Soweto and Vulindlela in South Africa. It found that individuals may sometimes feel compelled by illness to disclose. One respondent reported that she felt the need for her and her husband to disclose their HIV-positive status to the family because she was overcome by a bout of shingles.

The time it takes for PLWHA to disclose their status either to family, friends and/or partners is also dependent on certain facilitators of disclosure. Hence, the importance of understanding the motivating factors and/or facilitators of disclosure.

2.5 Facilitators of disclosure

There are various effects of disclosing one's status, some positive and others negative. Hence an individual choosing to disclose their HIV status to the public may feel the need to first weigh the pros and cons of disclosure before disclosing. One of the main motivating factors of disclosure for PLWHA was trust. If the individual living with HIV had an individual they believed would treat their disclosure as sufficiently confidential, they were more likely to disclose their status to them. In a study conducted by Lemin, Rahman and Pangarah (2018) on Malaysian HIV-positive individuals, the participants easily disclosed to family members, friends and sexual partners with whom they had a good and trusting relationship.

In Murugan's (2009) study, social support both from significant others and from the social workers in prison acted as a motivating factor for the participants to disclose within while in prison. The support that the PLWHA received prior to disclosing makes it possible for the decision to disclose to be made much more easily.

Being on ART may also act as a facilitator of disclosure. Abdool Karim et al. (2015) found that initiation on ART increased the likelihood to disclose to sexual partners. The initiation of ART persuades PLWHA to disclose. For others, falling ill compelled them eventually to disclose. Murugan (2009) found that many of those in prison felt that they had to disclose their status because their sickness was worsening and they were in need of ARVs.

Once PLWHA have disclosed their HIV-positive status, they are able to live freely with their diagnosis. Norman et al. (2007) found that once PLWHA disclosed to family members they had no fear of keeping their diagnosis a secret.

The main facilitators, according to the reviewed literature, therefore, appear to be the ability to trust someone, having a good relationship with that individual, deteriorating health and the inability to conceal ARVs.

2.6 Barriers to HIV disclosure

There are multiple barriers that hinder the disclosure process. Studies conducted by Ssali et al (2010), Klitzman et al. (2004), Norman et al. (2007) and Driskell, et al. (2008) found that people were afraid to disclose their HIV status because of the adverse responses they expected to disclosure. These studies found that a number of participants reported instances of disclosure where they were discriminated against, stigmatised, abused, rejected and/or abandoned as a result of being HIV-positive. Cloete et al. (2010) conducted a study on 18-year and older HIV-positive South Africans in Cape Town and found that there are various barriers to disclosure, yet the fear of stigma appears to be foremost among them. In addition, Cloete et al. (2010) stated that gender also plays a pivotal role in experiences of stigma, where an AIDS-related stigma is much more intense for women because of their inferior role in society – hence the heightened fear of stigma related to disclosure. Consequently, many women, once they are diagnosed as HIV-positive, are afraid to appear as “loose” or as if they are the ones spreading the virus. Saki, Mohammad Khan Kermanshahi, Mohammadi and Mohraz (2015) supports this view, as participants in his study felt as degraded if they were HIV-positive. Hence it is for that reason that female participants in Lekalakala-Mokgele (2016) were afraid of being blamed for the HIV infection.

One of the other barriers to disclosure is PLWHA concern over others’ emotional well-being after hearing of their diagnosis. Findings of the studies conducted by Klitzman et al. (2004), Norman et al. (2007), Ssali et al. (2010) and Driskell et al. (2013) also indicated that some individuals were afraid to disclose because they did not want to cause emotional distress to their significant others. One of the barriers to disclosure found in Murugan’s (2009) study with ex-offenders was that the participants were afraid that if they disclosed they would lose their significant others. These fears may be implicit yet they still constitute a barrier to disclosure and therefore hinder the disclosure process.

PLWHA may believe that the disclosure of their HIV status may affect their loved-one’s health. In the study conducted by Maman et al. (2014) in Johannesburg and KwaZulu-Natal among HIV-positive individuals aged 18–32 years, a number of the participants maintained that they had not disclosed to some of their family members as they were motivated by the desire to protect their family’s physical and emotional well-being. This indicated that they were afraid of the way in which the knowledge of their HIV-positive status would affect their family. They mentioned that the family members were not well and the news of their diagnosis would cause

their health to deteriorate even further. Participants in this study did not disclose due to the negative consequences they feared from their partners, their partners were known to have anger problems (Maman et al., 2014). Therefore, the participants believed that the partner would not keep the confidence shared about their HIV-positive status. The above study indicates that as a result of gender imbalances and the fear of being abused after disclosing, female participants were reluctant to disclose. This is supported by Abdool Karim et al. (2015), who found that females may be reluctant to disclose their status to their partners due to patriarchal roles in their societies, whereby men are still seen as being above females. These female participants are also afraid of being stigmatised, Abdool Karim et al. (2015)

The main indicated barriers to disclosure as indicated is the fear of stigmatisation, fear of abandonment and rejection by family, friends and partner, fear of abuse from partners and the HIV status not being confidential.

2.7 Consequences of disclosure

The risk of disclosure comes with both advantages and disadvantages. There are some advantages, such as social support and financial support, which have been identified as positively affecting an individual's choice to disclose their HIV status. Norman et al. (2007), Ssali et al. (2010) and Maman et al. (2014) all proposed that there are a number of positive effects occurring as a result of disclosure: increased family and other social support, positive psychosocial outcomes, a reduction of sexual risk behaviours and the transmission of the virus, as well as the decrease in stigma associated with HIV. The above studies also found that there were positive consequences of HIV disclosure. These include: promotion of trust (including family and healthcare staff); better access to support services such as counselling services; better adherence to ARV treatment (as adherence is strongly linked to disclosure); increased family communication, and improved mental and physical health.

Abdool Karim et al. (2015) stated that by PLWHA disclosing they could receive treatment and support. The support will also assist in adherence to ARVS. The aim of ARVs is to promote longevity in PLWHA's lives by delaying disease progression. However, disclosing one's status may help to delay the progression of the disease because the person living with HIV can freely adhere to treatment. Moreover, PLWHA who disclose their HIV status have been reported as having delayed the progression of the disease compared to those who have not disclosed (Abdool Karim et al., 2015).

HIV disclosure to sexual partners helps to facilitate positive outcomes. Once PLWHA have disclosed to their sexual partners, they may be less likely to transmit HIV to their sexual partners, according to Abdool Karim et al. (2015). Furthermore, disclosure not only helps to delay disease progression but also assists both in the reduction of new infections and in preventing re-infection of PLWHA. Abdool Karim et al (2015) maintained that besides early treatment initiation, disclosing to sexual partners may have self-regulating HIV-prevention benefits: for instance, enabling the couple to make safe sex decisions. Based on their study, Maman et al. (2014) have stated that the disclosure of HIV status to family members and friends has assisted PLWHA with managing their viral load, through a greater adherence to treatment. This is possible in that once PLWHA have disclosed their status, they are at liberty to take their medication at the appointed time.

For other PLWHA, disclosure assists in ridding them of some emotional discomfort as they are then able to share their burdens with someone else. Maman et al. (2014) found that when PLWHA disclose their positive status they feel a sense of relief. Respondents reported feeling as if a weight was lifted off them after disclosing.

HIV disclosure also comes with some negative consequences, though. The barriers relating to HIV disclosure sometimes also act as a negative consequence of disclosure once PLWHA have disclosed their HIV-positive status.

For some PLWHA, it is unfortunate that the HIV disclosure to their sexual partners may lead to some form of abuse. In the study conducted by Ssali et al. (2010), a number of the participants reported that they were battered by their spouses after disclosing their status. Others may experience a much subtler form of abuse, or even rejection. Maman et al. (2014) maintained that the undesirable outcomes of disclosure to sexual partners may include blame, stigma, discrimination and violence, outcomes that are not reported widely.

The consequences of disclosure could be either negative or positive. In unfortunate cases, PLWHA are subjected to negative treatment such as abuse (physical and/or emotional), stigma, rejection and abandonment, as well as blame. However, there are some positive outcomes of disclosure: PLWHA could freely adhere to treatment, find social support and also find assistance in dealing with the emotional discomfort associated with the burden of non-disclosure. Hence, the negative impact of non-disclosure.

2.8 Consequences of non-disclosure

As a result of not disclosing their HIV status, some individuals have reported decreased adherence to treatment as they have to change the time of their daily dose of ARVs in order to avoid being noticed (Klitzman, 2004). Others have resorted to lying about what the medication was for when the time to take their daily dose arrived (Klitzman, 2004).

According to Abdool Karim et al. (2015), the alarmingly high rates of non-disclosure to sexual partners as evident in their study was a cause of concern, as this may influence behavioural change modalities of HIV-Prevention. Non-disclosure may also mean a decrease in adherence to treatment, increased treatment default and hence a weakened immune system. Moreover, non-disclosure of HIV-positive status may increase the inability to initiate condom use, which may in turn lead to an increase in the number of infections. Non-disclosure affects not only the person living with HIV, but also those around them.

Furthermore, non-disclosure may have an effect on an individual's emotional and psychological health, as it was previously mentioned that PLWHA felt relieved once they disclosed. Fick (2014) found that adolescents, especially those who had not disclosed, were at a higher risk of having mental health problems often leading to drug abuse and/ or taking their own lives.

Non-adherence to treatment (ARVs) may also be as a result of non-disclosure. Azia et al. (2016), in their study with non-adhering participants from Vredenberg regional hospital, found that the participants struggled to adhere to treatment plans as they had not disclosed their status.

A number of physical health, mental health and social issues can result from non-disclosure by PLWHA. We need to understand the reasons both for disclosure and for non-disclosure through the prevailing disclosure theories. It is also important to understand the relevance of those theories to the current infected population and also the effects in the wake of the roll-out of HAART. Accordingly, they are described in the next section of this chapter.

2.9 Disclosure theories

There are two main theories to consider in attempting to understand the issues concerning HIV/AIDS disclosure, namely, the disease progression theory and the consequence theory. Serovich (2001) examined these two theories in order to create a clear understanding of HIV

disclosure and the factors related to it. In his article, Serovich (2001) emphasises that it is important to understand what encourages individuals to disclose.

Reiterating his point, Serovich (2001) looked at the various reasons why HIV disclosure is important and why the understanding of these processes is crucial. According to Serovich (2001) disclosure helps in reduction of risky sexual behaviours. In doing so, there will be a reduction of infections reported. According to Serovich (2001), people who have disclosed their status have a much healthier state of mind as the disclosure helps with social support. In this regard, research conducted by Greenberg and Stone (1992) and Derlega, Lovejoy and Winstead (1998) found that those who disclosed their HIV-positive status to either family member, a friend and/or a partner or partners relayed lower indicators of stress and depression compared to those who had not disclosed.

This observation suggests that it will be worthwhile for the PLWHA to disclose as they will receive the support they need from close friends and family members. This support will also underpin the PLWHAs' adherence to treatment. Serovich (2001) states that the above is supported by medical studies conducted by Fennell (1994) and Hart, Einav, Weingarten and Stein (1990), who document that receiving social support from loved-ones helps the patients to adhere to treatment.

Following on the abovementioned research, Serovich (2001) conducted further research on HIV-positive men (aged 21–60 years) to ascertain the need to apply these theories in understanding disclosure. Accordingly, the HIV disclosure theories are described and discussed below.

2.9.1 Disease Progression Theory

The disease progression theory, according to Serovich, Lim and Mason (2008) and Serovich (2001), states that most individuals decide to disclose their HIV status once the HIV progresses into AIDS, because they can no longer conceal their illness. Serovich (2001) maintained that disease progression may sometimes result in hospitalisation and physical deterioration, which in most cases compels PLWHA to disclose their status. At this point, the individual's illness requires an explanation. If death is impending or individuals with HIV feel they will need additional resources, they decide to disclose (Serovich, 2001). Serovich (2001) stated that

disclosure to family members may be as a result of disease progression, yet disclosure to sexual partners may not be so motivated. A study reported by Duru et al. (2006) states that PLWHA disclose their status to a partner, especially if it is a lasting relationship, even if there is no disease progression. Duru et al. (2006) believe that this is due to the complexity of the relationship and the bond that they share.

Serovich's (2001) theorising seems to relate to the degree of visibility of the disease. His theory is based on HIV becoming visible through various forms of illness of the body (physical deterioration, hospitalisation). The situation in South Africa might be different, given the number of HIV-positive people who are taking ARVs. As previously discussed, the South African population diagnosed with HIV is close to 7 million (Ramjee et al., 2019), and of those who are HIV-positive, close to 3.4 million are on ARVs, making South Africa one of the countries with the largest ARV programme in the world (Moorhouse et al., 2019). This could account for the slow physical visibility of symptoms of HIV progression in the nation. This then raises the question of whether disclosure practices among students living with HIV relate to the visibility of the illness. This is highly unlikely, because most people living with HIV live for a very long period of time without showing physical signs of sickness, thanks to the introduction of ARVs. The quality of life of PLWHA on an ARV programme is highly improved. Cele (2019, p. 4), argues that "there has been a dramatic improvement in the quality of life of those with HIV since the introduction ART". He comments that the "South African National Department of Health (NDoH), on its ART Universal Test and Treat (UTT) fact sheet (KZN DoH, 2016a), indicates that putting HIV-positive people on ART improved the general life expectancy in South Africa in 2011 by three years for men (from 54 to 57.2) and by five years for women (from 55.5 to 62.8)" (Cele, 2019, p.4).

The above is also emphasised by Serovich (2001) who states that due to the inclusion of ART for PLWHA, there are increased health benefits and longevity of life. This accounts for the statement by Klitzman et al. (2004) that with the success of ARVs the relationship between disease progression and disclosure has become almost indistinct.

Therefore, we can no longer simply rely on the disease progression theory for an understanding of PLWHAs' reasoning for disclosure. We therefore also need to look at the consequence theory in understanding the reasons for and the outcomes of the disclosure of HIV status.

2.9.2 Consequence theory of disclosure

According to Serovich (2001), those HIV positive will measure the consequences of their disclosure, while waiting for the disease to worsen. Hence, even if individuals disclose because of the progression of their illness, they first consider the consequences, for instance, the support they will receive. Serovich (2001, p .2) argued that “as the disease progresses, stresses accumulate resulting in the need to evaluate the consequences of disclosure”. According to Leserman (2003), PLWHA are subjected to different traumatic stressors and may also be more likely to experience depression as the disease progresses. As a result, for the person living with HIV it may be in their best interests to disclose as they could receive and benefit from support. The consequence theory of HIV disclosure states that an individual first weighs the consequences of their disclosure before disclosing (Serovich et al., 2005).

Serovich et al., (2005) state that the consequences of disclosing are extensive, since individuals may open up themselves for emotional harm once they have disclosed. The anxiety and threats to well-being are mainly those related to the fear of stigmatisation and rejection. According to Serovich (2001), PLWHA may only disclose their status to significant others if it benefits them. Serovich et al. (2005) also stated that each of the consequences identified by the person may be important for the physical, emotional and social functioning of the person in question. According to Serovich, Lim and Mason (2008) participants who disclosed to significant others were more likely to get emotional support, physical support and resources to assist them. Serovich et al. (2008) state that the disclosure may also assist in PLWHA not having to keep their diagnosis a secret any more, therefore, enabling them to share the burden of the diagnosis. Having to disclose the status may be beneficial in that family members may also help them with financial resources (Serovich et al., 2008). These are some of the benefits of their disclosure to significant others.

The present study seeks to explore whether this is true of university students, as has been found with many other populations – according to Norman et al. (2007), Ostrom, Serovich, Lim and Mason (2006) and Murugan (2009), among others. Previous research conducted on disclosure has focused on MSM (Driskell et al., 2008), mothers disclosing to their children (Ostrom et al., 2006) and the general population (Norman, Chopra & Kadiyala, 2007).

According to Serovich (2001), the progression of illness related to HIV infection may trigger disclosure. However, as a result of the changes in HIV therapies, PLWHA are not

demonstrating a standard pattern of declining health; therefore, disease progression may no longer be a component of the disclosure process (Serovich, 2001).

This study also seeks to identify the challenges faced by PLWHA when it comes to disclosure. Moreover, the study aims to explore whether or not HIV disclosure affects adherence to treatment. In these ways, this study aims to contribute to the existing understanding of this problem by highlighting the issues identified by a group that is under-researched.

2.10 Summary

South African communities deal with the scourge of the HIV epidemic every day. However, this scourge appears to be much more prevalent among the youth of South Africa in the 18 to 35 years age group. Interventions such as HAART have been implemented to curb the spread of HIV and also the disease's progression. It is possible that, as a result of these interventions, people living with HIV no longer find the progression of the disease to be the main motivator of disclosure. An examination of the disclosure theories shows that the consequence theory is what is being most utilised currently. Nonetheless, people living with HIV still find themselves experiencing negative consequences as a result of their disclosure. On the other hand, individuals experience positive consequences of disclosure, such as the support of family and significant others. This may in turn further facilitate disclosure. It is unfortunate that there is limited literature on the HIV-positive student population. However, it would be best if more studies on this population were to be conducted.

2.11 Rationale of the study

2.11.1 Aims

The aim of this research was to understand the disclosure processes of HIV-positive university students currently on ARVs.

2.11.2 Objectives

The objectives of the study were:

1. To explore the participants' experience of their disclosure of their HIV/AIDS status.
2. To explore the challenges associated with disclosure.
3. To explore the processes involved in disclosure
4. To investigate the barriers and facilitators of disclosure

5. To understand whether being in the university context enables disclosure or constructs barriers to disclosure

2.11.3 Research questions

The research questions for this study were as follows:

What are participants' experiences of disclosure?

- 1.1 What are the perceived benefits of disclosure?
- 1.2 What are the perceived disadvantages of disclosure?
- 1.3 What challenges do participants find in disclosing?
- 1.4 What facilitates the participants' decision to disclose?
- 1.5 Who are participants most likely to disclose to first?
- 1.6 When and how do participants disclose?
- 1.7 What are the reactions of the person they have disclosed to after disclosure?
- 1.8 How does the university environment enable or hinder disclosure by HIV-positive students?

Chapter Three: Methodology

3.1 Introduction

This chapter outlines the methodology adopted in this study. Hence an in-depth description of the research design, sampling, recruitment, data collection and data analysis will be given to convey a better understanding of the study. Issues of credibility, dependability and transferability are also discussed.

3.2 Research design

This study implemented a qualitative research design in conducting the research. A qualitative research design allows for the exploration of peoples' lived experiences and makes an effort to interpret these experiences (Terre Blanche, Kelly & Durrheim, 2006). The study aimed to generate a rich set of data related to students' lived experience of being HIV-positive and managing their status. A qualitative research design allowed for the capturing of rich, detailed and contextualised data related to the research topic. Owing the nature of the topic, the study used an interpretive perspective. Terre Blanche et al. (2006) note that studies in the interpretive paradigm examine people's experiences with a focus on what is real for them. The researcher makes sense of these experiences by interacting with the participants and listening carefully to the participants' responses.

3.3 Sampling

The sampling technique used to recruit participants for this study was purposive. Purposive sampling depends on the availability and willingness of the participants to participate, as well as on how the characteristics of the sample represent the population (Durrheim & Painter, 2006). For instance, in this study, the sample was focused on students who are living with HIV and have already begun the ARV treatment. The study therefore carefully selected HIV-positive students who were currently on ARVs, because the study was concerned about the disclosure experiences of students. This form of sampling is non-probability sampling, which is not determined by the statistical principle of randomness (Durrheim & Painter, 2006).

The sample comprised five HIV-positive students on ARVs: two male and three female students. Focusing on a small group of participants enabled the researcher to spend more time with them and as a result obtain a rich and detailed account of their experiences. However,

there may be a limitation in not properly covering the population experiences owing to the small size of the sampled group. The sample consisted of students from different colleges on the UKZN Pietermaritzburg campus. The participants were between the ages of 19 and 25 years. The study sampled both male and female students to explore whether any gendered experiences of disclosure were evident. All of the participants in the sample were black South Africans, as no students from other racial groups responded to the recruitment process. This is likely to influence the data, and will be reflected on later in the thesis.

Of the five student participants, three lived in the student residences – one lived in an off-campus residence and two lived on campus in residences – and the other two lived in a student commune. At the time of the study, none of the participants were living at home.

3.4 Recruitment

Ethical approval to conduct the study was granted by the UKZN Humanities and Social Sciences Research Ethics Committee (Reference HSS/0873/015M, see Appendix A). For the study to be conducted on the university campus with students, approval was obtained from the Registrar of the UKZN (see Appendix B).

Recruiting HIV-positive students was a sensitive issue and raised various challenges. As HIV-positive students on campus might not have wanted to disclose their HIV status directly to a fellow student (and the researcher was a student), the UKZN Pietermaritzburg campus health clinic was approached as an intermediary recruiting site. The university's campus health clinic was a potential recruitment site because it is the site where a number of HIV-positive students collect their ARV medication.

In the recruitment process, the nurse at the clinic served as the first point of contact about the research. The researcher met the nurse and thoroughly briefed her about the nature of the study, what it entailed, and what her role would be. The nurse was given a written brief (see Appendix C), which contained details about the research study, the voluntary nature of the study, clear information about the possibility for participants to withdraw at any given time of the study, as well as the researcher's contact details, if they wished to participate in the study. The process was that when the nurse saw a student for ARV treatment, she would tell the student about the proposed research study. She would then read the brief to the student.

The student did not have to respond to the nurse about whether or not they were interested in the study: they would take the written document and respond to the researcher directly. In this way, the nurse would not know who chose to participate in the study.

However, in practice it proved difficult for the students to contact the researcher. The interested participants were reluctant to contact the researcher mainly due to time constraints and their busy schedules. Therefore, they left their contact details with the nurse, for the researcher to contact them telephonically.

There were challenges with the recruitment process because of certain logistical issues. The nursing sister administering ARVs would at times forget to inform the students of the study. There were 12 students who initially responded to the advertisement for the study. However, four of them pulled out even before the data-collection stage. This was due to student protests and also because the students knew the researcher and did not want to disclose their status to her, according to the nurse. Therefore, the number that responded to the study was less than six and most of them withdrew even before the interviews. Another difficulty may be due to the distance of the researcher from the campus, which caused the researcher to travel a long distance to the recruitment site, and only after a long period of time. This may have disheartened some of the participants.

Owing to the difficulty experienced in recruiting participants, the campus health clinic was assisted by the campus HIV/AIDS student support unit (CHASU), on the Pietermaritzburg campus, with the recruitment of students. CHASU is an on-campus organisation that deals with students' reproductive health, HIV testing and support for those living with HIV. The CHASU coordinator was given the brief for her to recruit students following the correct protocol. The participants were identified by the CHASU organisation coordinator by speaking individually to those students who had either tested at CHASU or those who had disclosed their status to the CHASU support group. She then referred the students to the campus health clinic for further information and also handed them the contact details of the researcher.

Once again the students preferred the researcher to contact them due to their busy schedules. They therefore left their contact details with the nurse at the clinic. The students preferred to leave both their email addresses and their cellphone numbers. It is interesting to find that the participants did not mind having a third party involved or knowing about their status, especially after the measures put in place that they be recruited by one intermediary person before

speaking to the researcher. An email was sent to the 12 students recruited by CHASU, explaining the research study and the process further, and they were also asked to choose a suitable time for the researcher to call them. The researcher then called each of the students, first confirming their student numbers for verification and an appointment time for the interview was set. However, not all of the students who appeared interested attended the scheduled interview –only five of the interested participants did so.

3.5 Data collection

In-depth semi-structured interviews were used to collect data. These involved conducting intensive individual interviews with a small number of people in order to explore their perspectives on a particular topic (Boyce & Neal, 2006). Legard, Keegan and Ward (2003) state that in-depth interviews, better known as unstructured interviews, are one of the main methods of data collection in qualitative research. This type of interview, according to Boyce and Neal (2006), involves an intense conversation between the participant and the researcher in a place where the participant would be most comfortable. This technique was seen as best for this study in that it assisted the researcher in attaining detailed accounts of the participants' process and experiences of disclosing their HIV status. Legard et al. (2003) also emphasise the importance of conversing with individuals in order to grasp their point of view as well as their lived experiences.

The interviews were structured in such a way that they were conversational and at the same time informative for the researcher. The in-depth interviews allowed the researcher to get a rich account of the participants' lived experiences of the process of disclosure, the challenges, and the outcomes and effects of the disclosure. Hence the use of in-depth interviews helped with exploring issues related to HIV disclosure among HIV-positive students, including the positive and negative effects of disclosure. The interview schedule (see Appendix D) was developed according to the literature gathered on the topic. The interview explored who disclosures were made to, the length of time between diagnosis and disclosure, the process of disclosure and the facilitators of and barriers to disclosure.

All the participants were isiZulu-speaking and tended to shift between isiZulu and English throughout the interview. The researcher, being multilingual and having a vast understanding of isiZulu, was able to understand both the isiZulu and English parts of the conversation.

3.5.1 Research process

A room in the Psychology building on the UKZN Pietermaritzburg campus was used for the first two interviews. The consultation room was secluded and the participants were not easily identified by other students. It was also quiet and there were no distractions. However, the venue of the interviews had to be changed after the second interview as it caused inconvenience to the students. The two participants who were interviewed in the Psychology building expressed some discomfort because of the venue. The students believed that there could be inadvertent accidental disclosure, especially to the researcher's colleagues (other Psychology Master's students), as they knew of her study.

The researcher then made arrangements with the campus health-clinic manager to use one of the clinic consultation rooms as an interview venue. The venue was convenient and easily accessible to the participants and they were therefore comfortable using it. Since the rooms in which the interview took place were private, none of the other students at the clinic knew what the participants were there for, which helped to protect the participants.

Once the participants and the researcher were settled in the room, the researcher proceeded to introduce herself to the participant. After that, she explained the study and what it sought to explore, that is, the facilitators, challenges and barriers related to HIV disclosure for the participants as students living with HIV.

The participants were handed an information sheet (see Appendix E) explaining the study, including the risks and benefits of the study. The information sheet included the aim of the study, the risks associated with participating in it (for example, although unlikely, that of a stigma being attached to them or being labelled as being HIV-positive), as well as the benefits of participating, such as the findings contributing to the body of literature on HIV and AIDS. The direct benefit to the participants were tokens of appreciation in the form of a meal voucher worth R35 to use at the campus coffee shop. Other benefits were that some participants could actually speak freely about their diagnosis without being judged. The participants were then asked to read through the information sheet carefully and to ask questions if there was anything they did not understand.

Permission was requested from participants to record the sessions, both verbally and also through an informed consent form, they were reminded that they could disagree and were also reminded of the benefit of audio-recorded interviews in that they would assist the researcher in

remembering all the information provided. If the participants agreed to being audio-recorded, they were asked to sign an audio-recording consent form (see Appendix F). The interviews were recorded on an audio-recording device. The recordings of the interview were stored in a locked filing cabinet in the supervisor's office and they were deleted once they had been transcribed. Transcriptions were saved in password protected files, with pseudonyms as labels. Hard copies of the transcriptions have been stored in a locked filing cabinet in the supervisor's office for a period of five years after the completion of the study and all records will be destroyed or shredded after that.

The participants were told that if they felt unsettled by having participated in the research process and they needed counselling services, they would be referred to the Child and Family Centre (CFC) on the campus. The researcher had made prior arrangements with the CFC to make this referral (see Appendix G). If a participant required this support, they would contact the CFC for an appointment with an intern psychologist, as indicated in the information sheet (see Appendix E). This information was also explained to them. Participants were also notified about the psychological services on the campus rendered by their different colleges.

The participants were also informed that they were not obliged to participate in the study and that they should not feel coerced to participate. They were also reminded that they could withdraw from the study at any given time if they felt uncomfortable about continuing, with no repercussions for them.

Once the students agreed to participate, they were asked to sign a consent form (see Appendix H). The participants were also informed that no identifying data of the participants such as names would be used in the research process. Instead, pseudonyms would be used to protect the participants' identity.

Five students consented to participate in the study and for their interviews to be audio-recorded. Most of the participants were concerned about confidentiality. They were concerned that their names would be mentioned in connection with their diagnosis. They were a bit nervous at first, yet they were later put at ease by being reassured that confidentiality would be maintained at all times. In particular, the participants' HIV status would not be linked to their names, as pseudonyms would be used.

The interview sessions varied from participant to participant, ranging from 45 to 90 minutes.

3.5.2 Data-processing

The audio recordings of the interviews were transcribed verbatim by the researcher. Every utterance was transcribed in as much detail as possible. This was done to assist in getting rich detail in the transcripts, therefore allowing for a detailed analysis. Since the interviews were in both isiZulu and English, they were first transcribed verbatim in both languages and then later translated into English. The data were transcribed verbatim by the researcher's carefully listening to the audio recordings. The data were translated by the researcher and then checked by two isiZulu-speaking persons. Throughout the translation process, both the audio clips and the transcribed data were used for reference. The translators were bilingual persons who were fluent in isiZulu and English. The use of backward and forward translation was used to translate the data, as per DeGroot, Dannenburg and Van Hell (1994).

3.6 Data analysis

The recordings were transcribed using the transcription notation of Jefferson (1984). These conventions assisted the researcher in making more sense of the data by also representing verbal and non-verbal cues.

After the researcher transcribed the data, she read and re-read the transcriptions many times to acquaint herself with the information. In doing so, the researcher jotted down some initial ideas while having in mind the research questions of the study which related to understanding the experiences students have in the process of disclosure.

In analysing the data, the thematic analysis process used was that of Braun and Clarke (2006). The researcher began by mapping out the codes and themes so as to make sense of the dataset. The data were then coded. Thereafter, the codes were organised into themes. The themes were then reviewed by the researcher. This was to see if the themes would work in relation to the coded extracts and the entire dataset, therefore creating a thematic map. The themes were then defined and named. As the process continued, themes were refined with an ongoing analysis of each theme.

This approach aimed at explaining and providing a deeper understanding of people's lived experiences (Braun & Clarke, 2006) in order to understand the processes of HIV/AIDS disclosure and the challenges and difficulties attributed to this process.

The researcher's interest in this study was HIV disclosure. The data were analysed with themes relating to this. The researcher therefore paid particular attention to themes relating to whether or not the participants disclosed, to whom they disclosed, the time frame between their diagnosis and the disclosure, the reason for disclosure and the effects of disclosure on adherence to treatment. Themes relating to the challenges of disclosure were also identified.

The analysis of this research was also conducted in relation to the two theories of HIV disclosure, disease progression theory and consequence theory; for example, in relation to the disease progression theory, the point at which disclosure took place was examined.

The research also looked at themes relating to positive and negative consequences of disclosure as well as the processes of disclosure. The research therefore also analysed the way in which these themes of negative and positive consequences contributed to the process of students' disclosing to significant others. Such themes were related to the Consequence theory.

3.7 Credibility, dependability transferability

3.7.1 Credibility

Validity is also known as credibility in qualitative research design. Credibility, according to Babbie and Mouton (2005), is the degree to which there is compatibility between constructed realities that exist in the minds of the participants and those attributed to them by the researcher. Credibility was strengthened by transcribing each participant's responses verbatim and capturing all their utterances. The credibility of this research was met by the research incorporating participants who are HIV-positive and are currently on ARVs. This meant that the participants were relevant to this research study. The study also looked at participants who were newly diagnosed and those who have lived with the diagnosis for some time. This then shows the different lived experiences of the participants.

This study conducted interviews in English and elaborated in isiZulu, a language that is familiar to the participants. This was done so that there was no language barrier, so that the quality of the research was not compromised. The researcher also transcribed the data verbatim from the

audio recordings. This data was translated into an English transcript, a backward and forward translation was used so as not to lose the meaning of the data.

The participants were given a voucher to use at the campus coffee shop in order to compensate them for their time during the research process. The voucher was handed to them after the interview, so that it did not interfere with the data collected or what participants said during the interviews.

3.7.2 Dependability

In qualitative research reliability is referred to as dependability. Dependability, according to Babbie and Mouton (2005), is where the study provides evidence that if it were to be repeated using similar participants in the similar contexts, the study's results would be the same or similar. The study methods were well documented, so that if another researcher were to use the same method, they may receive similar results.

3.7.3 Transferability

Generalisability is known as transferability in qualitative studies. According to Babbie and Mouton (2005), transferability is the extent to which the study's results can be applied to similar people in similar contexts. This research studied a sample of the population of HIV-positive students, which it set out to do. The transferability of this study was met by using qualitative data methods, of semi-structured in-depth interviews to get a gist of the student's story of HIV disclosure. The transcriptions of these interviews were well documented. The data found were also backed up by theory.

3.8 Ethical considerations

Wassenaar and Mamotte (2012) speak about principles of ethical research that are imperative to a research study. Those principles of ethical research are: social value, fair participant selection, confidentiality, scientific validity, informed consent and favourable risk–benefit ratio.

3.8.1 Social value

Wassenaar and Mamotte (2012) stated that any scientific research should take into consideration the social value of the study. Social value is described as the knowledge

generated to improve the health and social conditions of the society. This research aims to garner new knowledge that will assist with the improvement of the health and social conditions of the society at large. The social value of the participants was addressed in that the research questions as well as the interview questions sought to address the very difficulties HIV-positive students might be dealing with. Therefore, the data collected from the participants will potentially assist in creating spaces that are more accepting of individuals who are HIV-positive. Owing to the increased HIV rates at higher institutions, the researcher decided that research focusing on HIV disclosure would be of assistance and of social value. According to Bengu (2018), in achieving social value one should disseminate the information gathered in a language that the identified audience will find easy to understand.

The research, according to Bengu (2018), should be relevant to the community. This research study focuses on HIV-positive students and the way in which they process their diagnosis. Therefore, the research, and particularly the findings, may also benefit others who are HIV-positive.

Bengu (2018) also states that there should be accountability to sharing the research results with the public, so making this study available in the public domain will lead to its being shared with and of use to the public.

3.8.2 Scientific validity

Wassenaar and Mamotte (2012) indicated that a study should be feasible, justifiable and also rigorous in order to lead to valid answers to the research questions. The scientific validity of this study was met through the research design of the study. The semi-structured interviews used contributed to the data being scientifically valid. According to Bengu (2018), the scientific validity of a study should be based on the extensive knowledge of scientific research. In this regard, the researcher exhausted all possible avenues of literature based on HIV disclosure among HIV-positive students. Bengu (2018) states that scientific rigour should be employed at all times to reach scientific validity. This study was approached with scientific rigour.

The design of this study enables the sound interpretation of results, enables the study to be transferable to the host community (HIV-positive students), and also hopes to improve the lives of the participants by making recommendations for health and psychological services.

3.8.3 Fair selection of participants

Wassenaar and Mamotte (2012) stated that there should be a fair selection of participants for a study. The participants in this study were not recruited merely out of convenience but because their experience applies to a particular research question. In this study the participants were given the opportunity to volunteer for the study if they were HIV-positive, currently on ARVs and currently registered as students. Students who are part of this community who do not collect their ARVs and the clinic they attended might have been left out. Also, those who were too anxious and/or had just been diagnosed might have been left out. In future studies, to include those who were left out of the current study, perhaps other means or student databases could be used to advertise the study. The difficulty of recruiting students may be due to the sensitivity of the topic studied and also because this topic still has a lot of stigma and judgements attached to it. In the future, the researcher could try to engage with the student community as a whole on topics related to HIV. If possible, the researcher could use peer-to-peer discussions as a way of engaging with students. This way, those discussions would educate the student population but also put at ease those who would in future possibly be willing to participate in such studies.

3.8.4 Favourable risk–benefit ratio

According to Wassenaar and Mamotte (2012), all possible harm and benefits should be identified during the research process. The study was not aimed at harming the participants; nevertheless, measures had to be put into place to protect the participants from any kind of harm. So, for instance, the participants' identities were to be concealed, the venue in which the interviews took place was also in a secluded space, and the participants were ensured confidentiality at all times to protect them from their status being disclosed. Even though the study did not intentionally set out to elicit a traumatic experience, certain measures were put in place in the event that any participants became too emotional in the course of the research. Accordingly, provision was made for the participants to seek psychological assistance at the CFC or the counselling centres on campus should the study raise significant emotional issues for them. The participants undertook to make use of the counselling should anything arise subsequently; however, there was no feedback on whether or not the participants made use of the services. The participants were already attending the campus health clinic that provided their ARVs, medical attention and HIV counselling. Therefore, the study was not conducted independently of other services conducted at the campus health clinic. In these ways, the

benefit of the participants' participating in this study was maximised in that the study's results could initiate interventions that may be of assistance to them. The findings of this study will be disseminated to the campus health clinic in the form of a brief. Therefore, the researcher will get to sit with the management of the campus health clinic to discuss a way forward for reducing the sense of marginalisation that HIV-positive students experience. Also, the participants potentially found solace in sharing their experiences with the researcher.

3.8.5 Informed consent

All scientific research requires that the participants be treated with ongoing respect at all times, as identified by Wassenaar and Mamotte (2012). Bengu (2018) states that informed consent encompasses the following issues: disclosure, an understanding/comprehension of the study, decision-making capacity, voluntariness and compensation and incentives.

Disclosure of the study, according to Bengu (2018), should entail sharing full information with the participants about the study. This was met by the researcher's giving the participants an information letter explaining what the study was about. The researcher also emphasised the rationale of the study, how the study was going to be conducted, the risks and benefits of the study and the treatment plans, if necessary. The research made provision for the participants to have access psychological and medical assistance if need be.

According to Bengu (2008), it is imperative that the participants fully understand and comprehend the nature of the study. From the outset, this study ensured that the participants understood its nature by using a language they understood and were comfortable in. The participants were also given an opportunity to ask question and get clarity.

This research study gave consent forms to the participants who agreed to participate in the study. The consent forms were thoroughly explained to them and were then signed by the participants. Hence, the participants made a clear and sound decision to participate in the study.

The participants volunteered on their own to participate in the study; they were not influenced in any way to participate. The compensation of their time was given only after they participated in the study, therefore it could not have influenced their participation.

3.8.6 Confidentiality

Confidentiality is a vital aspect of research, according to Bengu (2018), who states that the data must be anonymised and stored. Therefore, in this research study the participants' identities were protected and kept confidential through the use of pseudonyms. Furthermore, the data will be stored in the supervisor's office until five years have lapsed, when it will then be destroyed. The participants were made aware of the measures to be taken to keep their data confidential. Pseudonyms also help in the event that the data are leaked by unauthorised persons, as they could not possibly be linked back to the participants. This is especially necessary to ensure since the topic researched is such a sensitive one.

The above chapter looked at the different methods employed to undertake this research study. The chapter also concentrated on the ethical obligations undertaken to protect the participants. The following chapter considers the findings of this research study.

Chapter Four: Findings

4.1 Introduction

This study aimed to explore HIV-positive students' experience of disclosure of their HIV status and the challenges associated with such disclosure. The study also aimed to explore the processes involved in disclosure and to investigate the different barriers to and facilitators of disclosure. This chapter presents the analysis of the data.

It is both important and beneficial to give a brief overview of each of the participants before presenting the analysis of data so as to create a greater understanding of the study and its outcomes for the reader.

4.2 Description of participants

Participant 1 was a 21-year-old heterosexual male student who was at the time not in a romantic relationship. He was studying towards a BSc Computer Science. He lived in an off-campus residence, which is a shared residence. His family did not live too far from the campus. He found out that he was HIV-positive about three years previously at a community health clinic. He attempted suicide four times after learning of his diagnosis. The participant disclosed his status only five months after he was diagnosed, after his fourth suicide attempt. The first person he disclosed to was his friend. The manner in which he disclosed to his friend was in a hypothetical way. He asked his friend how he would react if he knew that he was HIV-positive, and the friend responded by saying he would be supportive. He received support from his friend after disclosing.

Participant 2 was a homosexual male, a 20-year-old second-year Commerce student. The participant lived in a student commune off campus where 12 other students were living. He had his own room in the commune. At the time of the interview the participant had known about his diagnosis for six months and had disclosed this status to his sister three days after he found out that he was HIV-positive. His sister was supportive. He had also disclosed to his then sexual partner, who had rejected him.

At the time of the interview **participant 3** was a 22-year-old heterosexual female, in her second year of studying towards a BCom degree. She was from Durban, but lived in a student

commune off campus. This participant had not disclosed her HIV status to anyone. She, however, shared with the researcher that both her sister and her father were HIV-positive and her grandmother worked as a community caregiver with HIV-positive individuals. This, however, did not influence her in any way to disclose her status. This particular participant had known about her HIV status for five months prior to the interview, when she tested positive at the campus health clinic. Her events unfolded differently from the other participants. She had already suspected that she was HIV-positive three years prior to her testing HIV-positive, although she was reluctant to test. She became suspicious when her then boyfriend fell ill and was rumoured to be HIV-positive. Her suspicion grew, however, when she started experiencing physical symptoms herself, such as shingles and swollen glands, and it was then that she decided to test.

At the time of the interview **participant 4** was a 22-year-old heterosexual female studying her third year in Chemistry and Chemical Technology. At the time she had two children. The participant discovered that she was HIV-positive when she was pregnant with her second child. She had known her status for about a year at the time of the interview. The participant reported having disclosed to a friend and her sister a day after she found out she was HIV-positive. What made it easier was that her sister was also HIV-positive. She, however, found it difficult to disclose to her sister that she was pregnant as she felt that her sister may have disappointed by her falling pregnant a second time.

Participant 5 was a 24-year-old heterosexual female studying for her Postgraduate Certificate in Education; at the time of the interview the participant had a four-year-old son. She was diagnosed as HIV-positive when she found out she was pregnant with her son. She found it easy to disclose, and her mother was the first person to whom she disclosed straight after she was diagnosed. She believed that she was infected years previously while caring for her niece, whom she suspects was HIV-positive.

Through the process of analysis, a number of themes were identified in the data. The themes identified were closely related to the research questions, prior research on the topic of disclosure, as well as to the theories related to HIV disclosure highlighted in the literature review. However, themes that were totally unrelated were also identified. Four main themes were identified from the data set: blame, challenges or barriers related to HIV disclosure, facilitators of HIV disclosure, and disclosure and adherence.

In this presentation of the results, the researcher will illustrate the themes with extracts from the transcripts. In these extracts “P” refers to the participant and “T” refers to the interviewer. The line numbering in the extracts refers to the lines of the interview transcription. The (.) refers to the pauses in the transcription. The transcription conventions can be found in Appendix J.

The following sections elaborate on the themes from this research study: blame; being the victim; the need for blame. Some participants find it difficult to accept their HIV positive status, hence they begin to either blame themselves or other parties for their HIV diagnosis.

4.3 Blame

Once an individual is diagnosed with HIV, there are multiple processes that they undergo, disclosure being one of them. Yet before the individual even discloses their status to the next person, they need to have fully processed their diagnosis on their own first. The way in which they process their own diagnosis may affect their process of disclosure. The theme of blame was evident in the participants’ accounts. This theme appeared to have two aspects to it, depending on how the participants perceived their HIV diagnosis. For those participants who believed that their infection was due to their caring for someone else and that they were a victim, it was much easier to accept their diagnosis and therefore they also found it easier to disclose their status. These participants also expected some sort of pity from those they disclosed to as it was not their “fault”. However, those participants who were unsure about how they contracted HIV found it much more difficult to disclose their status.

4.3.1 Being the victim

P5, a 24-year-old female student, found out that she was HIV-positive when she fell pregnant. She concluded that she had been infected by her niece years ago as her current partner was HIV-negative and she did not have a previous sexual relationship. She had apparently had to take care of her niece when she was younger and this is how she may have contracted HIV. She believes that her brother and his wife (her niece’s parents) died of an HIV-related disease. She also appeared to be aware that her HIV status may be linked to moral judgements. When

the researcher asked the participant how she thinks people would have responded had she been infected in a different way, this is how she responded:

Extract 1

190 P5: infected like, by sleeping around like some choice or something, I would have hated myself

In extract, 2, P5 (24 years, female) elaborates on how the contracting of the HIV virus was not her fault. Therefore, she deserves sympathy. She also feels that if she had been infected in a different way, she would have experienced hatred or contempt towards her boyfriend or herself and would have found it difficult to accept her status (lines 189–191). The blame of the infection appears to be placed on everyone else but herself (lines 192–195)

Extract 2

187 I: Do you think if you had been infected *hlamphe* (maybe) in a different way do you think people would react the same or would you be as accepted in the same way?

189 P5: (.) erh I don't think so. I don't think I would have accepted; I would have like hated myself. Cause I got infected like,

190 P5: by sleeping around like some choice or something, I would have hated myself. If I would uhm uhm

191 P5: infected by like a boyfriend or something I would be hating him but now I don't have anybody to hate.

192 P5: Cause it wasn't it was my niece she (.) she died when she was three years old I think, so it wasn't her fault that she

193 P5: infected me, she didn't know. Okay, it could have been my mom and my aunt's fault for not telling us for us not

194 P5: to (.) but then sometimes I do blame them but then I don't know why they did it so I'm not gonna judge them.

195 P5: I don't know why they didn't tell us. Even though they knew we were the ones that were taking care of the kid.

Again, the researcher wanted to find out how the participant thought other people would react when she disclosed, had she contracted HIV in a different form than what she explained. In extract 3 she continues to show that her mode of infection warrants the sympathy she receives (lines 200–201). In line 203 she emphasises that she is a victim. She also believes that people have no reason to judge or blame her for her HIV status (line 199).

Extract 3

199 P5: I think so, jah I think so, cause (.2) people have this thing that you wanted it that you got it, why were you

200 P5: doing that, jah but then since I didn't do anything I got it from my (.) my nephew niece (.) I think people sort of

201 P5: feel for me. Because I was trying to help somebody else (.2) and unlike nje (just)

202 I: So you became the victim?

203 P5: Jah

This suggests that when an individual is diagnosed with HIV and they feel as if they are victim, the diagnosis is easier to accept.

4.3.2 The need for blame

For participants who were in a relationship and were uncertain as to who infected them or how they were infected, it was much more difficult to accept their diagnosis. This also made the process of disclosure quite difficult and uneasy for them. The difficulty in accepting their status arose from their being uncertain about whom to blame – themselves, previous partners or current partners – for their diagnosis. Again, the issue of the process of accepting one's diagnosis is intertwined with their process of disclosure.

P4, a 22-year-old female student (extract 4), expressed that she was confused about whom to blame between the father of the first child and the father of the child she was pregnant with. The participant struggled with her diagnosis, because she struggled to locate how she was infected. She went back and forth in her mind, trying to figure out if her current or ex-boyfriend was to blame for the infection (lines 146–149).

Extract 4

146 P4: Because sometimes you end up hating the person, because you feel it is their fault.

147 P4: Because with me it had a huge effect, because I didn't know if it was the father of my

148 P4: first child or the current one. It was difficult for me because I didn't know exactly who to blame.

149 P4: I had to blame on either side.

Even though P2, a 20-year-old homosexual male (extract 5), had an idea that it might have been his previous partner who might have infected him, he still wanted to blame someone. More importantly, though, for this participant, he believed that he was to blame, by asking himself "where did I go wrong?".

Extract 5

75 P2: And jah it has been a tough process an erh at times you just ask yourself where did I go

76 P2: wrong? You understand? Because as much as I wasn't in denial I still needed the answers.

It appears from the above extracts (extracts 4 and 5) that the participants found it important to understand how they contracted HIV in order to fully come to terms with their diagnosis and therefore to have the ability to disclose their status to other people.

Only these two participants, P2 (20-year-old homosexual male) and P4 (22-year-old female), use their diagnosis as a means of educating or advocacy. In extract 6, P2 discloses his status to his friend, and warns her of the risk of risky behaviour (lines 164–166: extract 6). P4 also discloses to a friend, advising her that she should not find herself in the same situation (lines 143–144). However, both P2 (extract 6) and P4 (extract 7) remove themselves from the part they played in contracting HIV. P2 is found saying "this is the situation I am in" (line 166: extract 6). P4 also reflects on her diagnosis and also her disclosure by saying "She shouldn't be in the same situation I am in" (line 144: extract 7).

Extract 6

164 P2: It was different, I erh [...] my friend, my other friend. Erh it was based on (.)

165 P2: relationships. Do you understand? Jah. I was like hey protect yourself; protect

166 P2: yourself and erh I just told her like mngani (friend) this is the situation that I am in erh

P4 (a 22-year-old female, extract 7) expressed that she did not want her friend to repeat the same mistakes as her own:

Extract 7

143 P4: Cause I wanted to be the first one to tell my friend, that she shouldn't find

144 P4: herself in the same shoes as myself. She shouldn't be in the same situation.

The participants undergo various processes of disclosure. Each participant experienced the disclosure differently due to their experiences of the diagnosis. For some participants it was difficult to accept their disclosure because they did not know whom to blame, whereas, on the other hand, another participant found it easier to disclose because she felt she was a victim. Some participants believed that their diagnosis could be used in an advocacy role. The above may also affect whether or not participants find it easy to disclose.

4.4 Challenges or barriers related to HIV disclosure

The participants reported having experienced a number of challenges related to HIV disclosure. This was especially since they were members of a student population. Some of the challenges identified by the students were implicit whereas others were explicit. It appeared as if the challenges faced by the participants may hinder their disclosing further. These barriers to disclosure include rejection and judgement. The judgement was also strongly related to the participants' fear of being stigmatised or labelled.

4.4.1 Judgement

The fear of judgement was also a challenge, as mentioned by two participants. The participants reported that they would rather not disclose to certain people as they already perceived them as being judgemental. P3, a 22-year-old female, had not disclosed her status to anyone. When asked by the interviewer how her "friends" would react if she disclosed her status to them, she responded in extract 8 that they would be judgemental (line 189: "I know they are

judgemental”). She elaborated further that her housemates would gossip about her (line 191), even though she does not specifically say what it is they would be saying about her:

Extract 8

188 P3: Like the people I live with now? That I call friends? I guess I will make sure that

189 P3: they don’t find out at all. Since I live with them I know they are judgemental; we are
all

190 P3: judgemental when together. So I know the type of people they are so I will make sure
they

191 P3: never find out. They will gossip about me.

One other participant, P5, a 24-year-old female, at different points in the interview spoke about being judged. In extract 8 she elaborates how she feels about being judged. In the first instance, after being asked if she had disclosed to anyone else, she mentioned that she had disclosed to certain friends only, those whom she was certain would not judge her after she had disclosed (lines 141–144). She maintained further that she hated being judged after the interviewer asked if she was afraid of being judged. The same participant stated that what angered her most and what she disliked were the judgemental reactions of some people when they learned of your status (line 177):

Extract 9

140 I: Have you disclosed to anyone else besides your family members?

141 P5: Uhm my friends, I’ve told my friends, few of my friends but I choose which

142 P5: friends should know, cause there are some chatterboxes who I wouldn’t want
to
know.

143 P5: But I’ve got friends who know. (.) Cause I have a lot of friends so I, (.) they not, I

144 P5: wouldn’t say I disclosed to my best friends but I disclosed to people that I
know that she would be okay, she wouldn’t judge me when I share this, jah.

145 I: So are you afraid to be judged?

146 P5: I hate being judged.

174 I: Are you afraid of people's reactions towards you or, as you said, the judgement?

175–178 P5: It's basically the judgement. I don't care how people react or I don't care,

176 P5: but it's their judgements and people sometimes make assumptions from far. They like

177 P6: this chick that slept around. So it's not like they talking to you, like what happened?

178 P5: What's going on? No they be like(.) show other people with whatever, jah. I just hate being judged.

It is evident in the above extract that P5 felt uncomfortable disclosing her status, as she was afraid of being gossiped about. It is also evident that she was afraid of being labelled as promiscuous, a "chick that slept around". Even though the participant mentioned that she did not care what people say, it was contradictory to her fear of being gossiped about. This may have also been the case for P3 (22-year-old female), because she mentioned earlier in the interview that her family would be disappointed that she had contracted HIV as she may have been promiscuous. The above reactions may also be the same judgemental reactions. P3 (extracts 9 and 10) was afraid she may receive judgemental reactions from her housemates.

P3 spoke of her fear of the judgement she might receive from people if she were to disclose her status (extract 10). P1 (21-year-old heterosexual male) was also afraid that people would judge him based on what they thought about how he contracted HIV (extract 9: lines 125–126). The participants were afraid that disclosing their status would expose them to being judged as being promiscuous and being sexually active:

Extract 9

125 P1: I'm scared of the way people are gonna start looking at me because basically

126 P1: people always think that you are HIV-positive because you have been having sex
and stuff and (...) for my case no.

Extract 10

171 P3: It's that there is this thing that if you are HIV-positive you had multiple

172 P3: partners. So I don't know if it's that. Many people will link us with being loose.

It is evident from the above that disclosure involves being cautious about to whom they disclosed as this may have various consequences. The participants feared two main consequences of their HIV status being revealed. One of these was that people would make assumptions about the type of person they were and make judgements about their behaviour, for example, that they must be a promiscuous person. The second fear was that people to whom they had not disclosed would discuss them and their status freely. This fear of being the subject of gossip was illustrated in the accounts of two participants.

4.4.2 Rejection

Another of the challenges experienced by the participants was that of rejection. Although this was not found to be common across all of the participants, for two of them it stood out as a highlighted factor. One of the participants, P4 (22-year-old female, extract 11), reported that she was rejected by her partner once she disclosed that she was pregnant and later that she was HIV-positive. This left her feeling deserted and alone.

Extract 11

262 P4: I told him I was pregnant and also found a way to tell him about my status.

263 P4: After that he reacted badly. After that I think the status had a huge effect on our relationship, because after that we broke up.

P2 (20-year-old homosexual male) also reported in extract 12 that he was rejected by his partner after disclosing that he was HIV-positive:

Extract 12

186 P2: Jah went on it went on until eventually I found out that I was (.) HIV-positive.

187 P2: So uhmmmm [...] in such a state he started withdrawing himself, you know, after I found out I was HIV-positive.

P4 trusted his sexual partner and may also have believed that the burden of being diagnosed HIV-positive was for both of them to share, but his partner withdrew instead of supporting him.

The above-mentioned challenges of HIV disclosure, rejection, judgement and fear of stigmatisation may have an effect on the way in which participants disclosed as well as to whom they chose to disclose.

4.5 Facilitators of HIV disclosure

This theme was related to one of the study's research questions about what facilitates or motivates the participant's decision to disclose. Despite the barriers to disclosure, there was a range of factors which facilitated the process of disclosure. These were support, trust and awareness.

4.5.1 Support

One of the main motivating factors of disclosure was the need for support. This support included physical affection, advice and encouragement from friends, family, organisations on campus such as CHASU and the campus health clinic. When the participants were asked why they chose to disclose, they commented on the types of support that they had received. Support was also helpful in managing the reaction to their initial disclosure.

Extract 13

127 P2: Because at the end of the day you know that you are not alone throughout this process and you have someone.

P2's sister was the first person he disclosed to and he received support from her. He spoke of receiving hope once he disclosed to her in extract 14: "She gave me hope."

Extract 14

137 P2: You know and (...) erh (hhh) jah she was the first person to know about my apparent you know (...) status and so forth. But nonetheless she gave me hope.

P2 (20-year-old homosexual male) told that the isolation he felt due to being HIV-positive was broken when he disclosed to his sister (extract 14). He said: "You are not alone" (extract 13).

P1 (21-year-old heterosexual male, extract 15) reiterated what P2 said above. P1 also believed that disclosing his HIV status allowed him to break the isolation caused by his being HIV-positive:

Extract 15

111 P1: uhmm nothing was different just that erh I knew I was not alone.

This support was also evident when participants were asked what the reaction of the first person they disclosed to was. They also received support from those whom they chose to disclose to, family and friends, in the form of physical touch and comforting words, as is evident below. In extract 16, P4 (22-year-old female) discusses what happened when she disclosed to her sister. Her sister comforted her and showed affection. This affection was reassuring that her sister empathised with her situation (line 177):

Extract 16

177 P4: She hugged me and told me she loved me. She showed empathy towards my situation.

P5 (24-year-old female) also received support from her friends after she disclosed (extract 17):

Extract 17

180 P5: Okay erh two of them cried, but they felt for me because I told them how I got infected.

P4 (22-year-old female), although confident that her family would finally accept her status, was still afraid that her status might cause heartbreak for her mother and that her mother might be disappointed in her (extract 18). She believed that her mother would support her as she supported her sister who was also HIV-positive:

Extract 18

230 P4: My mom would be heartbroken but she would support me as she supported my sister.

4.5.2 Trust

The participants also believed that trust played a major role in their disclosure process. Before disclosing their status, they would first have to negotiate whether they could trust who they were disclosing to with their status. One participant mentioned that they disclosed because they trusted the person they disclosed to.

P4 (22-year-old female, extract 19), made trust critical to disclosure, but she did not elaborate on this issue of trust. She talked about her sister being the person she could rely on in most cases when she was in trouble:

Extract 19

173 P4: Oh my sister is the one that I trust, if I find myself in trouble she is the first to know.

P1 (21-year-old male, extract 20) at first refused to disclose his status to his grandmother because he believed he could not trust her with his status. He was, however, able to disclose to his friend because he trusted his friend not to go and tell another person, as he stated that his friend is not that kind of a person.

Extract 20

117 P1: (...) uhhhh (.2) the thing is I do not trust anyone, yes, I know “ukuthi” (that)

118 P1: erhh (...) mmm a person has two people that they trust. Like my grandmother

119 P1: trust me and someone else so if I tell her (...) she is going to tell that other

120 P1: person and that other person has two people that they trust and then that

121 P1: person is gonna tell the other one and so on and so on. So I’m just [...] I know that er my friend is not that kind of a person no. He’s blessed in that so.

There are various facilitators to disclosure, as mentioned above. These facilitators – support and trust – play a major role in HIV disclosure and are beneficial to it.

4.5.3 Healthy living

Some participants disclosed their status so that they could live a healthier life, both physically and emotionally or psychologically, without keeping secrets.

P5 (24-year-old female, extract 21) felt that, although it was difficult at first to disclose to other people, she felt relieved afterwards:

Extract 21

124 P5: So telling her was (...) the best thing I could ever do to myself (...)

Even though P5 (extract 22) did not fully clarify what this meant, she spoke of how, after disclosing, her mother encouraged her to take her medication. P5 later also reiterated that her disclosing assisted her in living a healthier life and also living freely without keeping secrets.

Extract 22

134 P5: (...) I thought it was the best thing to do, in order for me to live a healthier

135 P5: life. So that I get it out there, so that they understand and then I don't have to

136 P5: live in like a corner and have to hide things from them and everything. So that's

137 P5: what pushed me to disclose in the first place.

The disclosure patterns that PLWHA employ and whether or not they disclose their status affect their adherence to treatment, as is confirmed in the next section.

4.6 Disclosure and adherence

It appeared as if the participants' adherence to treatment was determined by whether or not they had disclosed their status. At present, the government has piloted a test and initiate campaign to ensure quality of life. That ideally means that patients who test positive need to be initiated onto treatment. However, the participants in this study were initiated onto treatment for different reasons. The two participants who tested positive while pregnant were initiated

onto the treatment to protect the unborn baby from contracting the HI-virus, and the other three participants were initiated due to their having a low CD4 count.

Patients are put onto treatment after attaining the above-mentioned criteria. This treatment is taken once daily, preferably at night, for the rest of the individual's life. The treatment, which is a fixed-dose combination (FDC) of ARVs, helps the patient's immune system to fight the HI-virus, therefore suppressing the virus.

All five of the participants were on the FDC. ARV treatment requires diligence from the patient's side. Together with this diligence, patients are encouraged to practise healthy living such as safe-sex practices, exercise, a healthy diet and a decrease in their stress level, in order to curb the replication of HIV in the body and the spread of HIV.

Owing to the stigma attached to HIV and treatment being the proof of one's HIV status, PLWHA find it difficult to adhere to treatment plans. PLWHA may find it especially difficult to adhere to treatment if they are around people who are unaware of their status.

4.6.1 Non-adherence due to non-disclosure

The analysis of the data illustrated that there is a correlation between adherence and disclosure. All the participants agreed to having adhered to their treatment plan. However, in situations where they had not disclosed their status, they had constantly to change the time when they took their medication so as not to divulge their status. Hence, those who had disclosed were more adherent to treatment. However, there were cases where participants adhered to treatment even though they had not disclosed.

One of the participants (P2, extract 23) said that he was able to adhere to treatment when at home even though he had not disclosed to his parents:

Extract 23

287 P2: When I go home I take my medication jah, I take my medication normal jah.

One participant, P3 (22-year-old female), who had not disclosed to certain people, for example friends or family members, found it difficult to keep to her medication time (extract 24). This participant mentioned that when she was at home, living with family members, she usually

took her medication a few hours before the usual time. This was due to her not having disclosed her status to her family.

Extract 24

393 P3: If I don't drink them at half past seven, I drink them early, maybe if I see that

394 P3: everyone is watching TV, then maybe I drink them at six or at eight because my

395 P3: grandmother sleeps early. But it does not happen that I don't drink them. It doesn't.

For this participant, not having disclosed her status to her family affected her adherence to her treatment regime. She adjusted this to conceal her treatment.

Another participant, P4 (22-year-old female), said at times it was difficult to keep to the allocated time, especially if she was with her friends, studying at the library or at the student computer labs. This participant had not disclosed to some of her friends. The context of the library or the computer lab also played a part in her non-adherence, as she would have not disclosed to students there (extract 25).

Extract 25

192 P4: Yes it happens that I don't drink it at 10 exactly and maybe drink it at half past.

As seen in the above extracts, the lack of disclosure meant that the participants had to take their treatment in secret. This created constraints and might have affected adequate adherence to treatment regimens.

4.6.2 Concealment in order to adhere

Some participants had to take extra measures or precautions in order to adhere correctly to their treatment without having to disclose their HIV status unwillingly. As a result, some of the participants said that they had to hide their ARVs in their multivitamins. Participants had to conceal taking their treatment in various forms. At times, concealing their medication could also lead to non-adherence to treatment.

P1 (21-year-old male, extract 26) had not disclosed his status to his roommate so he had to conceal or hide taking his treatment so that the roommate did not notice.

Extract 26

161 P1: (laughs) erh mmhm (.2) uhh this is quite erhh stupid but I did it anyways.

162 P1: Sister (nurse) gave me some vitamins and stuff. So that container for vitamins was quite

163 P1: huge so each time when I go to the clinic when she gives me my medication I just take

164 P1: the medication and put them into the vitamin containers and just put them there. The guy just sees those vitamin thingies.

Participant 3 (22-year-old female) had not disclosed to anyone. When the participant was at home, she hid her treatment in her cosmetic bag so as not to disclose (line 386: extract 27):

Extract 27

370 I: How do you take them at home?

371 P3: At home I hide them. I don't know if I should say I hide them, yes I hide them.

385 I: How do you hide them?

386 P3: I hide them in my cosmetics.

If disclosure did not happen, the participants were non-adherent to treatment or found they had to conceal taking their medication. This was evident in the above extracts. However, one of the participants was unaffected by this non-disclosure and continued to adhere to his treatment regime as normal, even at home.

4.7 Summary

This chapter began by outlining the background of each of the participants before exploring the research data. This was to give the reader a clearer understanding of the data presented. The chapter then outlined the various themes as indicated by the data set as well as supporting sub-themes. The chapter also provided evidence in the form of extracts from the data set to substantiate these themes. Four main themes – blame, challenges or barriers to HIV disclosure, facilitators of HIV disclosure and disclosure and adherence – were identified from the data set.

Presented in the findings section was how the element of blame interplayed with participants' having closure with their diagnosis. The participants who thought they knew what or who to blame for their infection accepted their diagnoses much more easily compared to the participants who still wondered about the source of their infection.

The findings section noted the various challenges of and barriers to disclosure, as mentioned by the participants. It is important to note that the barriers to disclosure as mentioned by participants were judgemental attitudes from other individuals, rejection by those to whom they disclosed, both real and perceived, and the fear of being stigmatised and labelled. These barriers to HIV disclosure have hindered the process of disclosure in the student environment in such a way that students do not always receive the relevant and much-needed support.

The results section also indicated support to be one of the leading facilitators of disclosure, whether the support was shown in the use of supportive words or as a physical gesture.

The participants adhered to treatment as best as they could. However, they sometimes missed their treatment times due to non-disclosure. The participants also commented that they used unconventional methods in order to adhere to treatment times. It was evident in this section that adherence to treatment was related to disclosure of HIV status.

The participants seemed to have had different experiences when it came to the time of diagnosis as well as the process of disclosure of their status. They, however, concurred that the process of disclosure was never an easy one. They appeared to disclose first to a family member rather than a friend or a sexual partner. This may be due to the bond of trust formed between close family members, as trust is one of the elements which facilitate disclosure.

In Chapter 5 these research findings are discussed further, incorporating the findings with theories related to HIV disclosure.

Chapter Five: Discussion

5.1 Introduction

This research study aimed to understand the lived experiences of HIV-positive students living on ARVs on the UKZN Pietermaritzburg campus. In doing so, the study looked at the process of disclosure which each of the participants faced. It also unpacked the different mechanisms individuals used to disclose or to conceal their disclosure. The participants also shared their experiences of disclosure, which were both positive and negative. The study explored the various facilitators and barriers or challenges to disclosure. It also looked at the context of the university and whether or not the environment enabled disclosure.

This chapter discuss the findings of this study outlined in the previous chapter. It is divided into four parts, which represent the themes of this research study. The structure of this chapter draws on the continuum of disclosure which begins with the participants testing experience and then the disclosure process. The disclosure process includes the reactions the participants received from others after disclosing and the measures the participants took to conceal their disclosure.

The respondents were five HIV-positive students at the university, ranging from ages 18 to 30 years. The participants consisted of three females and two males. The participants all lived away from home, either in an on-campus residence or in an off-campus residence. All but one of the respondents had disclosed their HIV status to either a family member or a friend.

5.2 Blame

The continuum of the process of HIV disclosure begins with individuals processing their own diagnosis. The issue of blame is one of the first emotions that individuals experience after being diagnosed with HIV. The way in which they perceive their HIV diagnosis sets the stage for them either to disclose their status or not. Most often, as found in this research study, participants would confront their sexual partners. In this way they would start the disclosure process.

One of the elements influencing personal disclosure practices mentioned by the participants in Edwards' (2009) study was making sense of being infected. This process begins immediately

after an individual has tested HIV-positive. The issue of blame is central to the processing of this positive HIV diagnosis as well as to the process of HIV disclosure. In understanding and processing their HIV-positive diagnosis, HIV-positive individuals may entertain various scenarios about how they contracted the disease. Some may place the blame on other people, external forces or even themselves. According to Mwamwende (2013), people are usually restless until they find an external source for their illness. Two participants in this study reflected on how confused they were while going through the motions of thinking how they had been infected. Mwamwende (2013) also commented that individuals rarely internalise the source of the problem. However, in this study, the participants blamed either themselves or other people or events. The way in which a person processes their HIV-positive diagnosis may affect their disclosure process.

This study found that the interplay between the way in which the participants understood the cause of their infection and the disclosure process was crucial. Two of the participants in this study believed that they were not to blame for their HIV infection and managed to disclose much more easily.

However, for those participants who struggled to attach blame to anyone for being responsible for the infection, or who blamed themselves for contracting HIV, it was much more difficult to disclose their status. One of the participants even chose not to disclose her status as she also did not clearly understand how she had contracted HIV. This may be because of the stigma the individuals themselves attach to contracting HIV or being HIV-positive.

Most of the participants found it difficult to find someone to blame for their infection at first as they were in a state of confusion. However, they found themselves blaming their recent or current sexual partners in order to make sense of their diagnosis. Lekalakala-Mokgele's (2016) study on gender perceptions of risk of HIV infection found that male partners blame their female partners for the infection of HIV.

Blame may also be associated with moral judgements attached to individuals who are diagnosed as HIV-positive, especially women. These moral judgements stem from the stigma society has about HIV as well as the misconceptions in society about contracting HIV. In the study by Saki et al. (2015) the findings showed that HIV-positive participants were wrongly judged as a result of social stigma. The participants in this study refrained from disclosing their status to certain people out of fear of being blamed for contracting HIV. This would appear to

be quite strange in a university environment, where students are expected to have some knowledge about HIV and also to maintain some level of empathy and non-judgemental attitudes.

Saki et al. (2015) maintained that their participants were degraded by society and were said to be immoral because they were HIV-positive. Women who are HIV-positive are viewed as promiscuous by some societies, thus making it difficult for them to disclose, especially in a male-dominated society (Lekalakala-Mokgele, 2016). This was also evident in this study, although it took place in university setting. The study by Cloete et al. (2010) also found that women were viewed as “loose” or seen as if they were spreading the virus if they were HIV-positive.

The participants in the current study experienced anxiety about disclosing due to the moral judgements they expected to receive. The female respondents believed that they were more likely to experience moral judgements. They believed that they would be viewed as “loose” if they were to disclose their HIV-positive status. Women were also found to be blamed by other women in the community for the infection of HIV, according to Lekalakala-Mokgele (2016). He attributed this to the social constructions of gender differences and the lack of autonomy for females (Lekalakala-Mokgele, 2016). Males, according to society, are seen as more domineering and as decision-makers; women, on the other hand, are expected to be submissive. However, when it comes to the spread of diseases, especially in the case of a sexually transmitted illness such as HIV, women are blamed.

The stigma and judgemental attitudes related to HIV persist. Saki et al. (2015) believed that PLWHA are largely affected by HIV stigma, discrimination and judgements. This may therefore be detrimental to HIV-positive individuals disclosing their status freely. The students in this research study found it difficult to disclose their HIV-positive status to other students as they were afraid of being blamed for contracting HIV. They were also afraid that other students would label them for being HIV-positive and therefore chose to keep their diagnosis to themselves. This reiterates the point that blame, judgement and stigma are related. The next section illustrates how the challenges of disclosure affect students’ decisions to disclose.

5.3 Challenges and barriers to disclosure

PLWHA face many challenges when it comes to disclosing their status, more especially for students living with HIV. These challenges may exist due to students' lacking family support as they live away from home. Ssali et al. (2010), Klitzman et al (2004), Norman et al. (2007) and Driskell et al. (2008) found that people were afraid to disclose their HIV status because of the perceived adverse effects associated with HIV/AIDS disclosure.

The finding of this study reflected two prominent difficulties faced by HIV-positive students: judgement and rejection. These difficulties are also intertwined with the issue of stigma. Mavhandu-Mudzusi, Netshandama and Risenga (2014) conducted a study on HIV-positive university students and staff, and found that stigma and discrimination were a major concern for PLWHA.

5.3.1 Judgement

Stigma is reflected in the judgmental attitudes of individuals as found in the study by Cloete et al. (2010). Although participants of this study had not experienced any judgement about their HIV-positive status directly, they still feared judgemental attitudes, which hindered their disclosure. This was also found in a study of ex-offenders by Maman et al. (2014): according to them, the fear of stigma and judgmental attitudes may be implicit for PLWHA, but it still hinders them from disclosing their HIV-positive status. Participants may view disclosure as having negative consequences and may therefore perceive the reactions of others as judgemental once they do disclose. Gossip is associated with judgemental attitudes and therefore stigma, as was found in this study. The participants feared that if other students knew of their HIV-positive status, they would gossip about them.

5.3.2 Rejection

Rejection or the fear of rejection is one of the leading challenges to HIV disclosure in HIV research. The dilemma that PLWHA face is the fear of losing those closest to them after they have disclosed. This was supported in Murugan's (2009) study, which found that ex-offenders were afraid of disclosing as they might lose someone significant. The fear of rejection has hindered individuals in this study from disclosing. The issue of rejection is also closely linked to the stigmatisation of HIV: the limited knowledge and misconceptions people have about

HIV causes them to reject PLWHA. Cloete et al. (2010) wrote of this stigma as being predominantly experienced by women. Female participants in this study were found most likely not to disclose due to the fear of rejection. Although this study was conducted in a university setting, the participants were still subjected to patriarchal norms where females were still considered passive in comparison to men.

In this study, some participants commented that it was difficult for them to disclose their HIV status as people, mostly family members, might reject them. Other participants found the courage to disclose their HIV-positive status to their partner, and the sexual partner subsequently rejected them. Of the three participants who disclosed their HIV status to their current sexual partner, two were rejected by their partners because of denial of their HIV-positive status. One of the participants who was pregnant at the time recalled her then boyfriend denying impregnating her and also distancing himself from her because of the HIV-positive status.

Such experiences of rejection and withdrawal among the participants had a negative effect on the process of disclosure by PLWHA. The participants in this study who were subjected to rejection took longer to disclose to someone else compared to those who were accepted after the initial disclosure. The study by Maeri et al. (2016) found that individuals who were rejected by their partners after disclosing subsequently became reluctant to disclose to anyone else.

As previously stated, this study showed that the participants who were rejected after the initial disclosure were rejected by their current sexual partners. Maman et al., (2014) maintained that the negative social outcomes of disclosure to sexual partners may include blame, stigma, discrimination, violence and even rejection. Female participants in their study reported being beaten by their partners after disclosing their HIV-positive status. As a consequence of their disclosure to their sexual partners, the participants in this study endured rejection, blame and negative emotional effects. However, none of the participants reported having experienced any violence from their sexual partners as a result of their disclosure.

Globally, individuals living with HIV face a variety of negative outcomes due to disclosing their HIV status. This is no different for students living with HIV, as they face similar difficulties to that of the general population living with HIV. These negative outcomes of HIV disclosure in turn have negative effects on PLWHA, such as non-disclosure. However, despite

having experienced these negative outcomes of disclosure, students living with HIV still find reasons to disclose their HIV status.

5.4 Facilitators of HIV disclosure

There are multiple facilitators of disclosure for individuals living with HIV. However, this study found that there were three dominant facilitators of disclosure. The process of disclosure is a non-linear one and involves various steps. Murugan (2009) wrote of the various steps to HIV disclosure. After individuals have processed their diagnosis, they begin to decide whether they are ready to disclose to other people. For some of the participants in this study there was pressure to disclose from the KZN Department of Health (DoH). One of the participants was pregnant at the time when she found out she was HIV-positive. The nurse at the community health clinic explained to her that she needed to disclose to someone who was going to assist her with remembering checkup dates and also for adherence to treatment. HIV-positive individuals, according to DoH guidelines, have to have a “treatment supporter”. This supporter is someone one trusts enough to disclose one’s status to. The supporter’s role is to remind one to take medication on time and also to remind one of clinic visit dates. Murugan’s (2009) study on ex-offenders in KwaZulu-Natal also found that individuals felt pressure from the DoH to disclose after they had tested positive.

Serovich, et al. (2005) used two theories, the disease progression theory and the consequence theory, to understand the HIV disclosure process. The study by Serovich et al. (2008) on a test of HIV disclosure theories hypothesised that what might facilitate an HIV-positive individual’s disclosure is their deteriorating health. The findings of the study by Serovich, et al. (2005) were supported by Murugan’s (2009) study on HIV-positive inmates, which stated that many of those in prison felt that they had to disclose their status because their situation was worsening and they were in need of ARVs. Serovich et al. (2005) argued that disease progression triggers disclosure. However, as a result of treatment plans such as ART, the health of PLWHA hardly deteriorates. This was found to be the case with the students in the current study. All of the participants were on ARVs and did not necessarily have to experience any deterioration in health. They therefore did not need to wait for their health to deteriorate and therefore disclosed for reasons other than being sick.

Serovich et al. (2008) also argued that, according to the consequence theory, individuals weigh the cost and benefits of disclosure such as support and rejection prior to disclosing. Hence individuals no longer wait for the disease to progress before disclosing. The participants in this study had hardly any indicators of illness before disclosing their status; they did so because it would benefit them in some way. In addition, Serovich et al. (2008) stated that if the anticipated consequences are desirable to the individual, they will proceed to disclose. One of the participants in this study used a hypothetical situation first before actually disclosing. To test whether it would be safe for them to disclose. For instance, they would ask, “How would you react if you found out I were HIV-positive?” Once they received empathy and support, they proceeded to disclose. Norman et al. (2007) spoke of participants’ feeling out the situation first before disclosing to other parties.

The participants looked at various reasons for doing so before they disclose their status. The facilitators below enable participants to disclose their HIV-positive status. Despite living in a university setting, it was found that the participants in this study identified reasons to disclose that were similar to those of the general population.

5.4.1 Support

Ssali et al. (2010) suggested that even though there are multiple motivating factors to disclose an HIV-positive status, the main reason for disclosure is for PLWHA to receive support from others, especially one’s family. Three of the participants in this study first disclosed to their family members, even though they lived away from home. All of the participants who disclosed to their family members believed that they would be supported by their family. In contrast, the participants believed that they would not be supported by other students.

However, before the participants disclosed their status, they engaged in a decision-making process in which they evaluated the consequences of their disclosure. The participants evaluated whether or not someone in the same situation was supported. This is supported by the consequence theory of disclosure, which states that an individual begins by evaluating what they anticipate from disclosing their status (Serovich, 2001). According to Serovich (2001), the individual may link the consequence of their disclosure to a previous personal experience. This research study found that two of the participants who disclosed believed that they would be supported if they disclosed their HIV-positive status, because other family members had disclosed and had been supported. However, one of the participants refused to disclose her

HIV-positive status to her family, regardless of their being supportive of other HIV-positive family members. This participant did not want to disclose her status because she felt as if she was a disappointment to her family by contracting HIV. One of the participants believed that her mother would give her the same support that was given to her sister when she disclosed her HIV-positive status. Some participants, however, felt more supported by friends than family members. One of the participants was constantly reminded by his friends to take his medication.

Abdool Karim et al. (2015) stated that female participants were less likely to disclose to their sexual partners because they were afraid of rejection. Of the participants who disclosed their HIV status in this study only one was supported by her then sexual partner and father of her child. The rest of the participants who disclosed their HIV status to their partners were not supported by them. Although this is not very different from the general population in terms of disclosing to sexual partners, the university students in this study appear to have been most likely not to be supported by their partners.

Institutional support is also crucial in helping HIV-positive students disclose their status, especially in a university setting. This institutional support may come in the form of an established campus health clinic, student counselling or other organisations established to assist HIV-positive students. The students received support from the campus health clinic in the form of counselling and collecting their ARV treatment. CHASU also facilitated peer-mentored education on HIV and healthy living.

This research study showed that although students received support from family and friends, they did not receive the amount of support they required as they lived away from home.

5.4.2 Trust

In this study, trust was found to play an important role when it came to HIV-positive students choosing whether or not to disclose their HIV status. The issue of trust is related to whom the participants would most likely disclose first. Ssali et al. (2010) and Murugan (2009) also found that PLWHA would most likely disclose to a family member due to the close bond of trust between them. This was also found to be the case in this research study. This was supported by Maman et al. (2014), who stated that participants chose first to disclose to a trusted family member. However, one of the participants in the current study believed he could trust a friend

with his HIV status more than his grandmother. He believed his disclosure would not be kept secret by his grandmother.

Hence, the issue of trust in this study was divided into two aspects. The first was whether the PLWHA could rely on whomever they disclosed to be supportive. The second was whether that individual to whom they disclosed would keep the disclosure a secret. Ssali et al. (2010) found that previous experiences of trust and support enabled disclosure. Participants in this research study found it easier to disclose their HIV status to people they trusted previously with other matters. The participants in this study, however, trusted their housemates at the university more with other issues than with their HIV status.

The participants' decision to disclose may either produce the desired result of support or the undesired result of rejection. Whatever the results may be, PLWHA still need to prepare themselves for those results. Moreover, disclosure helps the participants to live a healthy life.

5.4.3 Consequences of disclosure

Serovich, et al. (2008) wrote of HIV disclosure being an aid to the mental well-being of individuals living with HIV: PLWHA are said to be relieved of stress and have lower levels of depression when they have freely disclosed to others. The findings of this study indicated that most individuals disclosed due to emotional or psychological wellbeing. The participants spoke of a load being lifted off their shoulders or a feeling of relief after disclosing their status. Maman et al's. (2014) also reported that after PLWHA had disclosed their positive status they felt a sense of relief as if a weight was lifted off them after disclosing. In this study, the participants felt that disclosing their status was the best thing they could have done as it allowed them to live their lives free of any secrets. The participants not only felt much better emotionally and psychologically after disclosing, but also started living a healthier life. Maman et al. (2014) found that once patients were dedicated to the treatment regime and attending clinic visits, they began to engage in safe-sex practices and also ate more healthily.

5.5 Disclosure and adherence to treatment

Disclosure and adherence to treatment appeared to co-exist. Adherence to treatment, according to Azia et al. (2016), is the ability of patients to follow their treatment plans and also to take medication at specified times. Non-adherence was defined by Azia et al. (2016) as the inability

to follow treatment plans and also the inability to take medication at the prescribed times. In this study, the participants who were unable to disclose found it very hard to adhere to their treatment plan compared to the participants who had disclosed. It seems, therefore, that disclosure has an effect on an individual's ability to adhere to treatment. Cloete et al. (2010) found that young adults who had not disclosed their status had difficulty adhering to the specified time of taking their medication. Non-adherence to treatment was found to be related to a fear of disclosure due to stigma attached to HIV, according to Cloete et al. (2010). The participants in the current study were afraid to be found taking the medication as that could unintentionally have revealed their status. Azia et al. (2016) argued that non-adherence to treatment is related to PLWHA being afraid of their status being disclosed through the act of taking medication and the ensuing discrimination.

In this study, most of the participants who had not disclosed either to family or those they lived with had to change their treatment time to conceal their HIV-positive status. This was a trend among the participants, for those who had not disclosed to family or to the house mates they lived with. This was also found by Klitzman et al. (2004) in a study where the participants who had not disclosed resorted to lying about what their medication was for when the time to take their daily dose arrived. One of the participants was found to conceal his ARVs in a multivitamin bottle in order to conceal his HIV-positive status. Three of the participants were also found to hide their medication when at home, as their families did not know about their HIV-positive status.

Klitzman et al. (2004) found that as a result of not disclosing their HIV status, there might be decreased adherence to treatment because PLWHA have to change the time of their daily dose of ARVs to avoid being noticed. In the present study, some participants who were not openly HIV-positive would alter their time to take the ARV medication in order to conceal the fact that they were on a treatment regime. Hence, this may have led to a non-adherence to their treatment time regimen. In this study, the participants also found it difficult to adhere to their medication regimen especially if they were studying in common areas such as the library or computer laboratories.

Adherence to treatment is of paramount importance for PLWHA to live a healthy life. However, the participants in this study often had to resort to extreme measures to conceal their HIV status and to adhere to treatment. The issues experienced by HIV-positive students are intricately connected. Their experience or fear of stigmatisation related to their status makes it

difficult for them to disclose. This in turn means that they need to conceal their treatment activities. This may have negative effects in that they may start defaulting on their treatment, therefore making it easier not only to progress to the next stage of HIV but also to increase infection rates if they remain sexually active.

5.6 Summary

The process of HIV disclosure is difficult. It involves multiple factors that an individual living with HIV has to consider before disclosing their status. This process usually begins by PLWHA accepting their diagnosis. The acceptance stage involves the individual going back and forth trying to make sense of their diagnosis. In that process, a number of participants experience the issue of blame. That is either an element of blame towards someone else or of self-blame. The issue of blame helps an individual to either accept or deny their status, and therefore affects the way in which they will disclose.

The process of HIV disclosure also involves PLWHA having to weigh the costs and benefits of disclosure. In this study, it was unusual, though, for participants to disclose as a result of the progression of the disease. This may be due to the fact that all the participants were on ARVs and their viral load was suppressed, hence they did not show any signs of illness. However, in the general population, unlike in the student population studied, it appears as if PLWHA tend to default on their treatment, show signs of illness and only then disclose. Of the participants in the current study who did disclose, they choose to disclose to family members rather than friends or sexual partners. The leading motivating factor to disclosure was support. Other motivating factors for participants to disclose were trust and healthy living. The participants found that it was easier to disclose to people whom they trusted to keep their disclosure a secret. Even more so, the participants felt relief after disclosure and were able to take their treatment openly.

Those participants who disclosed openly received a large amount of support either from the institution or from family or friends. However, although there are support systems in place at the institution, such as CHASU, the campus health clinic and the student-counselling departments, students living with HIV still cannot help feeling alienated and lonely. The support structure they desire is not only distanced from them but also has a different understanding of the disease and could not fully support them. This desired support system was

the family. The participants found that other students, partners and friends were not good support systems as they were judgmental and stigmatised those who were HIV-positive.

HIV-positive students go through multiple emotional and psychological difficulties, which are similar to those of the general population of PLWHA. However, the strain may be much more as students are expected to deal with other stressors, including financial difficulties and their HIV status, when away from home.

There were also barriers or challenges to disclosure that hindered the disclosure process. These challenges included rejection and judgement, which are also related to stigma. The participants were either afraid of experiencing rejection or had experienced rejection once they disclosed their HIV-positive status. The stigma attached to HIV/AIDs was evident in the behaviour of rejection and judgemental attitudes displayed towards PLWHA.

It was especially difficult for the students to disclose their status, even though they understood the benefits of disclosing. However, they felt that the costs outweighed the benefits of disclosing.

Chapter 6 will conclude the thesis and make recommendations.

Chapter Six: Conclusion

6.1 Introduction

This research study sampled and interviewed five HIV-positive students receiving ARV treatment. The sample was generated from the UKZN Pietermaritzburg campus situated in the province of KwaZulu-Natal, South Africa. The study aimed to explore the process of HIV disclosure among university students. It investigated the in-depth lived experiences of students on this particular campus living with HIV. The study explored the experiences of students who had either disclosed or not disclosed their HIV status. Interviews were used to understand the context and the lived experiences of the participants. To understand the experiences of the participants, the study used a thematic analysis to generate themes. Despite HIV having been closely studied, the current study, HIV disclosure, has had a limited literature.

The study had five objectives. The first objective concentrated on the participants' experiences of their disclosure of their HIV status. In the light of the findings of the study, the process of disclosure appeared to be a rather difficult one. In some instances, the participants had not as yet disclosed their HIV status. In instances where they had disclosed their status, they described the disclosure process as a daunting yet liberating experience. The process of disclosure also appeared to be an ongoing process in which the participants would have to go through the motions of fluctuating emotions each time they disclosed.

The second objective was to explore the challenges related to HIV disclosure. The study showed that the participants experienced a number of challenges and barriers when disclosing or when considering disclosing their status. Some of the participants were afraid to disclose due to the fear of being judged. This sense of judgement was also accompanied by the stigma attached to being HIV-positive and also being labelled. The female participants were afraid of disclosing as they might be judged and labelled by others as promiscuous. Some of the participants feared rejection after disclosing while others were rejected by their partners after disclosing their HIV-positive status.

The third objective was to look at the process involved in HIV disclosure. It appears from the findings of the study that the disclosure process inherently began with the participants' processing their HIV status. Once the participants had come to terms with their own diagnosis, they disclosed their status to other individuals voluntarily, hoping to find support. The process

of disclosure was intertwined with adherence to treatment. The findings of the study showed that the participants who had disclosed their HIV status were more likely to adhere better to their treatment regimen.

The fourth objective was to investigate the facilitators of disclosure. The research study showed that the participants disclosed their HIV status in order to attain support. The support received was mostly emotional support from friends and family as well as structures at the university. Another factor that facilitated the participants' decision to disclose was trust. One participant mentioned that they disclosed to someone they trusted not to disclose their status. The findings of the research indicated that if they previously trusted someone with something else, they would most likely disclose their status to them. The study also showed that healthy living was a motivating factor to disclose for some of the participants. Disclosure allowed them to adhere openly to their treatment regimen and also assisted them psychologically.

The final objective was to understand whether the university fosters disclosure or constructs barriers to disclosure. The results of the study showed that the university has different facilities that offered support to HIV-positive students, and, if used, they could enable disclosure. These facilities include the campus health clinic, student-support offices and CHASU, which all cater for students living with HIV. However, owing to the relationships most students have at university, which are mostly temporary, it appeared that the process of disclosure was hindered. Students living in shared student residences or communes found it especially difficult to disclose their status to their roommate as they did not have a close relationship. This in turn caused HIV-positive students to conceal their medication in order to adhere correctly to their treatment regimen.

Disclosing to friends on campus was exceptionally difficult but was beneficial in that the participants received support when they did so. However, for some individuals disclosing to friends on campus appeared too unbearable and they decided not to. Disclosing to family members was much easier than disclosing to friends on campus.

The findings of this study showed that university students at the UKZN Pietermaritzburg campus found it fairly difficult to disclose their HIV status. The participants in this study believed that the HIV disclosure process was not an easy one. However, they found it worthwhile to disclose as they received support after disclosing. Some found it easier first to disclose to a family member rather than to friends or someone with whom they were in a

relationship. There was also a trend that family members offered support after they were disclosed to, yet sexual partners were more likely to abandon the participants once being disclosed to.

6.2 Limitations and strengths

Owing to the sensitive nature of this study, it was a lengthy process to receive ethical clearance. The researcher also found it difficult to recruit participants because of the sensitivity of the topic. The researcher therefore had to make use of the campus health clinic to recruit participants as other means of recruitment may have ultimately disclosed potential participants' status. The above proved difficult as the researcher relied solely on the sister at the campus health clinic to make initial contact. Another challenge was relying on the participants to contact the researcher if they were willing to participate.

The research study could have potentially exposed the participants to harm even though it was not in the nature of the study to do so. However, to protect the participants from harm, pseudonyms were used to protect their identity. This put the participants at ease, as they understood that their diagnosis was to be kept confidential. The participants could have been further subjected to emotional disturbances, especially due to the nature of the study. However, measures were put in place to have the participants counselled should they experience any emotional disturbances. This also gave the participants an opportunity to make an appointment at the student counselling department should they need to speak about their diagnosis. This research then opened avenues of support systems for the participants.

The research study in itself allowed for participants to offload the burden of being HIV as mentioned by some of the participants. The findings of this study could assist in creating better interventions on the UKZN campus to assist HIV-positive students and to also curb the HIV infection rate.

6.3 Recommendations

Living away from family and being surrounded by strangers (other university students), some of the participants found it a bit difficult to disclose their HIV-positive status. The university setting at times may hinder the disclosure process as students may have temporary

relationships. Another factor may be that students living away from home may find it easier not to disclose. The study showed how imperative disclosure is to adherence to treatment. In addressing this concern, the clinic could offer disclosure readiness classes where HIV-positive students are counselled correctly and assisted emotionally and psychologically through the disclosure process. The above may include both the campus health clinic and student-counselling centres on the campus.

The research results also showed that some of the participants did not receive support from someone who was in close proximity to them. This may be due to their living away from home where they might have received that support from their families. A support group could assist in this instance where HIV-positive students would discuss their daily challenges and also ways of overcoming them. However, some participants were afraid of this putting them at risk of other students knowing their diagnosis. An alternative to this may be individual counselling sessions at the student counselling centre. In this way they could receive the support and the coping skills they needed.

Most participants reported being afraid to disclose their status due to the stigma, discrimination or judgement that may be directed at them by other students. This judgement, discrimination and stigma may stem from the ignorance most individuals have about HIV. The university should consider engaging the students as a whole in dialogues centring on the transmission of HIV and what it means to be HIV-positive. In doing so, students, including those who are HIV-positive, may be informed and educated about HIV. This could also be arranged in conjunction with CHASU.

It was also evident from the results that the participants did not adhere to their treatment regime, most especially due to non-disclosure. This may be addressed by intensive drug-readiness classes held by the campus clinic. In this way, the HIV-positive students would understand the implications of non-adherence to treatment. Moreover, the informative dialogues might assist students in adhering to treatment as their peers might somehow understand what it means to be HIV-positive.

More research studies need to be conducted using the same context of the university as there is a shortage of research in this area. The publication of those research studies may be informative and may help to close the gap in HIV research related to university students in South Africa. This thesis could also help universities to understand the burdens

faced by HIV-positive students at UKZN. It would therefore help with the creation of programmes and platforms for HIV-positive students to engage freely about their diagnosis. These platforms could also be used to educate other students about the psychological processes of HIV, the infection rate and how to be more accepting of those who are HIV-positive.

In the light of the research results, it is hoped that these recommendations will be well implemented. This would assist in creating an environment that is conducive to disclosure. It would also go some way towards eradicating some of the negative and judgemental beliefs people have about HIV. The findings will be presented to the campus health-clinic management as well as to the student-counselling departments through a written summary of the findings. This report will be circulated electronically. The development of any interventions with students about HIV and disclosure might benefit from the findings in this study. This could focus on students' wellbeing, emotionally, psychological and physically.

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Appendix A: Ethical clearance



19 November 2015

Ms Gellinda Pillay 210502532
School of Applied Human Sciences – Psychology
Pietermaritzburg Campus

Dear Ms Pillay

Protocol reference number : HSS/0873/015M

Project title: Challenges in the process of HIV/AIDS disclosure: Perspectives of HIV positive students in a South African university

Full Approval – Full Committee Reviewed Protocol

With regards to your response received on 18 November 2015 to our letter 06 August 2015, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shenuka Singh (Chair)

/ms

Cc Supervisor: Dr Mary van der Riet
Cc Academic Leader Research: Professor D Wassenaar
Cc School Administrator: Ms N Ndlovu

Humanities & Social Sciences Research Ethics Committee

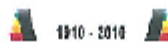
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100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

Appendix B: Gatekeeper permission



23 April 2015

Ms Gellinda Pillay
School of Applied Human Sciences
College of Humanities
University of KwaZulu-Natal
Pietermaritzburg
Email: gellybabez@gmail.com

Dear Ms Pillay

RE: PERMISSION TO CONDUCT RESEARCH

Gatekeeper's permission is hereby granted for you to conduct research at the University of KwaZulu-Natal (UKZN) provided Ethical clearance has been obtained. We note the title of your research project is:


"Challenges in the process of HIV/AIDS disclosure: Perspectives of students on the University of KwaZulu-Natal, Pietermaritzburg campus living with HIV".

It is noted that you will be constituting your sample by conducting interviews with students on the Pietermaritzburg campus at UKZN".

You are not authorized to contact staff and students using Microsoft Outlook address book.

Data collected must be treated with due confidentiality and anonymity.

Yours sincerely

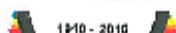

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100 YEARS OF ACADEMIC EXCELLENCE

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Appendix C: Nurse's information letter

Nurses information letter/brief

Dear Nurse

I would like you to recruit participants on my behalf for my master's thesis. The participants should be students at UKZN who are HIV-positive and on ARVs. The participants should be willing to participate and should not be forced or coerced in any manner. You could start by showing the students the pamphlet that I have given you. You then could continue stating the following:

A master's student interested in the perspectives of HIV disclosure among HIV positive students has asked me to recruit some participants on her behalf. The study is interested in the perspectives you have towards disclosing your HIV status. Your participation in this study is completely voluntary and you may choose to withdraw from the study at any time should you feel uncomfortable. You could contact the researcher should you wish to participate in the study or should you have any queries. The contact details of the researcher are on the pamphlet that I have given to you.

Due to the nature of this study it is important to protect the confidentiality of the participants, therefore I would like for you to agree to a confidentiality pledge. This you will sign and return to me.

.....

I(Full names) solemnly swear that I would not disclose any of the interested participants' names with any party.

..... (Sign)

..... (Date)

Appendix D: Interview schedule

Introduction phase:

Would you tell me about yourself? What year of study are you in? How do you find the university environment?

- 1) When did you find out that you were HIV-positive?
- 2) Can you explain this process to me?
- 3) How long after you found out that you were HIV-positive did you disclose?
- 4) What thoughts did you have before disclosing?
- 5) What facilitated your decision to disclose?
- 6) Who did you first disclose to?
- 7) Why did you choose to first disclose to that person?
- 8) How did you disclose? What did you say to them?
- 9) What was the reaction of the person you disclosed to?
- 10) Have you ever disclosed to anyone else, for example family or friends?
- 11) How did you feel after disclosing?
- 12) What role if any, has the circumstances surrounding your infection affected your decision to disclose?
- 13) How do you perceive the process of HIV disclosure?
- 14) How has your infection of HIV affected your life as a student?
- 15) What advice about disclosing would you give to an individual in a similar situation as yours?

Appendix E: Information sheet

The Study

I am conducting research on experiences of HIV disclosure among students of the University of KwaZulu-Natal. I would like to know how students have experienced the process of disclosing their HIV status. Moreover, the study is also interested in the challenges of disclosure as well as what facilitates or drives the decision to disclose. A potential benefit of participating in this study is that you will be able to voice your experiences and concerns about HIV disclosure, and particularly issues related to disclosure for university students. An indirect benefit is that the results of this study could inform health interventions among students, and health services for students on campus.

A risk of this study, though unlikely, is that of stigma or being labelled as being HIV-positive. All attempts will be made to ensure that your status and identity are not revealed to other people throughout the research process. This will happen through a) a recruitment only through the campus health clinic services, b) setting up an email address to which you can respond, c) ensuring that you are aware of the identity of the researcher before you inquire further about the research, in case you do not want this person to know your status, d) ensuring that all data is recorded and stored in a way which ensures confidentiality. All recordings will be undertaken with the participant's permission. Participants have a right not to give permission to be recorded. The recordings of the interview will be stored in a locked filing cabinet in the supervisors' office they will be deleted once transcribed. Recordings will be saved in password-protected files, with pseudonyms and as labels. All recordings will be deleted after transcribing; all transcripts related to the interviews will be stored with pseudonyms or code names, that is, Participant 1, Participant 2 and so forth. All identifying information within the interviews such as the names of places, names of people and etc. will either be anonymised and or removed. The transcriptions will be stored in a filing cabinet in the supervisors' office for a period of five years after the completion of the study, and they will be destroyed or shredded thereafter.

In this research process you will be asked to be involved in an interview. You will be compensated for your time in the research process in the form of a voucher for the Hexagon coffee shop, worth R35.

It is to be noted that this is a master's research project and all data emerging from the study would be used for degree purposes.

The interview process

The interview will take about 90 minutes. It will be held in a room in the campus health clinic. The researcher will engage with you in a discussion about HIV disclosure. The study wants to find out your experiences of HIV disclosure, the process involved and what you saw to be challenges in disclosing as well as what facilitated your disclosure of your status. There is no right or wrong answer. You are encouraged to express yourself freely and informally. You can answer questions you are comfortable to answer and leave the ones you wish not to comment on. To protect your identity your name will not be used in any file or recording of the interview, and or any transcription of the interview, you will be assigned a code name or pseudonym.

Recording

With your permission, the interview will be recorded so that the researcher can transcribe and analyse what you have said.

Be advised that your participation in this study is voluntary. You are free to leave the study at any time of the process.

After the interviews

After the discussion I will take the recording and transcribe it into a written form. In this process you will still be referred to by your pseudonym. The transcription will be analysed and reports will be written. This report will be used for a master's thesis, which will be examined by two examiners, one from UKZN and one from another university.

The data collected, in the form of the transcribed interviews may also be used in future research projects. The information collected in the research process might also be used to write research articles and to present at conferences so that other people may learn from the experience of this research. These written documents will use only pseudonyms or code names and not reveal any identifying information related to the participants in the study.

A synopsis of the results of the study will be made available to you as written feedback, on request.

Storage of information

The research data will be kept for future research purposes. It will be stored in a secure location, that is the locked filing cabinet in my supervisor's office for a period of five years, after which it will be destroyed.

Anything else?

If you feel the need for counselling or further support you can approach the Child and Family Centre at the University, for an appointment with an intern psychologist (Ms N Naidoo: naidoon2@ukzn.ac.za; 033 260 5166).

If you have any concerns about this study you can also contact Ms Phume Ximba of the Humanities and Social Science Research Ethics Committee (031 260 3587; ximbap@ukzn.ac.za).

If you have any questions about this study, then talk to the researcher and/or email the supervisor of this research study Dr Mary van der Riet (033 260 6163; vanderriet@ukzn.ac.za).

Appendix F: Letter from the Child and Family Centre



6 March 2015

To whom it may concern

This letter serves to provide the assurance that should any interviewee or member of a focus group discussion require psychological assistance as a result of any distress arising from the approved research process conducted by students in the Discipline of Psychology, School of Applied Human Sciences, Pietermaritzburg campus; it will be provided by psychologists and intern psychologists at the UKZN Child and Family Centre.

Yours sincerely

A handwritten signature in black ink, appearing to read "D.R. Wassenaar".

Professor D.R. Wassenaar
Academic Leader
Discipline of Psychology
School of Applied Human Sciences

Child and Family Centre
School of Applied Human Sciences

Postal Address: Private Bag X01, Scottsville, Pietermaritzburg3209, South Africa

Telephone: +27 (0)33 260 5166 Facsimile: +27 (0)33 260 5809 Email: Naidoo2@ukzn.ac.za Website: psychology.ukzn.ac.za

Appendix G: Consent form for interview



I hereby agree to participate in this study. I have had an opportunity to read and understand the information sheet given to me.

The purpose of the study has been explained to me. I understand what is expected of me in terms of my participation in this study and the time commitment I am making to participate.

I understand that my participation is voluntary, and I know that I may withdraw from the study at any point, without negative consequences.

I understand that my data will be stored securely for a period five years and may be used for future research. I understand that measures will be taken to ensure that my identity is protected and my participation in this research will be completely confidential in this regard. I understand that no identifying information about me will be published.

I have the contact details of the researcher should I have any more questions about the research. In the unlikely event that any personal issues should arise during the research, I have been given contact details for counselling services.

I have also been given contact information for the University of KwaZulu-Natal Humanities and Social Science Research Ethics office.

Signature of participant.....

Date.....

Appendix H: Consent to audio record interviews



In order to be able to understand clearly what has been said in this interview, and to remember it, I would like to record the discussion on this small digital recorder. I will then listen to the recording and write it down word for word.

After this transcription has been made, I will then delete the recording on the digital recorder.

I assure you that your name will not be linked to the recording or the written information from the recording. I will give you a pseudonym.

Tick one of the following:

1. I consent to the audio-recording of this discussion.
2. I do not consent.

sign here _____

Date _____

Appendix I: Recruiting advertisement

Research on the process of HIV disclosure

Invitation to participate in research on HIV

Are you a student at the University of KwaZulu-Natal Pietermaritzburg campus?

I am looking for participants who are HIV-positive to participate in our study.

We are interested in studying the processes and challenges of HIV disclosure, through the sharing of experiences of individuals who are HIV-positive.

Note that your identity will be kept completely confidential.

Appendix J: Jeffersonian notation

COGS102B * Cognitive Ethnography * Winter 2009

TRANSCRIPTION

Jeffersonian Transcription Notation includes the following symbols:

Symbol	Name	Use
[text]	Brackets	Indicates the start and end points of overlapping speech.
=	Equal Sign	Indicates the break and subsequent continuation of a single interrupted utterance.
(# of seconds)	Timed Pause	A number in parentheses indicates the time, in seconds, of a pause in speech.
(.)	Micropause	A brief pause, usually less than 0.2 seconds.
. or ↓	Period or Down Arrow	Indicates falling pitch.
? or ↑	Question Mark or Up Arrow	Indicates rising pitch.
,	Comma	Indicates a temporary rise or fall in intonation.
-	Hyphen	Indicates an abrupt halt or interruption in utterance.
>text<	Greater than / Less than symbols	Indicates that the enclosed speech was delivered more rapidly than usual for the speaker.
<text>	Less than / Greater than symbols	Indicates that the enclosed speech was delivered more slowly than usual for the speaker.
°	Degree symbol	Indicates whisper or reduced volume speech.
ALL CAPS	Capitalized text	Indicates shouted or increased volume speech.
underline	Underlined text	Indicates the speaker is emphasizing or stressing the speech.
...	Colon(s)	Indicates prolongation of an utterance.
(hhh)		Audible exhalation
? or (.hhh)	High Dot	Audible inhalation
(text)	Parentheses	Speech which is unclear or in doubt in the transcript.
((italic text))	Double Parentheses	Annotation of non-verbal activity.

Jeffersonian Transcription Notation is described in G. Jefferson, "Transcription Notation," in J. Atkinson and J. Heritage (eds), *Structures of Social Interaction*, New York: Cambridge University Press, 1984.