

**THE EXPERIENCES OF STUDENTS IN DISCLOSING THEIR HIV POSITIVE  
STATUS AT THE UNIVERSITY OF LIMPOPO, TURFLOOP CAMPUS**

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**by**

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**Mini-dissertation submitted in partial fulfilment of the requirements for the  
degree**

**Master of Curationis**

**in the**

**Faculty of Health Sciences**

**at the**

**University of Limpopo, South Africa**

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**2015**

## **DECLARATION**

I, Seponono Raisibe Mampa, declare that this mini-dissertation “The experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus”, hereby submitted to the University of Limpopo for the degree Master of Curationis (MCur) has not previously been submitted by me for a degree at this or any other university; that it is my own work in design and in execution; and that all material contained herein has been duly acknowledged.

Signature: .....

Date: .....

## **DEDICATION**

This study is dedicated to the students at the University of Limpopo, Turfloop Campus who are living with HIV/AIDS and who are afraid to disclose their status. It is also dedicated to all those students who were diagnosed and who had lost their lives to HIV before the inception of ARTs.

## **ACKNOWLEDGEMENTS**

First and foremost, I would like to thank God my creator, for His unsurmountable love; for having protected me through the heavy storms of life. My Lord! You kept me above the water surface level; You sustained me high when the external forces were trying to pull me down.

I would like to thank the following persons for their respective contributions to this dissertation:

A special thank you to my supervisor, Prof R. N. Malema. Professor, you shaped my academic skills and expertise. Without your guidance, I would be drifting like a ship without a captain.

Another particular thank you to my co-supervisor, Prof M. E. Lekhuleni. Professor, I never went astray; when my supervisor was unavailable, you were always there for me. Thank you so much for the guidance and the motivation.

Dr T. M. Mothiba, your soothing voice managed to reach my eardrums; you motivated me.

All the lecturers at the Department of Nursing Science at the University of Limpopo, you created an environment that augmented my learning.

The independent coder, Prof M. S. Maputle, thank you for your professional assistance. As an amateur in the research world, you broadened my horizons with regard to coding.

The author, Stephen King, once said "To write is human; to edit is divine." Thank you to André Hills for editing my dissertation.

My participants, do you think this research project would have materialised without your brave participation? Obviously not. Thank you.

My husband, Phillip Mampa, thank you for your unconditional love, support, and encouragement. You were always my pillar of strength during these trying times; you were always there to give me the courage to push ahead. What

more could I ask from God than to be blessed with a husband like you?

My three lovely children: Kgaogelo, Tshepisho, and Mpho. Thank you for your support and understanding. I was not always there to play and chat with and hug you, but you never complained. The melody of your names brings hope and fulfilment to my life.

My mother, Boledi, thank you for the pain you endured in bringing me into this world. I now appreciate the beauty of life because of you.

My aunt, Hlapjadi, and her husband, Baanthata, you had raised me, you guided me through all the passages of life, but above all, you gave me the best of life and education.

My mother-in-law, Moorane, you were always there to babysit your grandchildren while I was studying. Thank you for your selfless assistance.

My brothers and sisters, you never failed to understand when I at times failed to honour our family gatherings because of this project. In future, you will see more of me.

Mrs C. K. Kgosimore, oh Madam! Thank you for unleashing the undiscovered capabilities I never thought I had. You kept on saying “Sponono, register, study; I know you can”. What a diligent and a facilitating manager you are.

Mr Letebele, an award winning manager, thank you for the permission to allow students to participate in this research study. I am hopeful that these findings and the recommendations will accelerate the change we are envisaging in relation to HIV/AIDS disclosure.

My colleagues, you were always there to stand in for me and to ensure service delivery while I was attending contact classes. I would not have completed this project if it were not for your unstinting support.

The University of Limpopo, thank you for encouraging your employees to study, develop, and broaden their horizons.

## **ABSTRACT**

The purpose of this study was to determine the experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus. A qualitative, descriptive, phenomenological design was used to explore, describe, and understand the experiences of the students with regard to the disclosure of their HIV-positive status. A group of 20 students who belonged to the support group were purposively sampled. Semi-structured interviews were conducted for data collection until saturation was reached. Data analysis was conducted according to Techs open-coding method.

The study highlights the potential factors that might hinder access to HIV prevention, management, care, and support programmes.

The findings reveal that there is a marked societal shift in the perception and understanding of HIV, resulting in disclosure being a less difficult responsibility. However, rejection by sexual partners has also been revealed. This rejection is one of the negative consequences that might hamper future disclosure. It is recommended that counsellors should be highly skilled in counselling HIV-positive people, especially about issues of disclosure. An HIV disclosure model will greatly support the work of these counsellors.

## **KEY CONCEPTS**

Experiences, students, disclosure, HIV-positive status.

## **DEFINITION OF CONCEPTS**

### **AIDS**

An acronym for acquired immunodeficiency syndrome; a condition caused by a virus that destroys certain white blood cells (lymphocytes), resulting in loss of the ability of the body to protect itself against diseases (Collins English Dictionary, 1995).

### **HIV**

It is a virus that infects the lymphocytes and other cells bearing the CD4 cell marker, and then replicates, thus leading to progressive destruction of the immune system (Department of Health, 2008; Foundation for Professional Development, 2011).

### **STUDENT**

Student is a person who is studying, especially at a university or another place of higher education (Concise Oxford Dictionary, 2008). In this study, a student is any person enrolled at the University of Limpopo, Turfloop Campus.

### **DISCLOSURE**

Disclosure is an act of revealing or exposing the truth (Concise Oxford Dictionary, 2008). In this study, disclosure refers to an act of revealing an HIV-positive status to the family, friends, relatives, health care workers, and fellow students.

### **EXPERIENCES**

Experiences are defined as the actual observation of or practical acquaintance with facts or events (Concise Oxford Dictionary, 2008). In this study, experiences refer to what HIV-positive students are going through at the time that they are disclosing their status.

## **LIST OF ACRONYMS**

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>ART</b>	Antiretroviral therapy
<b>DOH</b>	Department of Health
<b>HEAIDS</b>	Higher Education HIV and AIDS Programme
<b>HESA</b>	Higher Education South Africa
<b>HIV</b>	Human Immunodeficiency Virus
<b>HCT</b>	HIV counselling and testing
<b>NSP</b>	National Strategic Plan
<b>PLWHA</b>	People living with HIV and AIDS
<b>SAACHS</b>	South African Association of Campus Health Services
<b>SANAC</b>	South African National Aids Council
<b>STI</b>	Sexually transmitted infections
<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	Joint United Nations Programme on HIV and AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>WHO</b>	World Health Organisation



**TABLE OF CONTENTS**

DECLARATION ..... ii

DEDICATION ..... iii

ACKNOWLEDGEMENTS..... iv

ABSTRACT ..... vi

DEFINITION OF CONCEPTS ..... vii

LIST OF ACRONYMS ..... viii

**CHAPTER 1**

**OVERVIEW OF THE STUDY ..... 1**

1.1 INTRODUCTION AND BACKGROUND ..... 1

1.2 PROBLEM STATEMENT ..... 4

1.3 LITERATURE REVIEW ..... 5

1.4 PURPOSE OF THE STUDY ..... 5

    1.4.1 Research aim ..... 5

    1.4.2 Objectives ..... 5

1.5 RESEARCH QUESTION ..... 5

1.6 RESEARCH METHODOLOGY ..... 5

    1.6.1 Research approach ..... 5

    1.6.2 Research design ..... 6

    1.6.3 Research site ..... 6

    1.6.4 Population and sampling ..... 6

    1.6.5 Data collection..... 7

    1.6.6 Data analysis..... 7

    1.6.7 Measures to ensure trustworthiness..... 7

1.7 ETHICAL CONSIDERATIONS..... 8

1.8 SIGNIFICANCE OF THE STUDY ..... 8

1.9 CONCLUSION ..... 8

**CHAPTER 2**

**LITERATURE REVIEW ..... 10**

2.1 INTRODUCTION ..... 10

2.2 VULNERABILITY OF YOUTH TO HIV INFECTION ..... 10

2.3 DISCLOSURE OF A POSITIVE HIV STATUS..... 11

    2.3.1 Meaning of disclosure ..... 11

    2.3.2 Barriers to disclosure..... 11

    2.3.3 Benefits of disclosure ..... 13

    2.3.4 Time of disclosure ..... 14

    2.3.5 Theory of HIV disclosure ..... 14

2.4 CONCLUSION ..... 15

**CHAPTER 3**

**RESEARCH METHODOLOGY ..... 16**

3.1 INTRODUCTION ..... 16

3.2 RESEARCH APPROACH..... 16

3.3 RESEARCH SITE ..... 17

3.4 RESEARCH DESIGN ..... 19

    3.4.1 Bracketing ..... 20

    3.4.2 Intuiting..... 20

    3.4.3 Analysing..... 21

    3.4.4 Describing ..... 21

3.5 POPULATION AND SAMPLING..... 21

    3.5.1 Population ..... 21

3.5.2	Sampling .....	21
3.6	DATA COLLECTION .....	222
3.6.1	Data collection approach and method .....	233
3.6.2	Characteristics of the data collection instrument .....	233
3.6.3	Data collection process .....	<b>Error! Bookmark not defined.</b>
3.7	DATA ANALYSIS.....	277
3.8	MEASURES TO ENSURE TRUSTWORTHINESS.....	288
3.8.1	Credibility .....	299
3.8.2	Dependability .....	30
3.8.3	Confirmability .....	311
3.8.4	Transferability.....	311
3.9	ETHICAL CONSIDERATIONS.....	311
3.10	CONCLUSION .....	333

## **CHAPTER 4**

	<b>INTERPRETATION AND PRESENTATION OF FINDINGS .....</b>	<b>344</b>
4.1	INTRODUCTION .....	344
4.2	DEMOGRAPHIC PROFILE OF THE STUDY PARTICIPANTS .....	344
4.3	DATA MANAGEMENT AND ANALYSIS.....	355
4.4	DISCUSSION OF THE CENTRAL STORYLINE, REFLECTING ON PARTICIPANTS' EXPERIENCES WITH REGARD TO DISCLOSING THEIR HIV-POSITIVE STATUS.....	366
4.5	DISCUSSION OF FINDINGS .....	366
4.5.1	Theme 1: Experiences related to disclosure of HIV-positive status .....	377
4.5.2	Theme 2: Strategies used to disclose HIV-positive status.....	444
4.5.3	Theme 3: Reasons for disclosing own HIV status .....	477

4.5.4	Theme 4: Support versus lack of support post disclosure of HIV- positive status .....	499
4.6	CONCLUSION .....	522
 <b>CHAPTER 5</b>		
<b>SUMMARY, RECOMMENDATIONS, LIMITATIONS, AND CONCLUSION .....</b>		<b>533</b>
5.1	INTRODUCTION .....	533
5.2	RESTATEMENT OF THE PROBLEM STATEMENT .....	533
5.3	SUMMARY OF FINDINGS .....	544
5.4	RECOMMENDATIONS.....	622
5.5	CONTRIBUTION OF THE STUDY .....	644
5.6	LIMITATIONS OF THE STUDY .....	644
5.7	CONCLUSION .....	644
REFERENCES.....		655
APPENDIX A: ETHICAL CLEARANCE CERTIFICATE FROM MREC.....		74
APPENDIX B: PERMISSION FROM ACTING DEAN OF STUDENTS .....		75
APPENDIX C: PERMISSION FROM HEALTH AND WELLNESS MANAGER.....		76
APPENDIX D: CERTIFICATE FROM INDEPENDENT CODER .....		77
APPENDIX E: INFORMED CONSENT .....		78
APPENDIX F: INDIVIDUAL IN-DEPTH INTERVIEW GUIDE .....		80
APPENDIX G: TRANSCRIPT OF VERBATIM DISCUSSION WITH ONE OF THE CLIENTS.....		81
APPENDIX H: EDITING CONFIRMATION.....		85

**LIST OF TABLES**

Table 4.1: Characteristics of participants .....344

Table 4.2: Summary of themes and sub-themes reflecting the  
experiences of students in disclosing their HIV-positive status .....366

# CHAPTER 1

## OVERVIEW OF THE STUDY

### 1.1 INTRODUCTION AND BACKGROUND

The Joint United Nations Programme on HIV and AIDS (UNAIDS) and the World Health Organisation (WHO) encourage disclosure that is voluntary, respects the autonomy and dignity of the affected individuals, maintains confidentiality, and leads to beneficial results for those individuals and for their families. UNAIDS states that disclosure leads to greater openness in the community about the human immunodeficiency virus (HIV) and meets the ethical imperatives of the need to prevent transmission of HIV (UNAIDS, 2008).

According to Deribe, Woldemichael, Wondafrash, Haile and Amberbir (2008), disclosure of an HIV-positive status to sexual partners, friends, or relatives is useful for prevention and care. They state that self-disclosure of sensitive information is generally thought to have beneficial effects on an individual's health, lowers stress, and leads to better psychological health. They further state that individuals who disclose their HIV-positive status are in a better position in terms of making reproductive choices, as well as seeking and accessing psychosocial support. Disclosure of an HIV-positive status enables individuals to access support from group members. In addition, disclosure facilitates other behaviours, such improving the management of HIV (Deribe *et al.* 2008).

Contrary to the abovementioned benefits, Kadowa and Nuwaha (2009) outline reasons why individuals do not disclose their HIV status. The reasons include fear of domestic violence, fear of familial or partner abandonment, and community rejection. They indicate that fear makes disclosure of one's status nearly impossible for many people, particularly for newly diagnosed individuals who are still trying to come to terms with the shock of their possible death. Worth, Patton and Goldstein (2008) add that HIV-positive people experience ambivalence between the need to maintain control over personal information and the moral and ethical obligation to disclose the HIV status to people around them. They corroborate this by indicating that disclosure of an HIV-positive status has potential risks; such as blame, divorce, abandonment, physical and emotional abuse, discrimination, and stigma. They also indicate that

circumstances and timing often vary, as some people may decide not to disclose because of concerns about potential negative consequences. Some may disclose partially to specific people while others may make a full or public disclosure (Kadowa & Nuwaha, 2009; Worth *et al.*, 2008).

Klitzman and Bayer from the Columbia University, as cited in Henry (2003), conducted a study on disclosure of a positive HIV status in the United States of America. Their study reveals that HIV-positive individuals' failure to disclose their status to their sexual partners, either intentionally or unintentionally is a significant but underreported factor in the continued spread of HIV in the United States. The study reports that many people who are interviewed report that they think they will be harmed or rejected when they disclose their HIV-positive status and the world might become hostile to them. As a result, their decision to disclose is shaped and influenced by their fear. Jennifer Kates, director of HIV/AIDS at the Kaiser Family Foundation in America, as cited in Henry (2003), indicates that social acceptance of HIV-positive people is seen to be playing a very influential role with regard to disclosure of a positive HIV status. She adds that in Brazil, there is a greater openness about sexuality and HIV, and their government has established a widespread HIV/AIDS treatment and prevention programme, thus encouraging people to disclose their HIV-positive status. She further mentions that individual counselling and educational campaigns encouraging disclosure are more effective than punitive laws in preventing HIV transmission (Henry, 2003).

In her study conducted in Malawi, Chirwa (2009) states that disclosure of an HIV-positive status is an important factor in preventive HIV/AIDS intervention. She further states that disclosure of an HIV-positive status improves access to prevention and treatment programmes, including adherence to antiretroviral treatment. Again, disclosure of an HIV-positive status provides increased opportunities for risk reduction and help in planning for the future.

The topic of disclosure of HIV status has been the subject of discussion, debate, and deliberation since the beginning of the AIDS epidemic in 1995, but even to date, disclosure is still weighing heavily on the individuals who are faced with an obligation to disclose. Whenever a person discloses intimate details about his or her personal life, emotions are involved. Disclosing intimate personal information may comprise

thoughts, memories, feelings, and sensations (HIV Disclosure and the Law, 2011). Even for the most self-affirming, self-confident person disclosure of an HIV-positive status is still a difficult subject to talk about. Psychosocial factors; such as self-image, self-perception, and self-esteem are involved. Counsellors need to be aware of all these powerful psychosocial factors that influence a person's decision to disclose or not disclose; such as fear of rejection, stigma, discrimination, violence, and possible death (Chirwa, 2009).

People who share their HIV/AIDS status often expose themselves to stigmatisation, discrimination, and potential loss of self-esteem. In South Africa, people who openly admit that they are positive are often treated as outcasts, and / or fired from their jobs, and / or sometimes chased from their home, while some are even killed. For instance, Gugu Dlamini was stoned to death by a group of men from her own home town, after disclosing her HIV-positive status. Her worst "crime" was disclosing her HIV status (Van Dyk, 2012). The consequences of stigma and discrimination are wide-ranging: From being shunned by family, peers, and the wider community; poor treatment in health care and education settings; an erosion of basic human rights, such as the right to dignity and respect; to psychological damage, such as loss of self-esteem (Frohlich, 2010).

According to Van Dyk (2007), a study was conducted in South Africa in 2002 on the psychosocial barriers to voluntary HIV counselling and testing. The study reveals that fear of being rejected is the main psychosocial barrier to voluntary HIV counselling and testing. From the study, 72% of the participants responded that they would partially disclose their positive status to other people, such as health workers but not necessarily to their sexual partners or family members and 28% indicated that they would keep their results a secret. Fear of rejection is outlined as the main reason for not willing to disclose (Van Dyk, 2007). From this background, it is assumed that people are willing to test for HIV but are still afraid to disclose in fear of being rejected. Worth *et al.* (2008) state that a gap has been identified across the world with regard to disclosure, and WHO (2004) has outlined the policy guideline on disclosure and how it affects the sexual partner and children, however, it is too silent on disclosure of students. This silence has inspired the researcher to conduct a



study to determine whether disclosure is still a problem despite all the ever advancing HIV/AIDS information, knowledge, and treatment availability.

## **1.2 PROBLEM STATEMENT**

Disclosure of an HIV-positive status is a difficult and emotional task for students, since it is associated with negative experiences including blame, abandonment, physical and emotional abuse, violence, depression, discrimination, stigmatisation, and risk of losing life time opportunities such as employment. Non-disclosure promotes transmission of HIV due to lack of safer sex practices and hinders access to medical care (Serovich, 2006).

Abdool Karim and Abdool Karim (2010) state that disclosure of an HIV-positive status is associated with stigma, as well as its concomitant discrimination are some of the critical reasons for the failure of prevention programmes, thus providing a major barrier to accessing HIV prevention, care, and support services.

On the other hand, Van Dyk (2012) outlines HIV disclosure as having the following benefits: Disclosure can help PLWHA to accept their HIV-positive status and can ease access to medical services, care, and support including access to antiretroviral therapy (ART).

In line with the objective of the National Strategic Plan (NSP) to address social and structural barriers to HIV, STIs, and TB prevention and care; the health and wellness centre has established a support group for students living with HIV, is in partnership with the Department of Health (DOH) issuing ART, and monitoring progress of those HIV infected students (SANAC, 2013). There are criteria applied to determine an individual's eligibility for initiating ART.

There are quite a number of students who are HIV - positive. Some of them are already on ART while some are eligible but not yet on treatment. When advised to join the support group or to start ART, some students who are eligible show some sign of reluctance. In most cases, the reason behind the reluctance is not being ready to disclose to anyone except health care workers. They are usually concerned that their families might somehow find out that they are taking some pills and demand some explanations for that. It seems that students are afraid to disclose their HIV-

positive status to any person except to the health care workers. As a result, the researcher who is a clinical nurse practitioner at the health and wellness centre, Turfloop Campus, decided to explore the experiences of the students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus.

### **1.3 LITERATURE REVIEW**

Various literature sources were consulted in relation to disclosure of a positive HIV status. These sources are discussed in more detail later in chapter 2 of this study.

### **1.4 PURPOSE OF THE STUDY**

#### **1.4.1 Research aim**

- To investigate the experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus.

#### **1.4.2 Objectives**

- To explore the experiences of the students with regard to disclosure of their HIV-positive status.
- To describe the experiences of the students at the University of Limpopo with regard to disclosure of their HIV-positive status.
- To provide recommendations based on the findings of the study.

### **1.5 RESEARCH QUESTION**

- What are the experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus?

### **1.6 RESEARCH METHODOLOGY**

In this chapter, only an overview of the research methodology is outlined. The research methodology is comprehensively discussed in Chapter 3.

#### **1.6.1 Research approach**

A qualitative research approach was used to explore and describe the experiences of the students with regard to disclosure of their HIV-positive status. Qualitative

research is defined by Denzin and Lincoln (2008) as a 'traditional field of inquiry which involves an interpretive and naturalistic approach to the world'. According to Babbie and Mouton (2011), a qualitative approach involves describing and understanding the human phenomena and provides the researcher with in-depth information about the personal experience. A qualitative approach enabled the researcher to collect data without formal, structured instruments and to also analyse narrative information in an organised, but intuitive fashion (Brink, 2006).

### **1.6.2 Research design**

A phenomenological design was used in this study to understand the students' experiences in disclosing their HIV-positive status. A phenomenological design refers to an inductive, descriptive, and qualitative methodology developed from the phenomenological philosophy for the purpose of describing experiences as they are lived by the study participants (Burns & Grove, 2009).

### **1.6.3 Research site**

The study was conducted at the University of Limpopo, Turfloop Campus, Limpopo Province. The University of Limpopo is situated in the Mankweng area, about 32 kilometres to the eastern side of Polokwane, the capital city of the Limpopo Province. The University of Limpopo presently has an enrolment of about 19 000 students from from a diversity of socio-economic backgrounds, including international students.

### **1.6.4 Population and sampling**

The population comprised all HIV-positive students at the University of Limpopo, Turfloop Campus, who were consulting at the Student Health and Wellness Centre. This population shared the common characteristics of being HIV-positive and of being university students (Brink, 2006).

A non-probability purposive sampling method was used to select the participants. Purposive sampling is also known as judgmental, selective or subjective sampling, and focuses on sampling techniques where the units that are investigated are based on the judgement of the researcher. In this study, a group of 20 students who belonged to the support group were purposively sampled based on the knowledge they have regarding disclosure of HIV -positive status. The support group held

meetings every second week of the month. It gave the researcher an opportunity to make appointments with individual participants for one-to-one interviews to coincide with these meetings. Data saturation was reached after interviewing the eighth participants.

### **1.6.5 Data collection**

The researcher used semi-structured, one-to-one interviews to collect data. The participants were requested to relate the experiences of disclosing their HIV-positive status. Semi-structured interviews encouraged the participants to participate in a more conversational manner and to air their views without being directed by the researcher. The researcher started with one general opening question, such as: “Would you please tell me about your experiences of disclosing your HIV-positive status?” (De Vos, Strydom, Fouché & Delpont, 2011; Polit & Beck, 2012; Brink, 2006).

The researcher voice recorded all interviews and field notes were also taken to support the recordings. Participants were observed during the interviews for non-verbal cues, which were also written down. The researcher used an interview guide during the interviews and probing questions were also asked (Cresswell, Ebersohn, Eloff, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen, Plano Clark, & Van der Westhuizen, 2012).

### **1.6.6 Data analysis**

The researcher started analysing data during the period of data collection. Data was analysed by using Tesch’s method (Creswell, 2003). The main aim of the researcher was to interpret and make sense of the information that was contained in the data.

### **1.6.7 Measures to ensure trustworthiness**

To ensure the quality of data and findings of this study, the researcher established trustworthiness and true value of data by ensuring the following: credibility, dependability, confirmability, and transferability (Babbie & Mouton, 2011).

## **1.7 ETHICAL CONSIDERATIONS**

The research proposal was submitted to the Medunsa Research Ethics Committee for ethical clearance and to the Dean of students for permission to conduct the study (Brink, 2006). The ethical principles of autonomy, confidentiality, anonymity, and no harm to the participants were adhered to throughout the study (Brink, 2006; Polit & Beck, 2012).

## **1.8 SIGNIFICANCE OF THE STUDY**

The findings of this study will be communicated to all professional nurses, the health promoter, and the lay counsellor at the health and wellness centre to provide them with an insight into the experiences of HIV-positive students with regard to disclosure of their HIV-positive status.

The findings will also be communicated to all the HIV counsellors from the non-governmental organisations; such as Shout-It-Now and the Foundation for Professional Development (FPD), other private sector organisations that offer HCT on campus, as well as clinics around the campus. All these providers have an explicit understanding of why students are reluctant to disclose their HIV-positive status.

The findings may also be presented to the health and wellness centres at other universities during the annual South African Association of Campus Health Services (SAACHS) conference and / or published in their newsletter, the Incorporosano.

The findings of this study will also lay the foundation on which strategies will be built to encourage students to disclose their HIV-positive status.

The findings are also going to help improve health care practice in relation to disclosure of a positive HIV status (Brink, 2006).

## **1.9 CONCLUSION**

The overview of the study is discussed in this chapter. The discussion includes the problem statement, research question, aim and objectives, research methodology,

the ethical clearance, and the significance of the study. Chapter 2 outlines the literature review related to HIV/AIDS disclosure.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

A wide-ranging literature review was done on the findings of other existing studies recently conducted about disclosure of a positive HIV status. This chapter presents the results from an extensive review of the relevant literature. According to De Vos *et al.* (2011), a literature review aims at contributing towards a clearer understanding of the nature and meaning of the problem that has been identified. The literature review was, therefore, undertaken to determine the experiences of HIV-positive youths in relation to disclosure of their status.

#### **2.2 VULNERABILITY OF YOUTH TO HIV INFECTION**

According to UNICEF (2011), almost quarter of people living with HIV are aged 15-24 years and they represent 45 per cent of all new HIV infections. UNICEF further states that at least 95 per cent of all new infections occur in less developed countries and Sub-Saharan Africa is the most severely affected region.

In the United States of America, half of all new infections are estimated to occur among people under the age of 25 years while the majority of young people are infected sexually, since they are sexually active. A demographic health survey of many countries indicates that adolescents nowadays are experiencing puberty at a younger age than the previous generation. As a result, they are involved in early initiation to sexual intercourse; most of it is unsafe, unplanned, and expose them to unwanted pregnancy, abortion, and sexually transmitted diseases, including HIV/AIDS (UNICEF, 2011).

The South African National Survey as reported by UNAIDS (2008) reflects that age of sexual debut has emerged as an important variable in the prevention of HIV in South Africa and globally. It also reflects that in 2007, young people aged 15–24 accounted for an estimated 45% of new HIV infections worldwide (UNAIDS, 2008). This implies that the youth are engaging in sexual activities at a very young age when they do not take responsibility to protect themselves, therefore, they are the most severely affected by HIV infection.

## **2.3 DISCLOSURE OF A POSITIVE HIV STATUS**

### **2.3.1 Meaning of disclosure**

Disclosure of HIV status is a multidimensional procedure in which individuals are advised, and not coerced, to disclose or to make their HIV status known (WHO, 2004).

The topic of disclosure of HIV status has been the subject of discussion, debate, and deliberation since the beginning of the AIDS epidemic in 1995, but even to date, disclosure is still weighing heavily on the individuals who are faced with an obligation to disclose. Whenever a person discloses intimate details about his or her personal life, emotions are invoked. Disclosing intimate personal information may involve thoughts, memories, feelings, and sensations (HIV Disclosure and the Law, 2011). Even for the most self-affirming, self-confident person disclosure of an HIV-positive status is still a difficult subject to talk about. Psychosocial factors; such as self-image, self-perception, and self-esteem are all involved. Counsellors need to be aware of all these powerful psychosocial factors that influence a person's decision to disclose or not disclose; such as fear of rejection, stigma, discrimination, violence, and possible death (Chirwa, 2009).

The WHO (2005) emphasises that partners should be encouraged to be counselled and tested together, which will then promote disclosure and encourage the establishment of support groups.

### **2.3.2 Barriers to disclosure**

Being diagnosed with HIV was effectively considered to be a death sentence prior to 2004 when ART was introduced in South Africa. HIV/AIDS was considered to be a socially degrading illness that resulted in stigmatisation of an individual who was HIV-positive (Chaudoir, Fisher & Simoni, 2011).

Adding to these circumstances, UNAIDS – in its 2008 report on the global AIDS epidemic – declares stigma to be one of the two most important factors to be considered internationally, in relation to the prevalence of the disease. This proves that not only is more research needed about HIV/AIDS, but particularly about the discrimination and negative experiences that surround the disease and the people



affected by it (UNAIDS, 2008). Stigma is often internalised by people who are living with HIV, for example, if society is ashamed of the individual, the person feels ashamed of himself. This results in decreased self-esteem, feeling dirty, ashamed, and depressed. A study conducted in Cape Town, South Africa, reports that 30% of people with HIV admitted to being depressed (Simbayi, Kalichman, Strebel, Cloete, Hendra & Mqeketo, 2007).

Worth *et al.* (2008) describe stigma as a social barrier to disclosure of a positive HIV status. They also acknowledge that some progress has been made in terms of shifting the public perception of HIV since the beginning of the epidemic. Nevertheless, despite that progress, PLWHA continue to be particularly stigmatised worldwide. They further state that HIV/AIDS-related stigma is not static; it changes over time as infection levels, knowledge of the disease, and treatment availability vary.

In 2003, when launching a major campaign to intensify treatment in the developing world, the WHO as cited in HIV Disclosure and the Law (2011) by an anonymous author, states that as HIV/AIDS becomes a disease that can be both prevented and treated, attitudes will change and denial, stigma, and discrimination will rapidly be reduced. Stigma also varies depending on the dominant transmission routes in a country or region. The author further mentions that in Sub-Saharan Africa, for example, heterosexual sex is the main route of infection, which means that AIDS-related stigma in this region is mainly focused on promiscuity and sex work. This mind-set greatly influences HIV-positive individuals' decision not to disclose their status in fear of being demeaned (HIV Disclosure and the Law, 2011). Gaskins (2006) and Medley, Garcia-Moreno, McGill and Maman, (2004) corroborate this by indicating that common barriers to disclosure include fear of discrimination, stigmatisation, fear of blame, rejection and abuse, and a lack of understanding the disease.

Greeff, Phetlhu, Makoe, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2008) conducted a multinational African study in five African countries; namely Lesotho, Swaziland, Malawi, South Africa, and Tanzania to explore and describe the meaning and effect of stigma in relation to the experiences of PLWHAs and the nurses who took care of them.

Their study revealed that PLWHAs are judged as less valuable than people who are HIV negative. This was the overarching expression of stigma. Furthermore, in other countries where the study was conducted, stigma was found to discourage people from seeking voluntary counselling and testing and obstructed the development of an enabling environment that promoted disclosure.

Their study findings claim that stigma impedes programmatic efforts in relation to HIV testing, disclosure, prevention, care, treatment, and support (Greeff *et al.* 2008).

### **2.3.3 Benefits of disclosure**

In South Africa, the national ART programme was launched in April 2004 and brought hope to society in general. The South African Government launched its five-year Strategic Plan for HIV/AIDS in 2000. That plan created the framework within which interventions aimed at initiating and implementing an inclusive response to the epidemic were undertaken. The strategic framework identified the following key areas of intervention; namely prevention, treatment, care, support, research, monitoring and surveillance, and the legal and human rights. Disclosure of a positive HIV status was regarded as the cornerstone of prevention, treatment, and care by the South African Government (Department of Health, 2003). According to Abdool Karim and Abdool Karim (2010), disclosure of an HIV-positive status to sexual partners and / or close relatives and friends (significant others) is an important public health strategy because it offers a number of benefits to the infected individual and to the general public. HIV Counselling and Testing (HCT) programmes, adherence, counselling and care, as well as continual counselling emphasise disclosure of an HIV-positive status by PLWHA. They also state that disclosure of a positive HIV status to significant others would provide emotional and psychological support to PLWHA, whereas disclosure to sexual partners could lead to the partners also undertaking HCT. Since disclosure creates the awareness of HIV risk to untested sexual partners, it subsequently leads to a greater uptake of HCT.

Furthermore, Van Dyk (2012) complements Abdool Karim and Abdool Karim (2010) that disclosure to sexual partner enables couples to make informed reproductive health choices that may ultimately lower the number of unintended pregnancies among HIV-positive couples, and even the risk of re-infection. He also mentions that

disclosure motivates people to reduce risky sexual behaviour thereby decreasing the transmission of HIV. It is also associated with improved access to HIV prevention and treatment programmes, adherence to ART, and better treatment outcomes. Other benefits of disclosure as stated in Van Dyk (2012) include the ability to accept one's HIV-positive status, access to medical services, care and support, and access to ARVs. Disclosure is also seen as a way of reducing stigma, discrimination, and denial that surround HIV/AIDS.

#### **2.3.4 Time of disclosure**

It is said that the ability to disclose one's HIV-positive status can be related to the degree to which an individual has accepted his or her HIV diagnosis. It is often most difficult to disclose soon after diagnosis when a person is dealing with the initial impact of his or her HIV-positive status.

Deribe *et al.* (2008) indicate that the time from diagnosis to disclosure varies from one day to two years. In a study conducted by Deribe *et al.* (2008), it is found that 73% of HIV-positive persons disclose on the day of the results, but it is not specified to whom. These results are supported to some extent by Wong, Van Rooyen, Modiba, Richter, Gray, McIntyre, Schetter, and Coates (2009) who report that 13% never disclose to anyone and 36% do not disclose to their sexual partners. The average time of disclosure is 16 months. Visser, Neufed, De Villiers, Makin, and Forstyth (2008) also corroborate this by indicating that 59% of women disclose soon after diagnosis (time not specified) to one other individual, though to whom specifically is unknown. According to Medley *et al.* (2004), 22% of pregnant women disclose two months after diagnosis and 41% by the fourth year. Research thus indicates that over time, more women reveal their HIV-positive status. This indicates that the rate of disclosure increases over time.

#### **2.3.5 Theory of HIV disclosure**

##### **2.3.5.1 Disease progression theory**

According to the disease progression theory as indicated in (Serovich, 2005), individuals disclose their HIV diagnosis only when they become ill because with the progression of HIV to AIDS they can no longer keep it a secret. Disease progression

often results in physical deterioration that might lead to hospitalisation. This deterioration in some cases mandates individuals to explain their illness. Not only would hospitalisation require explanation, but if death is imminent, the individual may disclose as a means of accessing support and preparing people (Serovich, 2005).

### **2.3.5.2 Consequence theory**

The consequence theory of HIV disclosure as indicated in Serovich (2005), suggests that the relationship between disease progression and disclosure is moderated by the consequences one anticipates that will be resulting from the disclosure. That is, as the disease progresses, accumulating stresses result in the need to evaluate the consequences of disclosure. Persons with HIV are likely to reveal to significant others and sexual partners once the rewards for disclosing outweigh the associated disadvantages (Serovich, 2005).

## **2.4 CONCLUSION**

Chapter 2 reviews the literature with regard to the experiences of disclosure by HIV-positive people. Chapter 3 discusses the methodology that the researcher used to collect data from study participants about their experiences in relation to disclosure of a positive HIV status.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

This chapter describes the research approach that was adopted to explore the experiences of students who were living with HIV about the disclosure of their HIV-positive status. The research design, research site, population and sampling method, as well as the data collection and analysis techniques are described at length in this chapter. In addition to the academic rigor, these research activities are informing the research findings. Ethical considerations and limitations to the study are also discussed in this chapter.

#### **3.2 RESEARCH APPROACH**

A qualitative research approach was used to explore and describe the experiences of university students with regard to disclosure of an HIV-positive status. Qualitative research is defined by Denzin and Lincoln (2008) as a 'traditional field of inquiry which involves an interpretive and naturalistic approach to the world'. According to Babbie and Mouton (2011), a qualitative approach involves describing and understanding the human phenomena that provide the researcher with in-depth information about the personal experience of the participants. Burns and Grove (2003) refer to qualitative research as an inductive, holistic, emic, subjective, and process-orientated method that is used to understand, interpret, describe, and develop a theory on a phenomenon or setting.

In principle, Denzin and Lincoln (2008), Babbie and Mouton (2011), Burns and Grove (2003) support one another in defining what a qualitative research approach is. They all agree that a qualitative approach is both descriptive and interpretive in the sense that it focuses on understanding and interpreting the meanings and intentions that underlie human experiences (Schurink, 2008). The researcher allowed HIV-positive students to describe their personal experiences and the meaning they ascribe to those experiences. The researcher then tried to make sense of and to interpret the students' personal experiences in respect of disclosure of a positive HIV status.

A qualitative approach uses an inductive form of reasoning; develops concepts, insights, and understanding; as well as captures and discovers meaning once the researcher becomes immersed in the data (De Vos *et al.* 2011). Unlike quantitative research that seeks to confirm hypotheses, qualitative research seeks to explore human phenomena. In this study, the researcher explored the experience of disclosing a positive HIV status.

According to Polit and Beck (2010), qualitative research follows a naturalistic or a constructivist paradigm that always takes place in its natural setting. Naturalistic or constructivist researchers emphasise the inherent complexity of human beings, their ability to shape and create their own experiences, and the idea that truth is a composite of realities. As a result, naturalistic inquiries are deeply focused on understanding the human experience as it is lived; usually through careful collection and analysis of qualitative material that is narrative and subjective (Burns & Grove, 2003). As such, narrative and subjective data was collected directly from HIV-positive students who had already disclosed in a real world and in a natural setting. A thorough account of the data collection process is provided in Section 6.3.

The researcher collected data from participants without formal structured instruments, but in an intuitive fashion (Brink, 2006). It implies that the researcher was as natural as possible and developed an awareness of the lived experiences of HIV-positive students. The researcher paid full attention to the description given by those students in this study.

### **3.3 RESEARCH SITE**

The study was conducted at the University of Limpopo, Turfloop Campus, in the Limpopo Province. The University of Limpopo is one of 23 South African universities. It came into being on 1 January 2005 as a result of the amalgamation of the former University of the North (now the Turfloop Campus) and the former Medical University of South Africa (now the MEDUNSA Campus).

The University of Limpopo, Turfloop Campus is situated in Mankweng area, about 32 kilometres to the eastern side of Polokwane, the capital city of the Limpopo Province. It provides tuition for about 19 000 students from diversity of socio-economic backgrounds, including international students.

The Turfloop Campus is only about 2 kilometres away from the Mankweng Hospital of the Polokwane–Mankweng Hospital Complex (PMHC), which is a tertiary hospital in the Limpopo Province. The Polokwane-Mankweng Hospital Complex comprises two hospitals, the Polokwane Hospital and the Mankweng Hospital. The main role of the PMHC is to provide tertiary services to all Level 1 (district) and Level 2 (regional) hospitals in the Limpopo Province. The University of Limpopo, Turfloop Campus is surrounded by precipitously growing villages; such as the Mankweng Township with all its eight zones (A, B, C, D, E, F, G, and GG), Thoka, ga–Mothapo, Nobody, Makanye, Mentz, Boyne, ga–Mamabolo, ga–Molepo, and ga–Mothiba. Each village consists of smaller sections.

Both hospitals have HIV/AIDS wellness clinics. These Health and Wellness Centres are always full to capacity. It was estimated that 500 000 adults and children were receiving ARVs in South Africa by mid-2008, with about 34 000 of them in the Limpopo Province (Nwobegahay, Bessong, Masebe, Mavhandu, Iweriebor & Selabe, 2011). It is not known how many people were collecting their ARVs from the Mankweng and Polokwane Hospitals. On record, the Health and Wellness Centre had  $\pm 100$  students who were on ARVs at the end of 2013. The information of the total number of HIV-positive students was treated confidentially in accordance with departmental protocol. At the time of the study, the Health and Wellness Centre was not yet accredited to issue ARVs, however, some of the students were collecting their treatment from the Mankweng Hospital, and some were collecting from the Polokwane Hospital while fewer were collecting their ARVs from their local health institutions. The HIV support group was established mainly for the infected students with the purpose of providing social and moral support to one another. Undoubtedly, the support group is doing very well by offering support to members who need that support.

The Campus Health and Wellness Centre provides integrated and comprehensive services that include but not limited to primary health care, HIV/AIDS, STIs and TB prevention, care and support services, dispensary services, treatment of minor opportunistic infections, and referral to hospital for ARVs and further management and care.

Literature illustrates that students at tertiary institutions are highly susceptible to HIV and have the potential to spread HIV further despite the high levels of HIV/AIDS knowledge and information (HEAIDS, 2012). In response to the above statement and in an attempt to combat HIV/AIDS, as well as ensuring general healthy, the Campus Health and Wellness Centre has implemented certain health promoting projects. The programme involves awareness campaigns on HIV/AIDS, health talks about sexually transmitted infections, condom demonstration and distribution on campus, as well as promotion of HIV counselling and testing. These projects are mainly managed by fully trained and well equipped peer educators under the leadership of a health promoter. The Campus Health and Wellness Centre also offers continual counselling and support for those students who have tested positive, including the ones who are eligible for ARVs.

### **3.4 RESEARCH DESIGN**

A descriptive phenomenological design was used in this study to understand the university students' experiences in disclosing their HIV-positive status. Streubert and Carpenter (2011) define descriptive phenomenology as a "direct exploration, analysis, and description of [a] particular phenomenon, as free as possible from unexamined presuppositions, aiming at maximum intuitive presentation". Descriptive phenomenology stimulates people's perception of lived experiences while emphasising the richness, breadth, and depth of those experiences. The researcher used the paint brush of the participants' words as they were describing their personal experiences on disclosure of HIV-positive status and painted a clear phenomenal picture of these experiences of HIV disclosure (Neuman, 2005).

A phenomenological design refers to an inductive, descriptive qualitative methodology developed from phenomenological philosophy for the purpose of describing experiences as they are lived by the study participants (Burns & Grove, 2009). Chin and Kramer (2008) describe phenomenology as a research method designed to describe or interpret the subjective, lived experiences of people and to comprehend the meanings that people attach to these experiences.

Phenomenologists emphasise that all human beings are engaged in the process of making sense of their own individual worlds. They believe that people continually



interpret, create, give meaning to, define, justify, and rationalise their actions (Babbie & Mouton, 2011). In this study, the students were regarded and treated as unique individuals with different experiences in relation to the disclosure of their positive HIV status, and were individually given an opportunity to describe their personal experiences.

Descriptive phenomenology involves four strategies; namely bracketing, intuiting, analysing, and describing (Polit & Beck, 2012).

### **3.4.1 Bracketing**

Bracketing is defined by Polit and Beck (2012) as “the process of identifying and holding in abeyance any preconceived beliefs and opinions about the phenomenon under study”. Bracketing is crucial throughout the research process, especially during data analysis. Bracketing requires the researcher to remain neutral with respect to belief or disbelief in the existence of the phenomenon under study (Streubert & Carpenter, 2011).

Bracketing was treasured in this study, since the researcher put aside any preconceived beliefs and opinions about disclosure of a positive HIV status. With an open mind, the researcher was aiming at discovering new and fresh ideas and experiences as lived by the participants.

### **3.4.2 Intuiting**

Intuiting refers to the second step in descriptive phenomenology that occurs when a researcher remains receptive to the meaning attributed to the phenomenon by those who are experiencing it (Polit & Beck, 2012).

Intuiting was also respected, since the researcher entirely immersed herself in the phenomenon, looking at it without layering it with preconceived ideas that were bracketed (Brink, 2006).

Through the intuitive process, the researcher acquired an understanding of the students' experience with regard to disclosure of a positive HIV status (Streubert & Carpenter, 2011).

### **3.4.3 Analysing**

Analysis refers to the process of organising and synthesising data in order to answer research questions and to test hypotheses in qualitative and quantitative studies respectively (Polit & Beck, 2012). In this study, the researcher extracted significant statements, categorised, and tried to make sense of the essential meanings of the participants' responses.

### **3.4.4 Describing**

Describing is the final strategy of descriptive phenomenology and aims at communicating and describing distinct, critical elements of the phenomenon; thereby communicating to other interested parties what the study has found (Leedy & Ormrod, 2010). In this study, the researcher endeavoured to guard against premature description of the findings.

## **3.5 POPULATION AND SAMPLING**

### **3.5.1 Population**

Brink (2006) defines population as a complete set of persons or objects that possess some common characteristics that are of interest to the researcher. Procter and Allan (2006) distinguish between two populations. They describe the target population as the total population that forms the focus of a study while the study population is a subset of the target population from whom the sample is taken.

In this study, the target population was all registered students at the University of Limpopo, Turfloop Campus, whereas the study population was all HIV-positive students at the University of Limpopo, Turfloop Campus, who consulted at the Health and Wellness centre.

### **3.5.2 Sampling**

Sampling refers to the process of selecting a sample (Gerrish & Lacey, 2006). A non-probability purposive sampling method was used to select the participants. Purposive sampling is also known as judgmental, selective or subjective sampling, and focuses on sampling techniques where the units that are investigated are based on the

judgement of the researcher (Gerrish & Lacey, 2006). In this study, a group of 20 students who belonged to the support group were purposively sampled based on the knowledge they have regarding disclosure of HIV -positive status.

The group consisted of 12 females and eight males aged between 19-43 and 20-40 years respectively. All members of the support group had disclosed to their family members, friends, and / or sexual partners. The support group held meetings every second week of the month. The researcher informed the group that she was conducting a study about the experiences of students at the University of Limpopo in disclosing their HIV-positive status and requested them to voluntarily participate in the study. She further requested them to visit her individually at the Health and Wellness Centre during their spare time to avoid interference with their academic schedules. The group member who arrived first on a particular day was interviewed.

The sample size was determined by reaching data saturation. Data saturation was reached after interviewing the eighth participant. At that stage, no new information was obtained and redundancy was reached (Polit & Beck, 2012).

The exclusion criteria:

All the University of Limpopo, Turfloop campus students who were HIV-positive but not members of the support group were excluded.

The inclusion criteria:

All members of the support group because they had disclosed their HIV-positive status to their family members, friends, and / or sexual partners.

### **3.6 DATA COLLECTION**

Data collection refers to the gathering of information to address a research problem (Polit & Beck, 2012). Burns and Grove (2003) define data collection as a precise, systemic gathering of information relevant to the research sub-problems, using methods such as interviews, participant observation, focus group discussions, narratives, and case stories.

The empirical phase, which involves the actual collection of data, is followed by the preparation for data analysis. Data collection begins after a researcher has decided from where and from whom data will be collected. The researcher was the main research tool or the primary research instrument. The researcher conducted interviews without the help of interview assistants.

### **3.6.1 Data collection approach and method**

Semi-structured, face-to-face, individual interviews were used to collect data, since the researcher wanted to thoroughly understand the students' lives in order to gain a full understanding of their experiences in respect of the disclosure of their HIV-positive status. Semi-structured interviews encouraged the participants to share their experiences in a more open manner and to air their views without being directed by the researcher.

An interview is defined as “a form of conversation in which the interviewer restricts oneself to posing questions concerning behaviours, ideas, attitudes, and experiences with regard to social phenomena, to the participants or interviewees, who mainly limit themselves to providing answers to these questions” (Maso as cited in Boeije, 2010). Boeije (2010) further states that qualitative interviews take place in a reciprocal relationship. These relationships become easier when both partners get along well or have established a good rapport.

A face-to-face interview was preferred in this study because it provided the researcher with an opportunity to probe and to investigate hidden and suppressed views and experiences of the HIV-positive students. It also provided the researcher with an opportunity to observe body language and to interpret emotions, distress, anxiety, and silence and to respond accordingly (Tod, 2006).

### **3.6.2 Characteristics of the data collection instrument**

Semi-structured interviews were suitably and essentially conducted to achieve the desirable balance between direction and flexibility. Semi-structured interviews were chosen because it provided a clear set of instructions for interviewers in order to provide reliable, comparable, and qualitative data (Cohen & Crabtree, 2006). The interviewer developed and used an interview guide that comprised list of questions

and topics that needed to be covered during the conversation, usually in a particular order. The data collection instrument was divided into sections according to the interview sequence. The sequence was as follows: Introduction, warm-up, main interview questions, wind down, and closing the interview.

- **Introduction**

The study was introduced. The purpose of the interview, ethical issues, and their right to withdraw at any time were explained. Each participant's level of understanding was confirmed. Consent was obtained. A relaxed atmosphere was created by a nonthreatening tone of conversation. A jug of water was available (Cohen & Crabtree, 2006).

- **Warm-up**

Neutral, nonthreatening questions were asked. Factual background information was collected (Cohen & Crabtree, 2006).

- **Main interview questions**

The main interview started with a broad question about the research topic. The broad question was followed by semi-structured follow-up questions according to the sequence on the interview guide. Prompts and probes were used to generate deeper and richer data (Tod, 2006).

- **Wind down**

Since the HIV issue was still regarded as a sensitive and emotional topic to discuss, the researcher started concluding the interview by asking a few simple questions to allay any feelings of discomfort. While winding down, the interviewer started a sentence with "on conclusion..." to prepare the participant that the interview was reaching the end. Participants were asked whether they had any additional information to add (Tod, 2006).

- **Close the interview**

The researcher checked once more to whether the participants had anything to add. The participants were thanked for their participation (Cohen & Crabtree, 2006).

### **3.6.3 Data collection process**

The researcher made an appointment with each participant at a time which suited them, and prepared a quiet room that was conducive for face-to-face conversations. The researcher voice recorder all interviews and field notes were taken to support the recordings. Participants were observed during the interviews for non-verbal cues; those cues were written down. The participants were requested to share their stories, pass on their knowledge, provide their own perspective, and relate their experiences of disclosing their HIV-positive status. After the introduction and the warm-up stages of the interview, the researcher started by asking the broad opening question: "Would you please tell me about your experiences of disclosing your HIV-positive status?" (De Vos *et al.* 2011; Polit & Beck, 2012; Brink, 2006).

The researcher used an interview guide and probing questions were put to each participant. Prompts and probes were used to solicit more points of view and clarity from the participants about their personal experiences of disclosing their positive HIV status (Creswell *et al.* 2012). In this study, interviews were conducted in a quiet, safe, and private environment that was free from any distraction. The interview took place at the Health and Wellness Centre of the University of Limpopo, Turfloop Campus, and lasted between 20 and 40 minutes.

While the researcher was learning about personal experiences, bracketing and intuition processes were highly observed with the purpose of minimising any biases. To this end, the researcher asked open-ended questions, since such questions were not based on preconceived ideas. The researcher also identified and removed any preconceived beliefs and opinions about the study phenomenon, i.e. the experience of HIV-positive disclosure (Todres & Holloway, 2006; Brink, 2006).

The researcher remained receptive to the meaning attributed to the experiences by university students of disclosing their positive HIV status (Todres & Holloway, 2006; Brink, 2006).

#### **3.6.3.1 Skills used by the researcher**

In order to direct and control the interview, as well as to strike a balance between guiding and being guided, the researcher used the following interview skills:

observing and attending to behaviour, communication, coping with conflict, and probing skills as described in Schurink (2008).

- **Observing and attending**

The researcher maintained appropriate eye contact, facial expression, and a relaxed natural posture without trying to either intimidate the interviewee or to invade his or her privacy.

- **Communication**

Communication is regarded as the vital part of interview and the mutual interaction between the interviewer and the interviewee. In order to encourage communication, the interviewer leaned slightly forward, nodding her head, and making small affirming utterances; such as “umm”, “hmm”, “okay”, or “yes”.

- **Coping with conflict**

Since the study dealt with HIV disclosure that was sensitive and contained highly personal information, the researcher anticipated that the participants might somehow feel that their intimate privacy was invaded which might have resulted in possible hostile reactions. To this end, the researcher avoided confrontation as far as possible.

- **Probing**

Probing refers to eliciting more useful or detailed information from a participant in an interview than was volunteered at first (Polit & Beck, 2012).

According to Schurink (2008), the objective of conducting a social research project is the collection of reliable information. The researcher used specific probing techniques, i.e. open-ended questions, tracking, clarification, and reflective summary.

- **Open-ended questions**

The interviewer used open-ended questions, since they did not require one-word answers, therefore, the interviewees had ample opportunity to express their feelings

(Schurink, 2008). Those questions also encouraged interviewees to respond in their own words (Polit, Beck & Hungler, 2012).

- **Tracking**

Tracking or tracing means a delicate mark or pattern (Concise Oxford Dictionary, 2008).

Schurink (2008) likens tracking to a process during which the interviewer acts like a needle tracking the grooves of a record. In this study, both the interviewer and the interviewees were showing interest, they adjusted and were both following the conversational rhythm of the interview process.

- **Clarification**

Clarification requires that something is made more comprehensible and easier to understand (Concise Oxford Dictionary, 2008).

The interviewer asked participants for clarification and more information in a nonthreatening, casual way. For example, the interviewer asked: "Would you please tell me about your experiences in disclosing your HIV-positive status?" Such a question simply implied that the interviewer wanted some explanations from the interviewees about their personal experiences with regard to disclosure of a positive status.

- **Reflective summary**

A reflective summary encompasses the repetition of what someone has said, as a way of verifying the true meaning of his or her verbal expression (Polit & Beck, 2012). In a question form, the interviewer repeated the ideas, opinions, and feelings of the interviewees by using their own words with the purposes of confirming that she had understood the interviewees correctly.

### **3.7 DATA ANALYSIS**

Data analysis refers to the systematic organisation and synthesis of qualitative research data (Polit & Beck, 2012).



The researcher started analysing data concurrently with the data collection process. Tesch's method was used to analyse the data (Creswell, 2003). The main aim of the researcher was to transcribe, interpret, and make sense of the information contained in the data.

The researcher used Tesch's eight steps of data analysis (Creswell, 2003):

- The researcher listened to the voice recordings, read and re-read the verbatim transcripts thoroughly in order to familiarise herself with and to make sense of the data.
- The researcher selected one verbatim transcript and went through it while thinking about the underlying meaning and writing her thoughts or any impressions in the margin.
- The researcher continued analysing the transcripts one by one until all the transcripts were analysed. The researcher compiled a list of all the topics. Similar ideas or topics were clustered together and organised into columns that were arranged into major topics, unique topics and exceptions.
- The topics were abbreviated into codes and the codes were written next to the appropriate segments of the text. The researcher checked whether new categories and codes were emerging.
- The researcher identified the most descriptive or meaningful wording for the topics and turned them into categories. The researcher then grouped the topics that related to one another thereby reducing the total list of categories. Lines were drawn between categories to show interrelationships.
- The researcher made a final decision about the abbreviation for each category and wrote them in alphabetical order.
- The researcher assembled data belonging to each category in one place to make a preliminary analysis.
- The researcher recoded existing data.

### **3.8 MEASURES TO ENSURE TRUSTWORTHINESS**

Lobiondo-Wood and Haber (2006) describe trustworthiness as "criteria to establish the validity and reliability of a qualitative research" project. Qualitative research is trustworthy when it accurately represents the experience of the participants. Gerrish

and Lacey (2010) refer to trustworthiness as academic rigor that comprises the strength of a body of research in terms of confirming that all procedures have been followed judiciously, that all potential confounding factors have been removed, and that the reader judges conclusions to be dependable or trustworthy.

To ensure the quality of data and findings in this study, the researcher used Guba's model for establishing trustworthiness, since it was well and conceptually developed and had been used extensively by qualitative researchers.

### **3.8.1 Credibility**

Credibility refers to the confidence in the truth of data and interpretations of that data (Polit & Beck, 2012).

According to Babbie and Mouton (2011), credibility is demonstrated when the participants recognise research findings as their own. That is, there should be compatibility between the constructed realities that exist in the minds of the participants and those realities that are attributed to them. Credibility is achieved by applying the procedures of prolonged engagement, persistent observation, triangulation, member checks, and peer debriefing.

#### **3.8.1.1 Prolonged engagement**

Prolonged engagement refers to the investment of sufficient time during data collection to acquire an in-depth understanding of the group or phenomenon under study, thereby enhancing credibility (Polit & Beck, 2012). The researcher spent six months collecting, processing, interpreting, and analysing data. This prolonged engagement assisted the researcher with developing an individual in-depth understanding of the students' experiences in respect of disclosure of a positive HIV status. By spending sufficient time in the field, a trusting relationship was established between the researcher and the students. The students eventually felt at home and started to interact naturally.

#### **3.8.1.2 Persistent observation**

Persistent observation refers to identification of those characteristics and elements in the situation that are most relevant to the problem or the issue being pursued.

Focusing on the issue implies sorting out irrelevancies or the characteristics that are of no value (Gerrish & Lacey, 2010). The researcher persistently observed, identified, and assessed elements according to their relevancy.

#### **3.8.1.3 Triangulation**

Triangulation refers to the use of multiple methods to collect and interpret data about a phenomenon with the intent of arriving at an accurate representation of reality (Polit & Beck, 2010). The main aim of using different methods is to mitigate the intrinsic bias that results from single-method, single-observer, and single-theory studies (Polit & Beck, 2012). Various methods of data collection; such as voice recordings, documented observations, and field notes were used as a means of ensuring credibility.

#### **3.8.1.4 Member checks**

Participants as the primary source of information were allowed to review, validate, and verify the researcher's interpretations and conclusions to ensure that data was authentic and that facts had not been misinterpreted (Brink, 2006; Chirwa, 2009).

#### **3.8.1.5 Peer debriefing**

A group of peers who were also enrolled for a Master's degree probed the researcher's biases. The peers gathered and the researcher presented the methodology used, the data collection method, the data analysis, and the interpretation method used in this study. The peers analytically and constructively probed the researcher's work for any biases. Peers assisted in building the researcher academically to inform the appropriate steps or decisions to be taken (Babbie & Mouton, 2011).

#### **3.8.2 Dependability**

Polit and Beck (2012) refer to dependability as the stability of data over time and conditions. An inquiry audit was used in order to assess whether the study would produce the same results when repeated with the same or similar respondents in the same or a similar context. The researcher comprehensively explained and documented the research design, as well as the operational details of data gathering

and analysis to provide future researchers with evidence against which they can verify their results (Polit & Beck, 2012).

### **3.8.3 Confirmability**

According to Babbie and Mouton (2011), confirmability is the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher. Confirmability refers to the objectivity or neutrality of data, or the potential for congruence between two or more independent people about the accuracy, relevancy, or meaning of the data (Polit & Beck, 2012).

The researcher kept all the raw and processed data from the voice recordings, written field notes, documents, summaries, and condensed notes, methodological notes, themes that were developed, findings and conclusions, as well as the final report (Lincoln & Guba as cited in Babbie & Mouton, 2011). In this study, confirmability was ensured by the involvement of an experienced independent coder and the use of an audit trail during which field notes and transcribed data, findings, and recommendations were examined. The study project was submitted to the supervisor for verification (Babbie & Mouton, 2011).

### **3.8.4 Transferability**

Transferability refers to the extent to which the findings can be transferred to other settings or groups (Babbie & Mouton, 2011). Transferability was ensured by providing a sufficiently thick, rich, and detailed description in Chapter 2 of the research method used for data collection, analysis, as well as the setting where the study took place (Polit & Beck, 2012).

## **3.9 ETHICAL CONSIDERATIONS**

- **Permission and ethical clearance**

Ethical clearance to conduct the study was obtained from the Medunsa Research Ethics Committee (Appendix A). Permission to conduct the study was obtained from the Dean of Student Affairs, University of Limpopo (Appendix B), as well as from the Health and Wellness Centre manager (Appendix C) (Brink, 2006). Henceforth, the ethical principles that were observed are described.

- **Informed consent**

According to Parahoo (2006), informed consent is a process of agreeing to take part in a study based on access to all relevant and easily digestible information about what participation means, in particular, in terms of harms and benefits. Consent means to give approval of or to agree with participating in a study or a procedure (De Vos *et al.* 2011). In this study, accurate, complete, and simple information was provided to participants, who then digested and comprehended it. Participants made voluntary decisions about their participation.

- **Principle of autonomy**

Autonomy is the capacity for self-determination (Gerrish & Lacey, 2006). These authors further indicate that the right to self-determination implies that individuals have the right and competence to evaluate available information, to weigh alternatives against one another, and to make their own decisions. This implies that participants voluntarily agree to partake in a study, without being coerced. To protect the autonomy of the participants, the researcher informed the participants that participation was voluntary, and they could withdraw at any time if they wished to do so. The participants were given information about the study, including the possible risks and the benefits, the purpose and the significant of the study, and they were allowed enough time to decide whether to take part or not. The researcher avoided asking the participants about any personal information that was not relevant to the study (Brink, 2006; Polit & Beck, 2012).

- **Principle of beneficence**

The principle of beneficence is traditionally understood as the "first principle" of morality according to the dictum of "do[ing] good and avoid[ing] evil" (Ascension Health, 2012). Gerrish and Lacey (2006) refer to this principle as a principle of utility that requires us to attempt generating the largest ratio of good over evil. The researcher guarded against and limited the risks associated with participating in a research study – such as the emotional, psychological, and the social upsets –by avoiding irrelevant questions. The researcher was also vigilant not to pronounce any emotional judgement, either intentionally or unintentionally, on the participants' morality (Babbie & Mouton, 2011).

- **Principle of confidentiality and anonymity**

Participants were assigned fictitious names and were assured that their real names would not be used in order to protect their identity. Participants were promised and assured that personal information would be treated confidentially (Babbie & Mouton, 2011).

- **Principle of justice**

According to Boswell and Cannon (2014), justice refers to the ethical obligation to treat each person in accordance with what is morally right and proper and to give each person what is due to him or her. In the ethics of research involving human participants, the principle refers primarily to distributive justice that requires an equitable distribution of both the burdens and the benefits of participation in research. The ethical principle of justice requires that ethical theories should prescribe actions that are fair to the people who take part in those actions. Gerrish and Lacey (2006) declare that an ethical decision which includes justice has a consistent logical basis that supports the decision. Justice expects that everyone is entitled to equal access to basic care. The researcher ensured that all participants were treated equally and that the same information was distributed to all of them in the same manner.

### **3.10 CONCLUSION**

Chapter 3 describes the research methodology used to collect and analyse the data for this study. A qualitative research approach was chosen to determine the experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus. Semi-structured interviews were conducted to collect data. Permission to conduct the study was obtained, and the ethical principles were observed. Chapter 4 discusses the research findings.

## CHAPTER 4

### INTERPRETATION AND PRESENTATION OF FINDINGS

#### 4.1 INTRODUCTION

This chapter discusses the findings of the research study conducted at the University of Limpopo, Turfloop Campus with regard to the experiences of students in disclosing their HIV-positive status. Four themes emerged from the semi-structured one-to-one interviews.

#### 4.2 DEMOGRAPHIC PROFILE OF THE STUDY PARTICIPANTS

The following section presents the first part of the findings that describes the participants' demographic information. Data saturation was reached at participant number eight, thereby bringing the total number of male participants to three and their female counterparts to five. Names used in this study were fictitious, i.e. not participants' real names.

**Table 4.1: Characteristics of participants**

<b>Fictitious name</b>	<b>Age</b>	<b>Gender</b>	<b>Educational level</b>	<b>Marital status</b>	<b>Religion</b>
Charlize	23	Female	Honours degree	Single	Christianity
Juju	24	Male	Basic degree (2nd level)	Single	Christianity
Lerato	26	Female	Honours degree	Single	Christianity
Mary-Ann	28	Female	Basic degree (2nd level)	Single	Christianity
Masilo	40	Male	Master's degree	Single	Christianity
Mathiba	21	Female	Basic degree (Final year)	Single	Christianity
Mokgadi	34	Female	Honours degree	Single	Christianity
Siphiwe	23	Male	Basic degree (2nd level)	Single	Christianity

- **Age**

The sampled participants' ages ranged between 21 and 40 years.

- **Gender**

As indicated above, three male and five female students participated in this study. Since we are living in a world with cultural and sexual diversities, one male indicated willingly without fear or favour that he was a gay. All these participants described their views with regard to the experiences around HIV disclosure.

- **Educational level**

All participants were university students, though at different academic levels. One male was busy conducting his Master's degree, three females were doing honours degrees, one female was busy with the final year of her basic degree; two males and a female were studying at the second level of a basic degree.

- **Marital status**

All the participants indicated that they were single; however, they all had sexual relationships.

- **Religion**

All participants were Christians. One participant even revealed that her niece encouraged her to pray hard and ask God to cure her from this virus.

#### **4.3 DATA MANAGEMENT AND ANALYSIS**

Semi-structured interviews were voice recorded. The voice recorder, a master book indicating the real name of the participants, and field notes were all stored and kept under lock and key, away from being accessed by unauthorised individuals. This facilitated an audit trail and ensured confidentiality.

The researcher sent coded transcripts to the independent coder for confirmability. The independent coder, who is an expert in the research field, analysed data using Tesch's inductive, descriptive coding technique.



#### 4.4 DISCUSSION OF THE CENTRAL STORYLINE, REFLECTING ON PARTICIPANTS' EXPERIENCES WITH REGARD TO DISCLOSING THEIR HIV-POSITIVE STATUS

**Central storyline:** Participants shared analogous experiences about disclosing their status, which included the benefits that they felt after the disclosure. Relatives, friends, partners, and healthcare professionals provided continued support after disclosure. On the one hand, experiences reflected that some of the participants were rejected by their partners after disclosure. Participants further shared the strategies that they had used in disclosing their HIV-positive status to family members without verbalising their disclosure. Disclosing ones' HIV-positive status is related to a person's attitude towards the virus.

#### 4.5 DISCUSSION OF FINDINGS

**Table 4.2: Summary of themes and sub-themes reflecting the experiences of students in disclosing their HIV-positive status**

Themes	Sub - themes
<b>1. Experiences related to disclosure of HIV-positive status</b>	1.1 Disclosure of HIV-positive status a difficulty versus an easy task 1.2 Fear of misconceptions by others related to disclosing one's status 1.3 Disclosure brings about feelings of relief 1.4 Improved family interpersonal relations after disclosure
<b>2. Strategies used to disclose HIV-positive status</b>	2.1 Processes of disclosure 2.2 The importance of disclosing to trustworthy persons 2.3 Preferred signals of disclosing without verbalising

Themes	Sub - themes
<b>3. Reasons for disclosing own HIV status</b>	3.1 Disclosure influenced by seeking support from others 3.2 Disclosure is related to protecting others from being infected 3.3 Disclosing HIV-positive status relates to eradicating misconceptions about the disease
<b>4. Support versus lack of support post disclosure of HIV-positive status</b>	4.1 Support experienced after disclosing to relatives and friends 4.2 Acceptance versus rejection by partners after disclosure

#### **4.5.1 Theme 1: Experiences related to disclosure of HIV-positive status**

Disclosure is something that every person living with HIV experiences and struggles with. The process is complex and terrifying with mixed emotions, and the outcomes can be unpredictable and difficult to handle. Despite the difficulty disclosure might present, non-disclosure has a detrimental impact on any HIV infected person due to its association with personal distress, loneliness, and social isolation (Chaudoir *et al.* 2011). Four sub-themes emerged from this theme: Disclosure of HIV-positive status a difficulty versus an easy task, fear of misconceptions by others related to disclosing one's status, disclosure brings about feelings of relief, and improved family interpersonal relations after disclosure.

##### **4.5.1.1 Sub-theme 1.1: Disclosure of HIV-positive status a difficulty versus an easy task**

Some participants experienced disclosure of a positive HIV status as a difficult task, whereas to some it was not that daunting. This is evidenced by the information provided by some participants.

- **Disclosure as a difficult task**

Mokgadi: *“Jaa, it was hard, I didn’t think I could have this. The first one was my boyfriend. Is like after coming back from the doctor I went straight to him, just after seeing him, I started crying. It was painful, we both cried, it was painful. We both didn’t expect this virus... I think it is hard to accept, but... is hard”.*

Mathiba: *“The first person I told was my friend. I was sitting alone and thinking and thinking. I was even thinking that, that will not happen; I can’t be positive. And then I thought maybe if I could tell someone, maybe she could share the same blanket with me. So, I told my friend the very same day when I found out I am positive. I was even crying”.*

According to HIV Disclosure and the Law (2011), whenever a person discloses intimate details about his or her personal life, emotions are engaged. Disclosing intimate personal information may involve thoughts, memories, feelings, and sensations. Disclosing one’s HIV status is not easy. HIV status is intensely personal information and the act of disclosure can lead to both positive and negative results.

From these quotations, it is evident that to these participants it was so difficult for them to disclose something that they had not yet admitted. Actually, they were in shock; they were emotional and they could not believe that they were positive. So, having to disclose something that they were still trying to internalise, trying to come to terms with was such a difficult experience.

A study conducted in China by Li, Sun, Wu, Lin, Wu, & Yan (2007) reports that PLWHA experience undue psychological pressure and it is difficult for them to disclose to their families and friends because of fear of being discriminated against.

- **Disclosure as an easy task**

Juju: *“Some things are just heavy when you are far from them. The closer you get, the more the easier you realise they are. With me, it was like ABC. I got what I was not expecting. I disclosed to my mother who then gave me all the support I needed. I can say she is spoiling me now. The love, attention, and care that I get from her, is now worrying me, because my*

*other siblings will start complaining. The experience was so good. She never said anything weird; instead she supported me and even tried to be my advocate. She told my whole family to take good care of me and to give me support”.*

*Charlize: “Sister, to me disclosure was a very pleasurable moment. I am not saying to be HIV-positive is a nice thing. No, it is not. My experience was good because it was a teaching moment for other people. I realised how much my family love me”.*

*Lerato: “For me, my experience was... eh... I guess it was so easy; it didn’t give me any problem. To make it easy in most cases when I disclose my status to somebody, I talk to that person first about HIV. If is he or she aware of HIV, then I will be able to disclose my status to that person, and this makes it easier for me. My mother is a home based career, so she understands this thing of HIV. It was easy for me. The experience was not bad at all. I got the support, though I was too afraid to tell her. I spend much time, I was like should I tell her or not. I didn’t know”.*

These quotations depict a societal shift in perception and understanding of HIV/AIDS. These participants received love and support from their social support system, without any negative experiences.

This is corroborated by the results of a study conducted in Kenya on the levels of accepting attitudes toward PLWHA. In that study, it was found that acceptance levels were relatively high. It was also found that being HIV infected did not seem to be a rare or deviant event in the daily experiences of the Kenyan populace. That moderated their stigmatising attitudes toward PLWHA, thereby strengthening the supportive relationship in their households. In addition, intolerance toward those members of society with HIV is considered one of the greatest barriers to the provision of treatment, care, and support to PLWHA (UNAIDS, 2006).

#### 4.5.1.2 Sub-theme 1.2: Fear of misconceptions by others related to disclosing one's status

It more than three decades since the world started experiencing the HIV pandemic and literature reveals how HIV-positive people have been ill-treated previously (Van Dyk, 2012). Van Dyk (2012) further states that people who share their HIV/AIDS status often expose themselves to stigmatisation, discrimination, and judgement. This observation was confirmed by some participants.

Mary-Ann: *"The other person that I have disclosed to was my uncle. And I still remember the day I was disclosing to my uncle, I was crying. I was crying because I thought maybe he was just going to show some kind of rejection, maybe think a lot of things about me that I haven't been myself, so maybe being promiscuous, like maybe fooling around and all those kind of things. So, I was just thinking he was going to judge me or shout at me, but he didn't do any of those"*.

Charlize: *"Others will think you were a prostitute, you were sleeping around or whatever, it does not matter"*.

Mathiba: *"I remember that day I was even crying, I told her I am HIV - positive. I was crying, because I thought she will shout at me, yell, curse me or whatever, but to my surprise, what she said, eh... I told her the whole story about my relationship with the father of the child. And she explained, no is fine, I will take care of the baby then you go back to school"*.

Siphiwe: *"Personally, me disclosing my status... eh... I was expecting various comments from people, but only to find that what I thought was very wrong. People didn't react the way I was expecting them to. Instead, they gave me the support, a full one. The one that I never thought about, I never thought they will"*.

Lerato: *"Yes. Before they can know my status, I talk to them about HIV. Like I ask them what do you know about HIV, and some people will tell you that... ah... that virus is killing. And if you've got that negative attitude, Hai,*

*no, I won't, I won't tell. People who speak badly that people who are HIV-positive are people who are like they were sleeping around. Ah shame, some of us were not sleeping around; we are just like stable then someone came and you know, infected us. Most of the people judge us".*

All the participants had some tormenting thoughts around disclosure. They feared being judged and rejected by their family and their loved ones. They were concerned about what would happen after disclosing and were all expecting worse outcomes. They feared being classified as promiscuous and living shabby lives. The misconceptions around HIV lead to potential loss of self-esteem; rejection by family, peers, and the wider community; poor treatment in healthcare and education settings; and an erosion of basic human rights, such as the right to dignity and respect (Frohlich, 2010).

Chaudoir *et al.* (2011) state that HIV/AIDS is perceived as a socially degrading attribute that negatively impacts on disclosure rates. Norman, Chopra and Kadiyala (2007) consider HIV/AIDS as a social construction that significantly affects the lives of individuals with HIV, their partners, family, and friends.

Simbayi *et al.* (2007) further states that stigma is often internalised by people living with HIV, for example, if society is ashamed of the individual, the person feels ashamed of himself, resulting in decreased self-esteem, feeling dirty, ashamed, and depressed.

Serovich, Oliver, Smith and Mason (2005) recommend that when unsure of what someone's reaction to HIV disclosure might be, the HIV infected person should probe, hint, and test the water. They should probe their target for stigma and perceptions about HIV. It is said that people who are knowledgeable about HIV or who knows someone else with HIV are inclined to be more accepting. Serovich *et al.* (2005) further explain that before disclosure, the individual might also set the stage by providing ample verbal or symbolic hints, listing HIV status to get an idea of how someone might react and to prepare the other person for their disclosure.

#### **4.5.1.3 Sub-theme 1.3: Disclosure brings about feelings of relief**

The following extracts indicate that disclosure brought about relief for the participants.

Juju: *“Like I said, I felt like a new born baby. I have never seen a person being angry to a new born. I felt so relieved, so loved and well taken care of. I started to see a family with another eye. I realised how important a family is”.*

Lerato: *“I felt so relieved. And this was a relief to my parents as well, because is like now they know what is eating their child”.*

Charlize: *“I felt free and happy to know that there are people who still love me, including my family. At times I used to stay alone, thinking that people will hate me, reject me. I was having pressure, stress and I withdraw myself. I felt like I was imprisoned, and now I am free. I had many sicknesses before disclosing my status, but after disclosing, they just fade away”.*

Siphiwe: *“I felt so relieved”.*

HIV-positive persons may also disclose in order to find relief from the stress of harbouring a secret (Obermeyer, Baijal & Pegurri, 2011). Informed by one of his case studies on disclosure, Van Dyk (2012) also indicates that HIV-positive individuals who decide to keep their status unknown, usually experience emotional problems; such as anxiety, guilt, stress, low self-esteem, and a general sense of loss. The toll of living a lie weighs heavily on their shoulders. They always have to think before they speak so that they don't let their HIV status slip out accidentally.

In a study conducted in Malawi, the study findings identified a feeling of relief as the major positive experience (Chirwa, 2009).

Conversely, Remien and Bradley (2007) state that disclosing an HIV-positive status can – and sometimes do – result in rejection, discrimination, or violence. Disclosing to certain persons can be more of a burden than a benefit. It is true that disclosing cannot always bring about positive outcomes, as it was the case in this study. Some participants were rejected or treated somehow badly by their partners (still to be discussed as a sub-theme). Disclosure can also be accompanied by negative

consequences; such as rejection, eviction in cases where women are disempowered, violence, and may also lead to one losing his or her life (Van Dyk, 2012).

#### **4.5.1.4 Sub-theme 1.4: Improved family interpersonal relations after disclosure**

Disclosure of a positive HIV status resulted in an improved social support and interpersonal relations.

*Charlize: "The other people I disclosed to, was my younger brother and sister. It was during university holidays, so I was at home. Um... my mum is late... eh... so I told my sister that I want to warn them that HIV is real. So I called them and told them my status. I knew that they were thinking that I will die any time soon. I realised that from that time they were so close to me, though they were not saying anything about HIV. After eating, they will take my plate back to the kitchen, do things that they were not doing for me before".*

Gurung (2010) states that "having a family means to have a sturdy wall to rely on, it is the only thing that have the greatest bonding involved, hence, without them, you might not be able to do much on your own..." The importance of family in current day society is to provide support to one another and to share our lives with other people whom we are related to.

Serovich (2006) describes disclosure of a positive HIV status as a way of strengthening relationships and improving family cohesion. It results from an increased level of trust and comfort to confide in.

These findings are corroborated by Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal and Ross (2014), since they indicate in a study conducted in Zambia that, at the interpersonal level, disclosure creates opportunities for PLWHA to access adherence support and other forms of psychosocial support from family members and peers.



## 4.5.2 Theme 2: Strategies used to disclose HIV-positive status

People react differently towards disclosure of an HIV-positive status. Again, people disclose their status differently owing to the fact that there is no right or wrong way to disclose (Arnold, Flannery, Rice & Rotheram-Borus, 2008).

Three sub-themes emerged from this theme: Processes of disclosure, the importance of disclosing to trustworthy persons, and preferred signals of disclosing without verbalising.

### 4.5.2.1 Sub-theme 2.1: Processes of disclosure

According to Van Dyk (2012), there are two primary disclosure processes; involuntary and voluntary disclosure. Voluntary disclosure of an HIV-positive status means revealing one's HIV status out of one's free will, whereas involuntary disclosure of an HIV-positive status means someone else discloses on behalf of the infected person, with or without concern as it is the case in China (Li *et al.* 2007). The following extracts depict both voluntary and involuntary processes of disclosure.

- **Voluntary process of disclosure:**

Mary-Ann: *"Yes I did. The first time where I disclosed in public was in Midrand. We had a dialogue, at Midrand. Actually, it was students from different universities, and some of them were positive some of them were just peer educators working with HIV. So, I just disclosed in front of them without any one asking me. So that was the first time I disclosed in public and... (Laughing shyly) And there was no bad reaction because they know and understand the HIV pendulum. So, I didn't have to feel somehow, maybe feel bad or feel like I am going to be judged".*

In a study conducted by Deribe *et al.* (2008), it was found that 65% of participants disclosed their status voluntarily without any external incitement.

- **Involuntary process of disclosure:**

Juju: *“We enjoyed our meal, thereafter my mom said my children there is something I need you to know. She was just looking down. We were all listening. She said, if you wake up one day and learn that I your mother am HIV - positive, how will you feel and what will you do? We remained quiet for some few minutes. Then my youngest brother said I will feel bad, and won’t do anything, but you will still be my lovely mother. The three of us remained quiet. Mom asked us individually, my sister, my brother and I responded like the first one. Mom said, okay, thank you for that response. She was struggling, her lips were even shaking. She said stand up and hold arms, we did, and she then said, you brother Juju (mentioned his real name) has got HIV. We stood that way for few seconds”.*

Li *et al.* (2007) state that in some societies, such as in China, family is typically regarded as the individual unit of parents and siblings, and as such secrets are not expected among family members, therefore, involuntary disclosure is commonly practised.

#### **4.5.2.2 Sub-theme 2.2: The importance of disclosing to trustworthy persons**

Disclosing a positive HIV status to a trusted person is one of the highly essential factors to consider before disclosing. In most cases, PLWHA disclose to people whom they trust and when they perceive a strong social network (Serovich, 2006). This is depicted in a quotation from the study.

Siphiwe: *“Uh, firstly I disclosed my status to my mum. My mum didn’t say anything. She just gave me a hug and say, you know what my son, the only thing that you should do now is that you must do some follow-ups. And if is about time for you to take some medicine, take it. And now she is the one who is giving me the support all day long, every day, day in day out. If maybe it happen for me to end up spending the whole day out like somewhere far from home, or it can be also around home, she will call me, to remind me that okay, won’t you come to take your medication?”*

Chaudoir *et al.* (2011) state that trust is the overarching theme and core value for disclosure among PLWHA. They also indicate that the idea and feeling of trust – in many ways – is a determining factor when deciding to disclose. Sowell and Phillips (2010) also indicate that individuals might only disclose when they feel that the recipient of their disclosure can be trusted to keep the HIV status information private. More importantly, the act of disclosure requires the trust that the HIV-positive person will not be ostracised, criticised, stigmatised, or rejected after the event. Apart from trust, the decision to disclose one's HIV-positive status depends largely on what the perceived benefits are and whether those benefits outweigh the potential risks and harms associated with disclosure (Sowell & Phillips, 2010).

Li *et al.* (2007) add that decisions to disclose are based on trust and the values attached to the relationship with the recipient; they describe the family as being more trustworthy. In their study, Li *et al.* (2007) show that all the participants revealed that the first people they disclosed to was their families as they trusted them.

#### **4.5.2.3 Sub-theme 2.3: Preferred signals of disclosing without verbalising**

The following quotation depicts different ways or strategies used by PLWHA to disclose their HIV status.

*Juju: "... (Laughing). My mum likes using my roll-ons when I am at home. So, I (smiling) put my ARVs in my toilet bag, they were in a container written "my ARVs – my life". I knew that no ways my mum will see them when she will be using the roll-on. Okay. Indeed it worked for me. I put it in a way that I will realise if somebody touched it. Fine, the first day I realised that it was touched. I pretended as if there is nothing wrong. I could see the change in my mum's attitude or behaviour. She was restless, was like she wanted to ask me, but didn't".*

According to Lee and Rotheram-Borus (2002), there is strong evidence that careful planning and preparation for disclosure increases the likelihood of positive reactions and of achieving the different goals of disclosure. The planning process includes decisions about who to disclose to, why to disclose, when to disclose, where to disclose, and how to disclose.

Furthermore, Spieldenner (2009) explains that choosing the appropriate method is beneficial. He adds that the large majority of disclosures are face-to-face. However, sometimes disclosure can happen in writing, or in any other way.

#### **4.5.3 Theme 3: Reasons for disclosing own HIV status**

Three sub-themes emerged from this theme as: Disclosure influenced by seeking support from other people, disclosure is related to protecting other people from being infected, and disclosing an HIV-positive status relates to eradicating misconceptions about the disease.

##### **4.5.3.1 Sub-theme 3.1: Disclosure influenced by seeking support from others**

Disclosure involves evaluating the appropriateness of disclosing to a potential recipient. Individuals disclose to people they regard as helpful. This is shown in extracts from some of the participants.

*Charlize: "I wanted to tell my colleague who is also my home-mate because I was even planning to use her as my treatment buddy the day I feel like starting. My CD4 was still above 350, but I was just planning ahead that should I start, I will use her as my buddy".*

*Juju: "The thought that one day I will be sick. Yes, I knew that even if I am taking good care of myself, one day I will be sick and will need my family's attention. So, I decided to tell them. Though I was planning to tell my mum alone, and tell others after I have completed my degree. And as I am doing social work, there is a module on HIV and I learned that disclosure is a way of reducing the burden on one's shoulders".*

There are two main reasons for disclosure: Disclosure for support when talking to a trusted person can help the person to deal with his or her feelings, and disclosure for ethical reasons when the person is obliged to disclose to a person who is at risk of contracting the virus; such as sexual partners, health care workers, or care givers (Van Dyk, 2012). The disease progression theory proposes that the main reason why people disclose their HIV-positive status is necessitated when their HIV infection progresses to AIDS (Serovich, 2005).

In her study, Chirwa (2009) mentions that that almost all participants expressed a high level of anxiety after being diagnosed with HIV. Their anxiety was related to the fear of disease progression. The need for reassurance and support, for instance, motivated them to disclose their HIV-positive status to other people.

#### **4.5.3.2 Sub-theme 3.2: Disclosure is related to protecting others from being infected**

According to Van Dyk (2012), some people disclose for ethical reasons, such as protecting others from contracting the virus.

*Juju: "The other thing was to protect my family from me. If they know my status, they will know how to live with me without putting themselves at risk of being infected".*

In the context of society and community, disclosure is considered to be important for public health purposes in terms of preventing the spread of HIV. It is regarded as an ethical obligation not to intentionally infect other people with HIV (Kennedy, Cowgill, Bogart, Corona, Ryan & Murphy, 2010). Furthermore, non-disclosure of one's HIV-positive status prior to a sexual act could lead to criminal prosecutions in some countries, such as Canada (HIV Disclosure and the Law, 2011).

The Constitution of the Republic of South Africa, Act No 3 of 2003 as amended, recognises the importance of maintaining the confidentiality of the HIV status of a patient. However, the National Health Act (South Africa, 2003b) makes an exception to the rule of confidentiality when non-disclosure of a patient's personal health information would pose a serious threat to public health.

In this study, all the participants revealed their status; especially to their loved ones in order to protect them from being infected. They acted within the National Health Act. That makes them responsible citizens of South Africa. This finding is supported by a study conducted in China in which one participant revealed that "because I had sexual contact with my husband, if I didn't tell him and without any protection, I could have transmitted this disease to him. I thought it was unfair and irresponsible to him. Therefore, I told him" Li *et al.* (2007).

#### **4.5.3.3 Sub-theme 3.3: Disclosing an HIV-positive status relates to eradicating misconceptions about the disease**

Mary-Ann: *“My friend started talking bad about HIV infected people. So like, is like the way of... I don't know how to put it. Like the way of showing some sort of discrimination maybe. So, I ended up disclosing my status order to show her (Makwena) that people with HIV can still live a normal life and they don't have to be symptomatic before we can say the person is HIV - positive. It doesn't have to be written on their face to show that this person is HIV - positive. I just told her 'I am HIV - positive' but she didn't believe it”.*

Disclosure is determined by the cultural perceptions, understanding, beliefs and influences of HIV (UNAIDS, 2004). UNAIDS (2004) further states that people denounce or stigmatise PLWHA because of ignorance, a lack of understanding the disease, and misconceptions about how HIV is transmitted. Kaye (2004) argues that disclosure often involves risk, particularly when the information revealed is potentially embarrassing, negative, or emotionally intense. He further states that a decision to disclose HIV status involves a cognitive appraisal of negative consequences that is based on an individual's knowledge of HIV, attitudes toward HIV/AIDS, and the perceived social attitudes towards PLWHA.

Yang, Li, Stanton, Fang and Naar-King (2007) support this finding in their recommendation that in countries such as China where HIV still remains mysterious to many people, studies of HIV disclosure need to consider promoting HIV knowledge and correcting public misconception about HIV infection and transmission.

#### **4.5.4 Theme 4: Support versus lack of support post disclosure of HIV-positive status**

Disclosing an HIV-positive status can result in the gain of emotional, physical, and social support (Chaudoir *et al.* 2011). The emotional benefits include social support, relief that comes from sharing a burdensome secret, and the built-in reward of educating other members of society about HIV.

Two sub-themes emerged from this theme as: Support experienced after disclosing to relatives and friends, and acceptance versus rejection by partners after disclosure.

#### **4.5.4.1 Sub-theme 4.1: Support experienced after disclosing to relatives and friends**

The following quotations indicate the support received after disclosing.

Mokgadi: *“My sister is very supportive and I knew she wouldn’t judge me; she has always been very supportive to me with everything”.*

Masilo: *“Then eventually they arranged a meeting, I was not around. Everyone when I come home was just normal as, and then the support I got was so much amazing”.*

Rodkjaer, Sodemann, Ostergaard and Lomborg (2011) uphold that studies reveal high levels of supportive reactions after disclosure in diverse settings. They further state that many individuals gain increased levels and better quality of social support. They mention that despite the fact that HIV/AIDS is considered to be a socially degrading illness, if PLWHA get the necessary support, they turn to overcome challenges; such as stigmatisation, discrimination, and loss of self-esteem.

In support of Rodkjaeret *et al.* (2011), Stirratt, Remien, Smith, Copeland, Dolezal and Krieger (2006) state that in addition to obtaining social support, disclosure often has positive benefits for the HIV-positive person’s physical and mental health. They indicate that social support is consistently associated with better medical adherence. Furthermore, those who have disclosed report lower levels of emotional distress, depression, and anxiety than the ones who have not, although this relationship depends largely on the level of social support garnered from disclosure.

In their study, Remien and Bradley (2007) state that disclosure of a positive HIV status results in improved social support from both family and friends. They further explain that some of their participants indicated that support played a vital role towards acceptance of the status, as well as accessing medical care.

#### **4.5.4.2 Sub-theme 4.2: Acceptance versus rejection by partners after disclosure**

Disclosure can lead to disrupted relationships with families and communities, rejection by friends and close ties, separation from partners, abuse, criticism, ostracism, and isolation (Le Masters, 2009).

Masilo: *“Okay. But some of the girlfriends... others they just throw off the relationship”.*

Mary-Ann: *“I really got hurt (Laughing). I really got hurt, like part of me like I was even regretting myself for telling him. One day I have to tell him, but maybe I should have waited for six months maybe or a year before I can tell him. I still remember telling this other lady; Makwena, and she said to me maybe you should have waited for him to get attached to you”.*

The outcomes of HIV disclosure can be stressful but also rewarding. There is no a ‘rule of thumb’ for outcomes or consequences to be either positive or negative. However, evidence in general suggests that positive reactions to disclosure outweigh negative ones (Arnold *et al.*, 2008).

Parsons, Van Ora, Missildine, Purcell, and Gomez (2004) draw attention to negative experiences associated with the disclosure of an HIV-positive status to sexual partners; including stigma, rejection, loss of intimacy, and threats.

Serovich, Graftsky and Reed (2010) indicate that very few HIV-positive individuals report regret over previous disclosures. The regrets are generally falling into one of six categories: Lack of preparation, poor timing, wrong context or setting, unsatisfactory disclosure content, second-hand disclosure, and negative outcomes.

Serovich (2000) corroborates with Serovich *et al.* (2010) that PLWHA should avoid divulging and disclosing the news unplanned, since this often leads to significant regrets. Serovich (2000) recommends that individuals should start by assessing their own mental state and their feelings where after they should consider the mental state and any special circumstances of the recipient.



The regrets about disclosure are probably due to a lack of preparation, poor timing, and the wrong context or setting. As Serovich (2000) indicates, PLWHA should have assessed the mental status and readiness of their recipients.

#### **4.6 CONCLUSION**

This chapter presents the findings of the study on exploring the students' experiences in disclosing their HIV-positive status. The findings show that HIV-positive status disclosure is a stressful and difficult process for some HIV-positive students, whereas it was an easy task for some. The participants described disclosure as positive experience when it brought relief while it was considered a negative experience when they were exposed to stigma and discrimination. The study found that the positive consequences of disclosure included: psychological support, accessing medical care, living positively with HIV, and safer sex practices. On the other hand, rejection by sexual partners seemed to be one of the negative outcomes.

## **CHAPTER 5**

### **SUMMARY, RECOMMENDATIONS, LIMITATIONS, AND CONCLUSION**

#### **5.1 INTRODUCTION**

This chapter provides a summary and interpretation of the research findings, as well as a description of the recommendations of the study. The recommendations are based on the identified themes. The limitations of the study are also discussed.

#### **5.2 RESTATEMENT OF THE PROBLEM STATEMENT**

Disclosure of an HIV-positive status is a difficult and an emotional task for students, since it is associated with negative experiences; including blame, abandonment, physical and emotional abuse, violence, depression, discrimination, stigmatisation, and risk of losing life time opportunities such as employment. Nondisclosure promotes transmission of HIV due to lack of safer sex practices and hinder access to medical care (Serovich, 2006).

Abdool Karim & Abdool Karim (2010) state that disclosure of and HIV-positive status is associated with stigma, and its concomitant discrimination, which are some of the critical reasons for the failure of prevention programmes. Therefore, nondisclosure remains a major barrier to accessing HIV prevention, as well as care and support services.

On the other hand, Van Dyk (2012) outlines HIV disclosure as having the following benefits: Disclosure can help PLWHA to accept their HIV-positive status; and can ease access to medical services, care, and support including access to ART.

In line with the objective of the National Strategic Plan (NSP) to address social and structural barriers to HIV, STIs, and TB prevention and care; the Health and Wellness Centre has established a support group for students living with HIV, has formed a partnership with the Department of Health in issuing antiretroviral therapy (ART), and is monitoring progress of those HIV infected students (SANAC, 2013). There are a criteria used to determine an individual's eligibility for initiation on ART.

There are quite a number of students who are HIV - positive; some are already on ART while some are eligible but not yet on treatment. When advised to join the support group or to start ART, some students who are eligible show some signs of reluctance. In most cases, the reason behind the reluctance is not being ready to disclose to anyone except to health care workers. They are usually concerned that their families might somehow find out that they are taking some pills and demand some explanations. It seems that students are afraid to disclose their HIV-positive status to any person except to the health care workers. As a result, the researcher who is a clinical nurse practitioner at the Health and Wellness Centre, Turfloop Campus, decided to explore the experiences of the students at the University of Limpopo, Turfloop Campus in disclosing their HIV-positive status.

Aim of the study:

- The aim of the study was to investigate the experiences of students at the University of Limpopo, Turfloop Campus in disclosing their HIV-positive status.

Objectives of the study were:

- explore the experiences of the students with regard to disclosure of their HIV-positive status;
- describe the experiences of the students at the University of Limpopo with regard to disclosure of their HIV-positive status; and
- Make recommendations based on the findings of the study.

Research question:

- What are the experiences of students at the University of Limpopo, Turfloop Campus in disclosing their HIV-positive status?

### **5.3 SUMMARY OF FINDINGS**

#### **Theme 1: Experiences related to the disclosure of HIV-positive status**

For some participants, it was difficult to disclose their HIV-positive status while for others, disclosure was easy. Those different experiences were caused by factors;

such as an individual's acceptance of the status, as well as the anticipated perception and reaction of people they considered disclosure to.

#### Disclosure of an HIV-positive status as a difficult task

The findings of the study show that disclosure of an HIV-positive status still remains a challenge for some PLWHAs. Most participants revealed that it was certainly difficult for them to disclose such personal information to their families and their loved ones. They were concerned about what their confidants might think about them and how they would react. Greeff (2013) indicates that disclosure is associated with anxiety because an individual who is ready to disclose would never be able to predict the response to their disclosure.

#### Disclosure of an HIV-positive status as an easy task

Some participants found the experience of disclosure easy while it might not have been easy to disclose. Like any other person who was diagnosed with HIV, they had some disturbing feelings about the diagnosis and how to disclose. The main disturbing issue was identified as fear of what other people would say or think about their HIV-positive status. Despite all the mixed feelings, some participants were easily accepted and embraced after disclosing their HIV status. That was owing to the substantial improvements in the awareness and understanding of the general public in relation to HIV issues. Disclosure is gradually shifting from a difficult (if not impossible) assignment to an easier issue to deal with. This is also acknowledged by HIV Disclosure and the Law (2011) that over the past twenty years of the HIV epidemic, there have been some understanding and wider acceptance of HIV than in the past.

#### **Fear of misconceptions by others related to disclosing one's status**

Participants were tormented by fear with regard to anticipated misconceptions by their confidants or the people they disclosed to. They feared being judged and rejected by their families and their loved ones. They were concerned about what would happen after disclosure and all of them expected worse outcomes. Some feared to be labelled as promiscuous, not taking care of themselves, and having multiple sexual partners. Congruent to the findings of this study, Liamputtong (2013)

states that HIV infected people are often classified as sinful and evil and perceived as disreputable and unworthy individuals with immoral characters.

This study found that fear of stigma, discrimination, and rejection were major barriers to disclosure. However, most participants indicated that they were anticipating any response or attitude from their confidants.

### **Disclosure brings about feelings of relief**

Participants indicated that they felt relieved after disclosure. Some revealed that they experienced a variety of emotions; such as regret, judgment, fear of rejection, fear of upsetting family members, and fear of accusations of infidelity. PLWHAs may experience many different emotions during the entire disclosure process because disclosure is a complex and multi-layered process. These emotions arise from an individual who share information without knowing how the receiver of that information would respond. Despite the negative feelings as indicated above, all participants indicated that they felt relieved after disclosure. The support they received from their families and their loved ones gave them a sense of belonging and freedom. An individual could experience the whole spectrum of emotional turmoil; however, it depends on the factors that accompany disclosure. Literature strongly suggests that with disclosure comes a heightened sense of self-understanding, healing, authenticity, an enhanced sense of accomplishment and pride, empowerment, purpose, and relief from the burdens of keeping HIV a secret (Holzemer, Uys, Makoe, Stewart, Phetlu, Dlamini, Greeff, Kohi, Chirwa, Cuca & Naidoo, 2007).

### **Improved family interpersonal relations after disclosure**

The findings of this study show that disclosure results in improved interpersonal family relations. One participant stated that after disclosure he even felt like the family was almost smothering him with love and support. In one instance, a participant indicated that he was afraid to disclose his HIV status to the family because his sister regarded him as a disgrace to the family owing to his sexual orientation. The participant mentioned that after his mother disclosed on his behalf, his sister was the first to give him a hug and reassured him of their undying love and support. Literature confirms that in a family unit, there is an increased level of trust

and comfort to such an extent that it becomes easier to confide in and get the support one envisages. The researcher of this study is convinced that disclosure of a positive HIV status strengthens relationships and improves family cohesion.

## **Theme 2: Strategies used to disclose an HIV-positive status**

People react differently to the disclosure of an HIV-positive status. Again, people disclose their status differently owing to the fact that there is neither a right nor a wrong way of disclosing (Arnold *et al.* 2008).

### **Processes of disclosure**

The choice to disclose one's status remains of the responsibility of the infected person. Nonetheless, disclosure might result in disadvantages; such as social isolation, diminished access to health and social services, and a diminished sense of personal control over one's status (Greeff *et al.* 2013). PLWHAs should disclose their status voluntarily without any external persuasion. These disadvantages support the opinion that disclosure should be voluntary. Unfortunately, disclosure is not always voluntary. At times, the status of PLWHAs is disclosed by other people without even considering the PLWHAs' right to privacy, confidentiality and autonomy (Greeff *et al.* 2013).

The findings of this study reveal that in some families family values deter HIV the the voluntary disclosure process. Some participants explained that the people they disclosed to, in most cases their mothers, decided to disclose their statuses to other family members without their consent. They (their mothers) felt that the families need to know the status of the ones who were infected in order for the families to give them support. Li *et al.* (2007) concur with the findings of this study that in some societies, such as in China, the family is typically regarded as a solid unit that consists of parents and siblings; secrets are not expected among family members. Consequently, involuntary disclosure is commonly practised.

### **Disclosing an HIV-positive status to a trustworthy confidant**

Disclosing an HIV-positive status to a trustworthy person is regarded as a good and beneficial strategy to overcome the burden of HIV. The decision to disclose one's HIV-positive status is dependent on the individual's decision with regard to whom,

what, where, and when to tell. PLWHAs see trust as the central theme and core value of disclosure. HIV infected individuals should only disclose when they feel that their confidants can be trusted to keep the information about their HIV-positive status confidential. More importantly, the act of disclosure requires the trust that the HIV-positive person would not be judged, humiliated, stigmatised, and rejected after disclosure (Sowell & Phillips, 2010).

Most participants in this study indicated that they disclosed their status to people they regarded as trustworthy. They still felt they needed to be in control of their highly personal information. Families and relatives were rated as the most trustworthy population in this study, followed by friends. Literature is congruent to this finding, since it shows that HIV-positive persons more frequently are inclined to disclose to family and relatives than to friends due to the perceived probability of gaining support and the inherent level of trust (Arnold *et al.* 2008). The trustful relationship with health care workers was also mentioned by the participants in this study. That was different from the findings of a study conducted by Greeff *et al.* (2008) that concluded participants had distrustful relationships with nurses and health workers.

Literature supports that distress of whom, how, and when to tell, as well as the management of information about their condition could potentially become a source of fear and anxiety for many PLWHAs and might prohibit them from disclosing. Therefore, they cannot access much-needed care and treatment. (Greeff *et al.* 2013).

### **Preferred and various methods of disclosing HIV status**

Literature provides strong evidence that careful planning and preparation for disclosure increase the likelihood of positive reactions and of achieving the desired goals of disclosure. The planning process includes decisions about whom to disclose to, why to disclose, when to disclose, where to disclose, and how to disclose (Murphy, Roberts & Hoffman, 2003).

In this study, participants used a variety of preferred methods other than verbal communication to disclose their status. They carefully planned their disclosure. They considered factors like whom, when and how to tell. Some participants used their medications to disclose. They revealed that they were taking their ARVs daily in front of other people at the correct time knowing exactly that the people would be

inquisitive about the condition they are taking the medications for; they were ready and willing to tell the truth. Another participant put his medication where his mother could see it, knowing very well that she would ask about the medication. Those experiences clearly indicated that they gave disclosure a careful thought and they tried to avoid either the stress or rejection during face-to-face encounters. The researcher of this study is convinced that the use of preferred methods of disclosure has proved to be effective and efficient, since it yields the desired outcomes.

### **Theme 3: Reasons for disclosing one's own HIV status**

Every person is regarded as a unique human being with unique needs, understandings, challenges, and reactions. Everyone reacts and discloses differently than other individuals. There is neither a right nor a wrong way and time to disclose (Ash & Rebellalo, 2008). Greeff *et al.* (2013) divide the reasons to disclose into personal needs, response to the needs of other people, and fulfilling interpersonal needs. In the same vein as Greeff *et al.* (2013), participants in this study disclosed for the following reasons.

#### **Seeking support from other people**

The findings of this study found that after accepting their status, participants disclosed because they needed support from the people around them. Although PLWHAs run the risk of stigma, the literature emphasises the therapeutic effect of HIV disclosure, particularly because it means they are then able to access social support. Participation in support groups encourages people to disclose their status, since they share their experiences and give one another psychological support during group therapy meetings. The findings in this study established that all the participants wanted support from their families. Some even confirmed that they knew for sure that as the disease progresses, they would somehow become ill and need family support. All the participants joined the support group because they wanted to share the burden of HIV and access psychosocial support. Research shows that disclosure could lead to important social support that might mitigate the negative effects of stress. Support from significant others is widely believed to buffer the impact of a wide variety of stressful life events, including chronic illness (Greeff *et al.* 2008). The researcher of this study established all participants disclosed to health



care workers in order to acquire some instrumental support in the form of psychosocial support services, medical treatment and care, and information about HIV / AIDS. In consistent with these findings, a study by Chirwa (2008) reports that the majority of patients disclose for expressive support, reassurance, and medical reasons.

### **Disclosing to protect other people**

The findings of this study established that participants disclosed in order to protect other people from being infected. One participant disclosed to the whole family because she wanted to comply with the prevention of mother-to-child transmission (PMTCT) programme. She wanted her child to be exclusively formula fed. For this reason, she had to disclose her status in order to protect her child. Some participants disclosed to their newly-found sexual partners in order to alert them about their HIV status. Other participants disclosed to their siblings because they wanted to assist them not to make the same mistakes. They tried to raise people's awareness about the reality of HIV. In that way, the PLWHAs used their status as a psychological shield not to infect others and to clear their conscience. These findings corresponds with the findings of the study conducted by Greeff *et al.* (2013) which points out that people disclose in order to clear their conscience.

### **To eradicate misconceptions about HIV**

Many participants disclosed their HIV-positive status in order to clear some misconceptions about HIV. Some participants felt that it was their obligation to inform and educate other people about HIV in order to change the misconceptions and the perceptions in relation to HIV / AIDS. At some point during this study, some participants disclosed impromptu because some people were talking badly about HIV and HIV infected people at that moment. One participant stated that she bumped into some community members who even alleged that some people on the HIV poster were looking as if they were hired to tell people that they are HIV-positive, since they were looking pretty healthy. She then had to disclose her status to clear those misconceptions. Participants learned to recognise teaching moments and started giving members of the community more information about HIV / AIDS. According to the literature, these findings are not unique. Greeff *et al.* 2008, emphasise that

people sometimes look at the physical appearance of HIV-positive persons and accuse them of getting paid to pretend that they are HIV-positive.

#### **Theme 4: Support versus lack of support after disclosure of an HIV-positive status**

##### **Support versus lack of support post disclosure.**

Literature points out that HIV-positive people experience an increased level of support after disclosure. In this study, a support group is a way of showing support to the students who have disclosed. The researcher indicated in Chapter 3 that all the participants belonged to the same support group. Those who were eligible to start treatment reaped the benefits of disclosure, since they accessed and enjoyed those support services.

##### **Acceptance versus rejection by partners after disclosure**

Disclosure of a positive HIV status could result in either partner rejection or acceptance. Most people with HIV have disclosed their HIV status to someone, often with mixed results. Although some people are accepting and supportive, others overtly reject or subtly distance themselves from the person with HIV (Liamputtong, 2013). In this study, some participants shared that they were rejected by their sexual partners after disclosing their status. They indicated that they had disclosed as soon as they found new love in order to protect their partners, not knowing that their partners would reject them. Some argued that they accepted it as their ethical responsibility and their moral obligation not to stay in a relationship while keeping such far reaching secrets. They did not consider their partner's readiness to receive such information. In this regard, readiness is discussed in terms of knowledge, information, attitude, and commitment to intimate relationships. Literature states that there is neither a right nor a wrong time to disclose but emphasises the importance of whom and when to tell.

In support of this study, Serovich (2000) indicates that the mental status and readiness of the recipients should be considered before disclosing. Literature confirms that lack of preparation, poor timing, and the wrong context or setting result in remorse, such as partner rejection.

## **5.4 RECOMMENDATIONS**

The recommendations of this study have been extracted from the findings of this study and from other studies that are utilised in the presentation and discussion of the research findings. The proposed recommendations relatively address the proposed significance of the study that aims at bridging the identified gaps and suggested research areas that would promote disclosure of an HIV-positive status among university students.

### **Awareness**

- The DOH, in partnership with all stakeholders, should embark upon an awareness campaign specific to disclosure. During this campaign, they should educate the community about the importance of disclosing, the importance of giving a receptive ear to the person disclosing, and the dangers that are associated with non-disclosure.
- There should also be a campaign that specifically addresses stigma, discrimination, and the impact thereof. Stigma and discrimination will continue to exist as long as societies generally have a poor understanding of HIV/AIDS and the pain and suffering caused by negative attitudes and discriminatory practices. The fear and prejudice that lie at the core of the HIV/AIDS-related discrimination need to be tackled at community and national levels, with AIDS education playing a crucial role.
- The health professionals should develop an HIV disclosure model without impeding other people's rights that will eventually normalise HIV, since it is an issue in some other countries such as China.
- HIV-infected students who belong to the support group and who have started ARTs should disclose in public, come out as role models, and lead by living fulfilled and successful lives in order to increase the visibility of students with HIV/AIDS and to sensitise people that HIV/AIDS is a normal part of any society.

## **Education and training**

- All HIV counsellors in their respective categories (from lay counsellors to nurses) should receive formal training with intensified counselling skills to enable them to provide thorough counselling, show the infected individual the pros and cons of disclosing, assist her or him to plan ahead, and be bio-psycho-socially ready for disclosure while bearing in mind the probability of negative societal attitudes towards PLWHA.
- PLWHA should be trained and educated on emotion management. This is a course about generally negotiating one's own and other people's emotions. This could be done in sessions during continual counselling. It was indicated from the study that some participants disclosed because other people were talking badly about HIV and HIV infected people. Although they wanted to clear the misconception around HIV, it appeared that they disclosed out of anger. They were not prepared; they did not even bother to establish the recipient's understanding and perception of HIV. This could result in negative outcomes.

## **Information**

- The strategies or signals that were used by participants to disclose their HIV status should be discussed among counsellors and health professionals as a way of encouraging students and all other PLWHA to disclose. This method is beneficial to those members of society who cannot bear the pain of having to disclose face-to-face. It also gives the recipient time to deal with his or her emotions and attitudes.
- The Health and Wellness Centre should have and display important, accessible, and prominent information about HIV, disclosure, and factors associated with non-disclosure; particularly in waiting areas and on websites.

## **Further research**

- The Higher Education HIV and AIDS Programme (HEAIDS) – as the custodian of HIV/AIDS programmes at institutions of higher education in association with all South African universities, universities of technology, and colleges – should conduct research to establish the pattern of disclosure at all universities in relation with access to HIV preventive, care, and support services.

## **5.5 CONTRIBUTION OF THE STUDY**

From the recommendations made, there is a possibility that counsellors' training could be upgraded for the benefit of society. Strategies used to disclose need to be widely discussed and, if workable or attainable, those strategies should be endorsed in their newsletter, the Incoperosano.

## **5.6 LIMITATIONS OF THE STUDY**

The study was conducted only at the University of Limpopo, Turfloop Campus. Therefore, the study cannot be generalised to other universities. The study was qualitative and comprised a small sample, therefore these, findings may not be generalizable.

The findings may be biased, since all participants belonged to the same HIV support group. That might have had an influence on the nature of the responses and views they expressed during the study.

## **5.7 CONCLUSION**

This chapter discusses the conclusion of the research that was conducted in relation to the problem statement, aims, and objectives of the study. A qualitative approach was used to explore the experiences of the students with regard to disclosure of their HIV-positive status as indicated in Chapter 3. In-depth interviews were conducted and participants described their experiences with regard to disclosure of their HIV-positive status as indicated in Chapter 4. Recommendations were made from the findings of the study as indicated above.

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## APPENDIX A: ETHICAL CLEARANCE CERTIFICATE FROM MREC

UNIVERSITY OF LIMPOPO  
Medunsa Campus



### MEDUNSA RESEARCH & ETHICS COMMITTEE

#### CLEARANCE CERTIFICATE

**MEETING:** 05/2013  
**PROJECT NUMBER:** MREC/H/109/2013: PG  
**PROJECT:**  
**Title:** The experiences of students in disclosing their HIV positive status at the University of Limpopo Turfloop campus  
**Researcher:** Ms SR Mampa  
**Supervisor:** Prof RN Malema  
**Co-supervisor:** Prof ME Lekhuleni  
**Department:** Nursing & Human Nutrition  
**School:** Health Sciences  
**Degree:** MCur

#### DECISION OF THE COMMITTEE:

MREC approved the project.

**DATE:** 06 June 2013

  
PROF GA OGUNBANJO  
CHAIRPERSON MREC



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

#### **Note:**

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

*Finding Solutions for Africa*



## APPENDIX B: PERMISSION FROM THE ACTING DEAN OF STUDENTS



### University of Limpopo

Executive Assistant to the VC and Principal  
Private Bag X1106, Sovenga, 0727, South Africa  
Tel: (015) 268 2141/2160, Fax: (015) 267 0142, E-mail:asaph.ndhlovu@ul.ac.za

Ms SR Mampa  
Department of Nursing & Nutrition  
University of Limpopo

11 July 2013

#### PERMISION FOR CONDUCTING RESEARCH (MASTER OF CURATIONIS)

In the light of your research proposal with respect to the your envisaged qualification and the ethics clearance certificate issued by MREC , you are granted permission to conduct research on your approved topic.

Kindly adhere to the necessary research protocol and procedure and matters of confidentiality on the part of interviewees.

Regards

  
Dr/AE Ndhlovu



## APPENDIX C: PERMISSION FROM HEALTH AND WELLNESS MANAGER



**University of Limpopo**  
**Student Health and Wellness Centre**  
Private Bag X1106, Sovenga, 0727, South Africa  
Tel: (015) 268 3726, Fax: 0865145967, Email: norman.letebele@ul.ac.za

Dear Ms SR Mampa

### PERMISSION TO CONDUCT A STUDY


Permission is here forth granted to you to conduct a study at the UL Health & Wellness Centre that will propel your fulfilment of your Masters of Curationis programme

We hope your findings will be for the purpose of your research only and not for publication without our consent

It will be expected of you to share the confidential findings with the centre management

We wish you the best with your academic year

Regards,



08/08/2013

ON LETEBELE  
Head: Health & Wellness Centre

## APPENDIX D: CERTIFICATE FROM INDEPENDENT CODER

Qualitative data analysis

---

Master's degree in Nursing Science

Mampa S

THIS IS TO CERTIFY THAT:

Prof Maria Sonto Maputle has co-coded the following qualitative data:

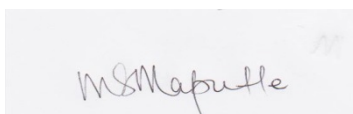
Eight Individual interviews and field notes

For the study:

The experiences of students in disclosing their HIV-positive status at the University of Limpopo Turfloop Campus.

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

Prof MS Maputle

A rectangular box containing a handwritten signature in black ink that reads "MS Maputle".

**APPENDIX E: INFORMED CONSENT**

Dear participant.

I, Seponono Raisibe Mampa, a Master’s of Curationis (MCur) student, am hereby inviting you to participate in a research study entitled **“The experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus”**.

I am presently enrolled at the University of Limpopo, Turfloop Campus, and I am also a clinical nurse practitioner at the Health and Wellness Centre on this campus. I have realised that there are students who are HIV-positive who seem afraid to disclose their HIV status to their family and friends. This somehow delays their access to ARTs and other benefits. You are requested to participate because you have already disclosed, you are in the support group. Your participation in this study could help other students who are HIV-positive but miss all the benefits of disclosure. Your participation is voluntary, you will not be penalised if you do not participate in the study or if you withdraw. If you agree to participate in the study, you will be given a copy of this document to sign. Kindly note there won’t be any remuneration for participating in this study.

By virtue of attaching my signature on this document, I ....., give consent to be interviewed by Ms S. R. Mampa, a student at the University of Limpopo. I understand that I will be part of this research aimed at describing the experiences of university students in disclosing their HIV-positive status. Information collected from this study will assist other students who are HIV-positive but who are afraid to disclose. I understand that I will be interviewed and asked personal information related to my experiences in disclosing my HIV status.

I understand that this interview is done freely and I have been informed that it is voluntary and that I can terminate at any given time without any penalties. I have been informed that my responses during the interview will be kept confidential and

only supervisors will have access to information. I have been told that I will be given a fictitious name which will be used throughout the study.

Signature of participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of witness: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of the researcher: \_\_\_\_\_ Date: \_\_\_\_\_

## **APPENDIX F: INDIVIDUAL IN-DEPTH INTERVIEW GUIDE**

Title of the study: The experiences of students in disclosing their HIV-positive status at the University of Limpopo, Turfloop Campus.

Participant folder number: \_\_\_\_\_

Date: \_\_\_\_\_

### **Section A: Social demographic data**

Please tell me about yourself.

(Probes: Age, gender, educational level, marital status, and religion.)

### **Section B: Individual in-depth interview guide**

Central question: Would you please tell me about your experience in disclosing your HIV-positive status?

Q1: What motivated you to disclose?

Q2: Describe how you disclosed your status and to whom did you disclose?

Q3: How did you feel after disclosing your status?

Q4: Describe the reaction of the person you disclosed to?

Q5: What advice would you give to people who would like to disclose?

Thank you very much for sharing this sensitive information with me.

## **APPENDIX G: TRANSCRIPT OF VERBATIM DISCUSSION WITH ONE OF THE CLIENTS**

Juju: (pseudonym)

Interviewer: Would you please describe your experiences in disclosing your HIV-positive status?

Juju: Some things are just heavy when you are far from them. The closer you get, the more the easier you realise they are. With me it was like ABC. I got what I was not expecting. I disclosed to my mother who then gave me all the support I needed. I can say she is spoiling me now. The love, attention and care that I get from her, is now worrying me, because my other siblings will start complaining. The experience was so good. She never said anything weird; instead she supported me and even tried to be my advocate. She told my whole family to take good care of me and to give me support.

Interviewer: What motivated you to disclose your status?

Juju: The thought that one day I will be sick. Yes, I knew that even if I am taking good care of myself, one day I will be sick and will need my family's attention. So I decided to tell them. Though I was planning to tell my mum alone, and tell others after I have completed my degree. And as I am doing social work, there is a module on HIV and I learnt that disclosure is a way of reducing the burden on one's shoulders. The other thing was to protect my family from me. If they know my status, they will know how to live with me without putting themselves at risk of being infected.

Interviewer: Would you describe how you disclosed your status and to whom?

Juju: I ..., (laughing). My mum likes using my roll-ons when I am at home. So, I (smiling) put my ARVs in my toilet bag, they were in a container written "my ARVs – my life". I knew that no ways my mum will see them when she will be using the roll-on. Okay. Indeed it worked for me. I put it in a way that I will realise if somebody touched it. Fine, the first day I

realised that it was touched. I pretended as if there is nothing wrong. I could see the change in my mum's attitude or behaviour. She was restless, was like she wanted to ask me, but didn't. The following day, I left my medication again in the toilet bag. She used my roll-on again. She said nothing, I also ignored her. I could see that the poor woman was struggling within herself. On the third day, she came to my room during the day. I was just chilling, listening to my music. She said to me, "Is it true". I said what mum. I like laughing, so I laughed as usual, and said mum what is true. She said again, is what I saw a reality or am I dreaming? I felt it. I didn't want to suspend her more than I did, so I said yes. I looked down. She came closer, gave me a hug and said, it's fine my boy. You will be okay. Keep studying; don't allow this to ruin your life. She asked me since when have I started taking ARVs, I told her. She then asked me if I am comfortable in telling my sister and my two younger brothers. Before I could respond, she said, "Yes they need to know so that they support you". HIV or not you are still their brother. You are still one of them. That evening, she prepared a very nice supper, she called us to sit around the table and eat together. Normally everyone sit and eat wherever he or she feels like. I knew that she wants to tell them. I didn't have any hard feelings on that. Okay. We enjoyed our meal, thereafter she said, "My children, there is something I need you to know". She was just looking down. We were all ears. She said, "If you wake up one day and learn that I your mother am HIV - positive, how will you feel and what will you do"? We remained quiet for some few minutes. Then my youngest brother said, "I will feel bad, and won't do anything, but you will still be my lovely mother". The three of us remained quiet. She asked us individually, we responded like the first one. She said, okay, thank you for that response. She was struggling, her lips were even shaking. She said stand up and hold arms, we did, and she then said, you brother has got HIV. She mentioned my name. We stood that way for few seconds. In mind I was so scared my sister will yell at me because she in the first place didn't accept my being gay. She was always calling me names, telling me that I am a disgrace in that family. You will be surprised one day; she was the first to give me a

hug, and to tell me how much she loves me. They all did. I realised that I took full three years, hesitating to disclose, because I was afraid of how they could react. They are all supportive. At times I feel that they are overdoing the support. That's how it went.

Interviewer: Okay. It was a touching event neh!

Juju: Very. I wished I could undo something, though I didn't know what.

Interviewer: Any other person you have disclosed to?

Juju: My sex partner. Actually I separated with the one I had before. Then this new one, I told him that I am positive the day we met. As to be fair, he is the one who disclosed first, then I also disclosed my status. It was like a give and take situation. No one was surprised or shocked. We were just even. Apart from them, only health workers.

Interviewer: Okay Juju. How was their reaction?

Juju: They were so supportive, so understanding like I said.

Interviewer: How did you feel after disclosing?

Juju: Like I said, I felt like a new born baby. I have never seen a person being angry to a new born. I felt so relieved, so loved and well taken care of. I started to see a family with another eye. I realised how important a family is.

Interviewer: What could be improved regarding how you disclosed?

Juju: Nothing sister. A toilet bag worked for me. I wanted to tell mum verbally, but each time I tried, I was like becoming dumb. So to me that was the best way of disclosing. The main aim was to send the message home, and in deed the message reached its destiny.

Interviewer: You delivered the message? Okay. On conclusion Juju what advises will you give to the people who would like to disclose?



Juju: Guys you are detaining yourselves if you are still living in fear, thinking that people will reject me, they will treat me like trash. No. Free yourselves. By telling someone, you are inviting that person to carry the luggage with you. You may end up infecting you family or whoever. You better be safe than sorry, thus you will be saving others

Interviewer: EH, Juju, I would like to thank you for taking part in this study. I hope one day HIV will be history. You will pad yourself on the shoulder and say "I have contributed". Thank you so much. Juju:

Juju: You are welcome.

APPENDIX H: EDITING CON



\* The stars that tell the spade when to dig and the seeds when to grow \*

\* Isilimela – iinkwenkwezi ezixelela umhlakulo ukuba mawembe nembewu ukuba mayikhule\*

P O Box 65251  
Erasmusrand  
0165

29 May 2014

Dear Ms Seponono Mampa

**CONFIRMATION OF EDITING THE THE MINI-DISSERTATION WITH THE  
TITLE THE EXPERIENCES OF STUDENTS IN DISCLOSING THEIR HIV  
POSITIVE STATUS AT THE UNIVERSITY OF LIMPOPO, TURFLOOP  
CAMPUS**

I hereby confirm that I have edited the abovementioned dissertation as requested.

Please pay particular attention to the editing notes AH01 to AH16 for your revision.

The tracks copy of the document contains all the changes I have effected while the edited copy is a clean copy with the changes removed. Kindly make any further changes to the edited copy since I have effected minor editing changes after removing the changes from the tracks copy. The tracks copy should only be used for reference purposes.

Please note that it remains your responsibility to supply references according to the convention that is used at your institution of learning.

You are more than welcome to send me the document again to perform final editing should it be necessary.

Kind regards

A handwritten signature in black ink, appearing to read 'André Hills', enclosed in a rectangular box.

André Hills  
083 501 4124

