A narrative study of students' and staff's experiences of living with HIV and AIDS at Rhodes University

by

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A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy in Developmental Sociology,

in the

Department of Sociology

of the

Faculty of Humanities

Rhodes University

Supervised by

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2020

“I didn’t know my own strength…” – Whitney Houston

ABSTRACT

A narrative study of students' and staff's experiences of living with HIV and AIDS at Rhodes University

Research on HIV and AIDS in university settings, especially research exploring the experience of living with the disease, has been minimal. As a response to the knowledge and research gaps, this thesis is a qualitative study involving students and staff living with HIV (LWH) and accessing treatment (ART) at the Rhodes University Health Care Centre.

This study explored the personal and social symbolisms as well as meanings attached to living with HIV, through in-depth interviews with ten students and staff living with HIV, all purposively sampled and recruited through the Rhodes University Health Care Centre.

Using social constructionism, symbolic interactionism and the theory of biographical disruption, the narratives revealed a positive and inspirational side of living with HIV and AIDS – especially emphasizing that PLWHA do not have to surrender to the deadly narrative of the disease. It became evident that stigma, both internal and external, largely influences illness narratives. Furthermore, the study revealed the social reconstruction of life narratives both in order to understand the illness in terms of past social experiences and to reaffirm the impression that life has a course and the self has a purpose. All participants found that accessing treatment from the Rhodes University Health Care Centre positively influenced their experiences of adherence and reconstruction of narratives.

The study indicates that HIV-related interventions in place at the university need to pay more attention to the psychosocial needs of PLWH, involvement of PWLH, as well as keeping up with the continuously changing global HIV narrative. The study argues for more attention to in-depth experiences and personal narratives in HIV and AIDS, and PLWHA education at Rhodes University.

Key words: HIV/AIDS, HIV at university, stigma, disclosure, adherence, HIV programmes, Rhodes University, illness narratives.

ACKNOWLEDGMENTS

My life is a testimony of God’s love and grace. To God be the glory!

I would like to extend my sincerest gratitude to the ten research participants without whom this research would not have been possible. Thank you for entrusting me with your stories and welcoming into a part of your lives. I appreciate the time, effort and input each one of you contributed to the interviews and the complete research project. I have learned immensely from each one of you.

To the Rhodes University Health Care Centre staff and Rhodes University Wellness Office staff – thank you for your service to Rhodes University and to people living with HIV. Your dedication and commitment to your work is commendable. Thank you for your patience and kindness towards me.

To my supervisor and friend, Professor Michael Drewett, thank you! You have guided and supported me through an Honour’s Degree, Master’s Degree and now Doctoral Degree – words cannot express how grateful I am. Thank you for being a part of the most challenging yet rewarding journey of my life.

Mama, Papa Joe and Mbojie, my family, ngiyabonga. The three of you have been my biggest cheerleaders and supporters since day one. Thank you for allowing me to follow my dreams even when they did not make sense to you. Thank you for the prayers and the unconditional love.

To all my friends and family who continuously encourage me and remind me how great I am when I need it the most, thank you! Your affirmations and support have kept me going throughout this journey. To Ntombi, your memory has kept me going; even though I wish you were here to celebrate with me, I know you are a proud sister.

Professor Moodly, my mentor, thank you for emboldening me to trust myself more and doubt myself less. You’re my greatest inspiration.

I would like to thank the Sociology Department for being my family away from home. You have all contributed to the amazing memories at Rhodes University.

The Oprah Winfrey Leadership Academy Foundation has been a part of my journey since first year and continues to be readily available to assist when needed, I appreciate the support. Mom Oprah, thank you for seeing the IT in me.

I would like to extend gratitude to my bursary holder, the Atlantic Philanthropies, for having provided me with the funding to engage in this research and pursue my fourth degree. The funding is truly appreciated and has contributed immensely in my ability to complete my research.

Thank you to Rhodes University for the conducive environment and all the opportunities I was presented with. Because of this university, I have qualifications, friendships and memories that will last me a lifetime.

Lastly, to every single person who has shown genuine interest in my learning and development and whose belief in me kept me going on days when I did not believe in myself, thank you eternally!

"I come as one, but I stand as 10,000" – Maya Angelou

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
DoH	Department of Health
DHET	Department of Higher Education and Training
GBV	Gender-Based Violence
GP	General Practitioner
HCC	Health Care Centre
HEAIDS	Higher Education HIV and AIDS Programme
HH	Higher Health
HHDC	Humanities Higher Degree Committee
HIV	Human Immunodeficiency Virus
NDOH	National Department of Health
NHI	National Health Insurance
OIs	Opportunistic infections
PLWHA	People Living With HIV/AIDS
PLWH	People Living With HIV
PEP	Post-Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
RUESC	Rhodes University Ethical Standards Committee
RUESCH	Rhodes University Ethical Standards Committee Handbook
RU	Rhodes University

SACPO	South African College and Principals Organisation
San	Sanatorium
SANBS	South African National Blood Service
SHARC	Student HIV/AIDS Resistance Campaign
TAC	Treatment Action Campaign
TVET	Technical and Vocational Education and Training
U=U	Undetectable = Untransmittable
UNAIDS	United Nations Programme on HIV/AIDS
USAf	Universities South Africa
UTT	Universal Test and Treat
WHO	World Health Organisation

CHAPTER ONE: INTRODUCTION AND BACKGROUND

"Research is formalized curiosity. It is poking and prying with a purpose."

— Zora Neale Hurston

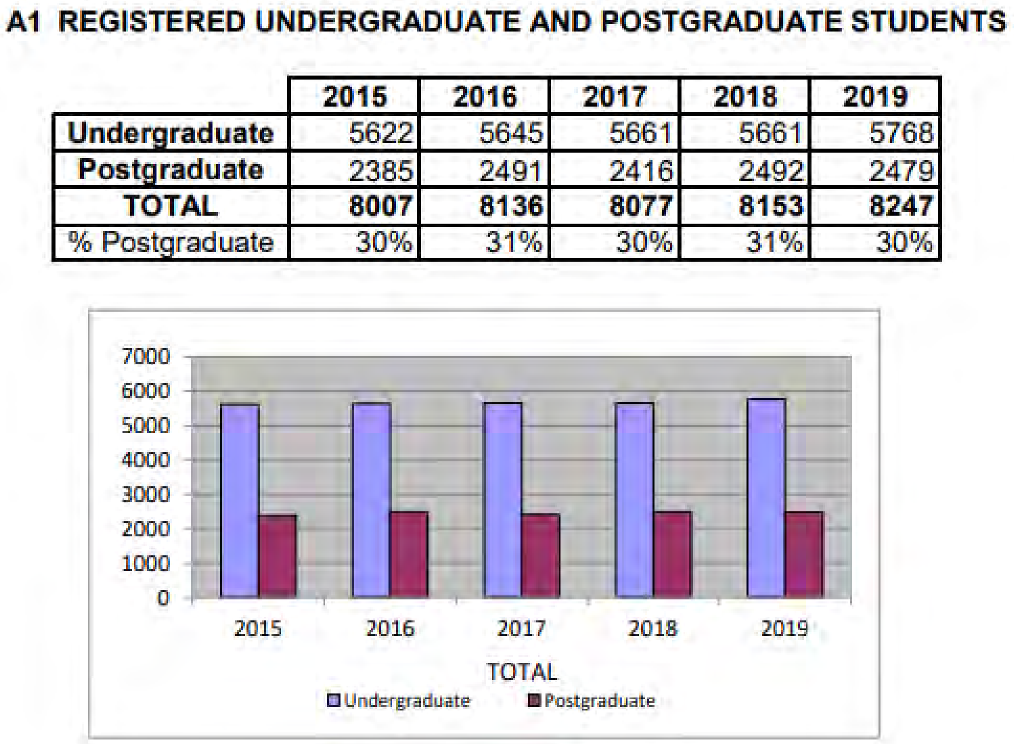
1.1 INTRODUCTION

Even though the treatment of HIV and AIDS is possibly one of the most remarkable success stories in the history of medicine (Bartlett & Finkbeiner, 2006), HIV continues to be a significant global public health issue as the number of people testing positive keep increasing. Over 33 million people have succumbed to the disease so far (WHO, 2020). At the end of 2019, 38 million people globally were estimated to be living with HIV (LWH). Of the 38 million, 68% of adults and 53% of children LWH were receiving lifelong antiretroviral therapy (ART). On a global and national scale, much work still needs to be done to combat the effects of the disease. South Africa has the largest HIV and AIDS epidemic and ART programme globally (Karim & Baxter, 2010: 37; Sabi & Reiker, 2017; UNAIDS, 2018, Avert, 2020) with an estimated 13.0% of the population living with the disease (Stats SA, 2020). The number of people living with HIV (PLWH) in South Africa has increased from an estimated 4.25 million in 2002 to 7.8 million in 2020. For adults aged 15-49 years, an estimated 18.7% of the population is HIV positive (Avert, 2020; Stats SA, 2020). The increase in numbers suggests that more needs to be done to link those who test positive for HIV to care as soon as they are tested to reduce transmission rates (HSRC, 2017).

Furthermore, health education and specifically HIV and AIDS education is necessary both for people infected with and those affected by HIV and AIDS. Considering this, an understanding of the experiences of PLWH, particularly in a university setting, provides a perspective that offers insights into their experiences and a focus on access to proper care and support in terms of treatment and psychological and social wellbeing. To contribute to this perspective, this study focuses on the personal and social symbolisms and meanings attached to living with HIV in a university setting.

This study documents experiences of members of the Rhodes University community who are LWH within the university context, the meanings they attach to those experiences, the complex challenges they face, the strategies they employ to cope, as well as the impact of accessing antiretroviral treatment at the Rhodes University Health Care Centre (HCC). The central question of this thesis is: *What are the experiences of living with HIV in the Rhodes University context?*. This study employed a qualitative paradigm and utilised semi-structured interviews conducted over a period of six months to capture the experiences of 10 members of the Rhodes University community (six members of staff and four students). The data were analysed through a thematic analysis where themes and categories were identified from the individual narratives of the PLWH.

Rhodes University is a small, rural, residential university located in the city of Makhanda, previously known as Grahamstown, in the heart of the Eastern Cape Province of South Africa. The campus is situated in the western half of Makhanda. The research-focused university was founded in 1904 and has over 8200 students (Rhodes University, 2019) and over 1500 faculty and staff. At the end 2019 the university had 1391 staff members. Of the 1391 staff members, 446 were in grades[1] 1 – 5 and 945 of these were in grade 6 and above (RU Digest, 2020).



A1 REGISTERED UNDERGRADUATE AND POSTGRADUATE STUDENTS

	2015	2016	2017	2018	2019
Undergraduate	5622	5645	5661	5661	5768
Postgraduate	2385	2491	2416	2492	2479
TOTAL	**8007**	**8136**	**8077**	**8153**	**8247**
% Postgraduate	30%	31%	30%	31%	30%

FIGURE 1: RU STUDENT BREAKDOWN

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[1] The level at which a job is positioned within the organization. Rhodes University's support staff job grades range from grade 1 (being the lowest) to grade 25 (being the highest). Academic job grades are matched to the PWC Rem Channel data and are denoted by letters: Junior Lecturer (JL), Lecturer (L), Senior Lecturer (SL), Associate Professor (AP) and Professor (P).

The university aims to “provide a safe and nurturing student support system as well as a diverse array of residential, sporting, cultural and leadership opportunities that will foster the all-round development of our students, the university and the region as a whole” (Rhodes University, 2020). In line with this, the university has, among other facilities and structures, the Health Care Centre[2], commonly known as the San; which is a campus clinic offering free services for all students and staff members. The services offered at the clinic include but are not limited to HIV Voluntary Counselling and Testing (VCT), Pre-Exposure Prophylaxis (PrEP), Post-Exposure Prophylaxis (PEP) and Antiretroviral treatment (ART).

The ART programme at the university clinic was initiated in 2010, and the PrEP and PEP programme in late 2018. These programmes are initiated in partnership with Settlers Hospital. Settlers Hospital is a Provincial government funded hospital for the Makana Local Municipality. The Eastern Cape Department of Health dispenses all medications, including ARVs, PrEP and PEP to Settlers Hospital, which then distributes drugs to the smaller clinics, including the Rhodes University Health Care Centre where community members access the drugs for free. As of September 2020, there was a total of 88 people (47 staff members and 41 students) accessing ARVs at the Rhodes University campus clinic.

This chapter serves to introduce and position the reader to the study by broadly contextualising and defining the disciplinary, socio-cultural, and theoretical underpinnings of the research. This includes a brief context of HIV and AIDS globally, locally, and in South African universities. Following that, the purpose and rationale of the study will be provided. Lastly, the organisation of the thesis will be outlined.

1.2 CONTEXTUALIZING THE STUDY

This study seeks to advance current knowledge, which mostly looks at the epidemic from a medical and biomedical perspective (Barnett & Blaikie, 1992), focusing on the evolution of the epidemic (Barnett & Blaikie, 1992; Karim & Karim, 2010), statistics behind it (Steinberg, 2007; Uebel, Timmerman, Ingle, & Van Rensburg, 2010), attitudes and perceptions towards and about HIV and AIDS and people living with HIV and AIDS (PLWHA) (Peltzer, Nzewi, & Mohan, 2004; Maswanya, Brown, & Merriwan, 2009; Houtsonen, Kylma, Korhonen, &

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[2] In this study the Health Care Centre, the San, and the Rhodes University/campus clinic are used interchangeably.

Suomnen, 2014; Ngundu, 2015), HIV testing knowledge, intentions and perceptions as well how it affects large groups of people (Barnett & Blaikie, 1992; Karim & Karim, 2010).

This study is in line with the *HIV Prevalence and Related Factors*[3] (HEAIDS, 2010) report by the Higher Education HIV and AIDS programme (HEAIDS) which states that "all institutions should strive to become environments which are sensitive to and accommodating of the needs of HIV-positive people" (HEAIDS, 2010: xxii). The report then makes recommendations[4] for the care and support of staff and students LWH. Furthermore, this study is inspired by the notion that universities are microcosms of society. Buldeo and Gilbert (2015: 210) assert that due to South Africa's high prevalence of HIV, there is a need for HIV and AIDS-related research to be centered on young people in universities, "particularly because they are the drivers of the future economy" and constitute a high-risk group for HIV infection (Buldeo & Gilbert, 2015: 210; Kelly, 2003: 9). Additionally, Mavhandu-Mudzusi (2014: 209) asserts that university staff members have become ill and some have died in ways that signal the impact of HIV and AIDS in the university context. This follows that LWH affects each part of everyday life including the workplace. Therefore, as Kau (2016: 1) claims, measures to sustain workplaces and prolong the productive work life of PLWH are crucial.

According to the *HIV Prevalence and Related Factors: Higher Education Sector Study* conducted by HEAIDS in 2010 (HEAIDS, 2010), an estimate of 3.4% of students in Higher Education Institutions were infected with HIV in South Africa. This percentage is in line with the notion that many young people between the ages of 20-24 are likely to be studying at universities and are the age group with the highest HIV prevalence and infection rate (HSRC, 2018). Even though the overall HIV prevalence among youth aged 15-24 years declined from 8.7% in 2008 to 7.1% in 2012 (Buldeo & Gilbert, 2015: 209), the 7.9% infection level among youth between 14-24 is still of concern (HSRC, 2018). According to Buldeo and Gilbert, although the prevalence of HIV among students and staff at higher education institutions is "less common than in the general population… it does not mean that any institution can be complacent since the sexual and social behaviours of sections of university communities put them at risk" (Buldeo & Gilbert, 2015: 209).

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[3] The report provides a broad outlook on HIV and AIDS perspectives, care and management in higher education institutions in SA. The report does not include specific institutional statistics of HIV prevalence and does not only focus on people living with HIV and AIDS rather, it looks at the whole university/college institution.

[4] Recommendations made include ART access, peer support, 'buddy' systems, and wellness programmes for HIV-positive people.

Mavhandu-Mudzusi (2014: 209) claims that HIV and AIDS is taking its toll on South African institutions of higher learning, such that there have been reports of students and staff becoming ill and some dying from HIV and AIDS-related conditions. Even though there is a high level of knowledge and awareness of HIV and AIDS, university students "continue to engage in risky behaviours such as early multiple and unprotected sexual encounters, which increase their vulnerability to HIV", hence the importance of Voluntary Counselling and Testing (Kelly, 2003: 10) and peer education (Kalunga, 2016) in combatting the epidemic. Further, Mavhandu-Mudzusi (2014: 214) proposes that there is a need for contextually relevant planning for managing staff and students living with HIV and AIDS in universities, which will improve the quality of life of the staff and students. According to Kalu (2015: 5), the needs of students living with HIV in university institutions are often ignored and hidden from the burden of shame to a point where "students living with HIV find it difficult to stand up for their rights" (Kalu, 2015: 5). Additionally, Kalu (2015: 195) emphasizes that each university student living with HIV develops different meanings which also impact social health, physical health, emotional/mental health, future goals, knowledge, and understandings of HIV and AIDS, and the process of transformation after testing positive for HIV (Kalu, 2015: 52).

Kelly (2003: 2) argues that HIV and AIDS awareness at universities is still only concentrated on during the brief period of orientation; other responses to the epidemic, if any, are rather uncoordinated and disorganized. The HEAIDS[5] report (2010: xvi) found similar results whereby students and staff perceived a lack of visibility and voice from campus management and student leadership. Moreover, it was reported that HIV and AIDS were not seen as a strong priority on most campuses (2010; xvi). The above reiterates Mavhandu's (2014: 214) findings that there is inadequate planning for managing staff and students living with HIV and AIDS. It is therefore of concern that Rhodes University currently relies on outdated information and statistics from *The Report of the Study on HIV Prevalence and Related Factors at Rhodes University: 2008-2009* presented in 2010 (Rhodes University, 2018).

South Africa's National Strategic Plan for HIV, TB and STIs 2017-2022 highlights that the national HIV burden varies widely by geography, key vulnerable populations, and age and sex; with more than 19% of adults in the country living with HIV. There has been progress in preventing mother-to-child- HIV transmission. Another success in combatting the epidemic has been the national antiretroviral rollout of 2003, which increased life expectancy from 58.3

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[5] In 2019, HIGHER HEALTH emerged from the Higher Education and Training HIV and AIDS Programme (HEAIDS), in this research the two names are used interchangeably.

years in 2011 to 62.4 years in 2015. As of December 2016, 3.7 million people have been initiated into ART (NSP, 2017: xiii). The needs of the key and vulnerable population continue to be addressed as well as the social and structural drivers of HIV, TB, and STIs since 2012.

There has been exceptional progress in the fight against HIV in the South African context (NSP, 2017: 4). However, more work needs to be done to address the pandemic. Institutions of higher education have a role to play in achieving the goals as they constitute of young people who are the drivers of the future economy. Much of the literature described above is vital, yet presents PLWHA as passive individuals who are studied, yet not given much room to speak of their experiences of living with HIV and AIDS and responding to the different strategies and policies put in place to address a condition that they are living with within the university context. Therefore, the current study contributes to the school of knowledge by centring the conversation to university settings..

According to Kelly (2003: 1), universities lack an institutional and consistent response to the epidemic. Instead, the epidemic is treated like a student or health issue and not an issue that must be integrated into a "university's core operations of reflecting on issues affecting society, teaching, research, and community engagement" (Kelly, 2003: 1). Kelly further argues that institutions need to focus on developing high-level university leadership and total management commitment. In the same light, Cairns, Dickinson and Orr (2006: 159) suggest that the key failure of HIV and AIDS programmes at universities lies with the configuration of power within the universities and the "funding logic that militates against institutions of higher education" which then creates the high cost of HIV and AIDS programmes. Moreover, there is a need for health campaign initiatives to be inclusive of young people as their concerns, feelings, and suggestions are barely considered despite the high rate of new infection among this age group (Maswanya, Brown, & Merriwan, 2009: 247). In 2006, the Rhodes University HIV and AIDS Plan was described, by the HEAIDS, as a "socially responsible" as it included "an informed definition of HIV and AIDS, consideration of models of transmission; support for condom distribution, counselling at a campus clinic, and consideration of education and changes to the curriculum" (Van Wyk & Pieterse, 2006: 1). Following that, HEAIDS (2010), based on findings of the national study, recommended that Rhodes University consider and respond to recommendations regarding, amongst others, care and support for PLWHA. This study then seeks to contribute to this response as some of the key themes that emerged from the findings revolved around the care and support of PLWH at the institution.

The study follows that when one is diagnosed with an illness, one's views of illness change. The relationship between one's body and oneself is disrupted, resulting in a different outlook on life and illness in general (Nettleton, 2006: 81). How people make sense of their conditions is "within the context of their biographies, and in turn, must invariably be influenced by, and meshed with, cultural values of the society in which they live" (Nettleton, 2006: 81). Therefore, these changes are explored.

Hsiung and Thomas (2001) provide insight into the coping strategies of PLWHA who had negative health care experiences. While the said study is not focused on higher education institutions, it highlights the role of stigma in the management of HIV and AIDS – an area that this current study uncovers from the experiences of the infected. Furthermore, Hsiung and Thomas draw out factors that contribute to adverse health care experiences, which include:

> "lack of supportive interpersonal interactions (insensitivity, barriers during interactions, lack of communication, overstepping personal boundaries and breaking confidentiality), lack of resources (vague messages, lack of information and declined services) and lack of autonomy (lack of control and choice under treatment decisions)" (Hsiung & Thomas, 2001: 750).

The above shows that many factors contribute to how PLWHA respond to and experience their illness. Hence Kalu (2015) and the current study argue for more attention to in-depth experiences and personal narratives in HIV and AIDS and PLWHA education.

1.3 GOALS OF RESEARCH

1.3.1 Primary goals

The main aim of this study was to explore HIV-positive staff and students' experiences and perceptions of living with HIV at Rhodes University.

1.3.2 Secondary goals:

- To explore strategies to address HIV and AIDS at Rhodes University, specifically relating to support, management, prevention, and education of the disease.
- To understand how staff and students living with HIV and AIDS experience the university's policies, practices, and responses.
- To investigate Rhodes University's institutional practices and responses to HIV and AIDS and PLWHA.

- To explore whether and how stigma is prevalent in the participants' communities and how these affect them.
- To uncover whether and how participants have to reconstruct their narratives when they are at the institution.

1.4 THEORETICAL UNDERPINNINGS

To gain a deeper understanding of the participants' experiences and narratives, the study integrated three closely related interpretive theories: symbolic interactionism, social constructionism, and the theory of biographical disruption, with the social constructionist theory being the central theory of choice. The approaches are best suited because of the common goal of understanding how individuals create meaning for themselves and others. Even though they have different intellectual backgrounds and emphasis, in practice, the strength of these theories is their value in a study of meaning creation (Leeds-Hurwitz, 2006: 229). Social constructionism broadly focuses on "making sense of the nature and structure of the social world", and symbolic interactionism emphasizes "making of self and social roles" (Leeds-Hurwitz, 2006: 238). The biographical disruption theory, meanwhile, uncovers the processes which people living with chronic illnesses go through to adapt their lives to accommodate their illnesses in pursuit of continuity. The study follows the symbolic interactionist view that the individual and society are inseparable and mutually interdependent. For a complete understanding of the one, there needs to be a comprehensive understanding of the other (Meltzer, Petras & Reynolds, 1975: 2). Russell (2009: 100) explains that broader inequalities such as class, gender, ethnicity, and age shape an individual's perceptions and experience of health, health care, and illness. In all these determinants, "biological and socio-cultural influences work in complex ways to influence health outcomes" (Russell, 2009: 100).

The theories are essential to the study as the aim is to delve into how individuals create or recreate a sense of self personally and in their social worlds (Rhodes University) due to living with HIV and AIDS. The study follows that "meanings allow people to produce various realities that constitute the sensory world (the so-called real world), but because these realities are related to how people create meanings, reality becomes an interpretation of various definitional options" (Lune & Berg, 2017: 17). Most importantly, the theories also follow the approach that the actor can shape and reshape his or her environment (Meltzer *et al*., 1975: 57).

1.5 RESEARCH DESIGN

In line with Skhosana *et al.*, (2006: 18), the study emphasizes that experiences of participants are informed by the recognition that being HIV-positive is not just "a single crisis moment but a complex ongoing process" therefore, individuals' ways of dealing with HIV involve manoeuvres, negotiations, adaptation, and growth.

Qualitative researchers study people in their natural/ social settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Marshall & Rossman, 1999: 106). Qualitative research is a multimethod and multifaceted field of inquiry that incorporates different orientations and methodologies, which enable the researcher to conduct in-depth studies about broad arrays of topics and consequentially to obtain an understanding of underlying reasons, opinions, and motivations (Yin, 2011: 1). This design explores phenomena under scrutiny by focusing on the participants. It endeavours to understand the social world, human experiences, and social meaning (Judgeo & Moalusi, 2014: 77), which is in line with the chosen theoretical frameworks of the study.

The research is predominantly reliant on the participants' experiences, perceptions, and voices, hence the choice to use in-depth interviews. Banister *et al.* (2011: 9) maintain that even though a degree of systematisation may be necessary, the participant's perspective should unfold as the participant views it. The study recognizes that the biographic disruption caused by chronic illness can lead individuals to "reconstruct a coherent self in narratives" (Reissman, 1993: 3).

The study used purposive sampling aimed directly at PLWHA who were recruited through the Rhodes University Health Care Centre and the Rhodes University HIV Office – both of which agreed to be gatekeepers of the study and strategic informants. It is worth noting that recruiting participants through the Health Care Centre and HIV Office limited the sample to primarily students and staff who accessed ARVs at the university campus clinic. As such, students and staff who are LWH and on medical aid or accessing treatment from other facilities other than the campus clinic could not be reached. Due to time constraints and ethical considerations, the researcher deliberately decided against the use of sampling through social media, the university top list[6], and word of mouth to enforce the integrity of the study, participants, and the researcher (Israel, 2014: 5). The study's ethics application was approved by the Rhodes University Ethical Standards Committee (RUESC).

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[6] The Rhodes University internal mailing list of all students and staff.

1.6 ORGANISATION OF THE THESIS

The overall structure of this thesis takes the form of ten chapters, including this introductory chapter. Chapter Two outlines the key concepts within the research and presents a literature review. The literature offers a discussion on the HIV pandemic in South Africa, in university settings, and at Rhodes University, specifically. Moreover, the chapter highlights and discusses common HIV prevention interventions on university campuses.

Chapter Three is a continuation of the literature review, focusing on the psychosocial, practical, and medical challenges of LWH. It highlights that while there have been tremendous biomedical developments of antiretroviral therapy (ART) in the last 30 years, there is still a prevalence of psychosocial, emotional, mental, physical, and psychological challenges faced by PLWH.

Chapter Four offers a description of the research method and methodology employed to answer the research question and achieve the goals of the study. The chapter also includes the rationale for the choices of the researcher while also outlining the ethical considerations made throughout the study. Lastly, the chapter includes a discussion of the challenges associated with the research design as well as conducting research amid the COVID-19 pandemic and how these have been mitigated.

Chapter Five outlines and discusses the theoretical foundations underpinning the study and contextualises illness and HIV/AIDS within such theories. The chapter reviews social constructionism, symbolic interactionism and the biographical disruption theory by highlighting how these theoretical frameworks relate to the qualitative research paradigm and how illness, with a focus on HIV and AIDS, can be understood from these lenses.

Chapters Six, Seven, Eight, Nine and Ten present a discussion of the results of the analysis. Consistent with the aim of offering participants' narrative experiences, these chapters present the results within the context of the literature and theory of this study in thematic form. Furthermore, each of these chapters addresses each key goal of the study. Chapter Six is a short chapter which offers an introduction to the research participants highlighting some factors that have shaped their experiences of LWH, in addition to being members of the Rhodes University community. Chapter Seven presents interventions implemented at Rhodes University as well as the perceptions of the university's responses to HIV and AIDS by PLWH. Chapter Eight discusses the themes which reveal participants' experiences of adherence and disclosure and the factors impacting this. Chapter Nine offers a discussion of participants' experiences of both internal and external stigma both at Rhodes University and in their lives. Lastly, Chapter Ten presents themes regarding experiences of disruption and reconstruction following an HIV-positive diagnosis and how these experiences shape illness experiences. The themes in this chapter also reveal the challenges the participants faced and how they navigate these challenges.

Finally, Chapter Eleven concludes the thesis by outlining the key findings in the analysis and how these relate to the literature and theory discussed prior. Furthermore, the chapter reflects on the methodology by considering the strengths and limitations of the study, followed by recommendations and suggestions for future related in research at Rhodes University and South Africa broadly.

1.7 CONCLUSION

This chapter presented an overview of the thesis by briefly contextualising the research topic bringing into account the aims of the research as well as the theoretical frameworks employed. After that, the chapter outlined what research methods and methodology were used in the research process and the ethical considerations. The next chapter critically analyses existing literature on HIV in South Africa and South African universities, with a focus on Rhodes University to separate what has been done in research and to establish the gaps that the current study seeks to address.

CHAPTER TWO: CONTEXTUALISING HIV AND HIV-RELATED INTERVENTIONS AT UNIVERSITIES

"The global HIV/AIDS epidemic is an unprecedented crisis that requires an unprecedented response. In particular it requires solidarity - between the healthy and the sick, between rich and poor, and above all, between richer and poorer nations. We have 30 million orphans already. How many more do we have to get, to wake up?"

Kofi Annan

2.1 INTRODUCTION

This chapter is set out to synthesise and discuss literature that is relevant to the understanding of HIV and AIDS in South Africa and in university settings, with a focus on HIV prevention initiatives and programmes for people living with HIV (PLWH). Furthermore, in discussing current literature on the above mentioned, this chapter will highlight the gaps which the current study aims to address. This embedded review of literature (Efron & David, 2019: 3) serves as a foundation within which the thesis will expand. In other words, this chapter contextualizes the study by discussing relevant literature.

As mentioned in Chapter One, this study primarily set out to explore HIV-positive staff and students' experiences and perceptions of living with HIV at Rhodes University. Secondary to that, the study set out to explore strategies aimed at addressing HIV and AIDS at Rhodes University, specifically relating to support, management, prevention and education of the disease. In line with these goals, this chapter will firstly define the main concepts in the study then provide a broad historical overview of the HIV epidemic in South Africa, the HIV epidemic in South African universities, and more specifically at Rhodes University. Additionally, the chapter will outline and discuss existing HIV prevention initiatives on university campuses, namely: Voluntary Counselling and Testing (VCT), Peer Support and Education, as well as Oral Pre-Exposure Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PEP). Lastly, the chapter will discuss the common wellness programmes for PLWH on university campuses.

It is worth noting once again, as mentioned in Chapter One, that there is little literature on HIV and AIDS at university campuses in South Africa, as will be seen in this chapter (Kau, 2016; Mavhandu-Mudzusi, 2014; Kruger *et al*., 2020). The existing literature commonly focuses on attitudes and perceptions towards and about HIV and AIDS and people living with HIV and

AIDS (PLWHA) (Peltzer, Nzewi, & Mohan, 2004; Maswanya, Brown, & Merriwan, 2009; Houtsonen, Kylma, Korhonen, & Suomnen, 2014; Ngundu, 2015), HIV testing knowledge, intentions and perceptions as well how it affects large groups of people (Barnett & Blaikie, 1992; Karim & Karim, 2010). Therefore, the literature review draws on research conducted in broader contexts.

Due to the length, the literature review has been split into two different chapters (Chapter Two and Chapter Three). The current chapter is the first part of the literature review. The first part of the literature review focuses on HIV and AIDS on university campuses and the different interventions and programmes thereof. The second part discusses the broad challenges of LWH.

2.2 DEFINING THE MAIN CONCEPTS

The following section seeks to define human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS), antiretrovirals (ARVs), disclosure, adherence, stigma, chronic disease, illness experience, and patient with the assertion that there is a causal relationship between these phenomena.

2.2.1 Human Immunodeficiency Virus (HIV)

The World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) define HIV as a retrovirus that targets cells in the immune system called CD4 cells which help the body fight off infections. Within the CD4 cell, the HIV replicates and consequently damages the cell, which results in the impairment and malfunction of the cells (UNAIDS, 2020; WHO, 2017). Infection with HIV results in the progressive weakening of the immune system, which then leads to immunodeficiency (UNAIDS, 2020).

2.2.2 Acquired Immune Deficiency Syndrome (AIDS)

As a result of the progressive weakening of the immune system mentioned in 2.2.1 above, symptoms and infections connected with acquired deficiency of the immune system form and result in AIDS (UNAIDS, 2020), which is the most advanced stage of the HIV infection (WHO, 2017). AIDS is most likely to occur in people with HIV who have not been tested, diagnosed at late stages of infection or not taking antiretroviral treatment.

2.2.3 Antiretroviral Therapy/Treatment (ART)[7]

Antiretroviral therapy (ART) is made up of the combination of antiretroviral (ARV) drugs to maximally suppress the HIV and stop the progression of HIV disease (WHO, 2017). ART also prevents the onward transmission of HIV; therefore, they are drugs that treat and not cure HIV (Avert, 2020). The drugs work such that they suppress viral load, delay or prevent the progression from HIV to AIDS, and the death of HIV-infected patients (Wood, 2010: 529; Bartlett & Finkbeiner, 2006: 67).

2.2.4 Viral load

Viral load is the term used to describe the amount of HIV in a millilitre sample of blood of someone living with HIV (UNAIDS, 2020; aidsmap, 2017). The more HIV there is in the blood, i.e. the higher the viral load, the faster one’s CD4 cells will deteriorate, and the immune system weakens, thus leading to AIDS, as explained above.

2.2.4 Undetectable viral load

The most measurable and significant clinical goal of ART has been the suppression of the viral load (Woods, 2010: 53). When ART has reduced the amount of HIV in the blood to such small quantities that it cannot be detected using standard blood tests, thus is not infectious and cannot be transmitted sexually, it is referred to as an undetectable viral load[8] (Van Dyk, 2011: 5; Avert, 2020). An undetectable viral load means fewer than 50 copies of HIV per millilitre of blood (<50 copies/mL) (Land, 2019).

2.2.5. Adherence

Adherence refers to the level to which an individual’s behaviours of “taking medication – following a diet, executing lifestyle changes – follows medical advice” (Skhosana *et al*., 2006: 17). In the case of HIV and in this study, adherence refers to the way in which an individual takes the prescribed regimen of ARVs, in the right doses, at the same time, every day for the rest of their lives.

2.2.6 Chronic disease

The Centers for Disease Control and Prevention (CDC) defines chronic diseases as conditions that last for a year or more and require ongoing medical treatment and attention. Sometimes these conditions limit daily activities (CDC, 2019).

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[7] In this thesis, antiretroviral therapy and antiretroviral treatment (ART) are used interchangeably.

[8] In this study, participants refer to themselves as “undetectable”, which is a colloquial term for having an undetectable viral load. For example: “I am undetectable”.

2.2.7 Disclosure

A process in which personal (often private and confidential) information is verbally communicated from one person (i.e. the discloser) to another person (i.e. the target) (Li, Qiao, & De Wit, 2015: 1). In the case study and HIV research, disclosure is the act of sharing information on one's HIV-positive status with anyone (Samuel, 2020).

2.2.8. Disease

A disease is a biophysical event which is the primary concern of medical practitioners (Nettleton, 2013: 73). This study echoes Ereshefsky's (2007) view that disease is complex term to be simply defined. Therefore, a disease in this study will be equated with an impaired performance of typical biological function (Lewens & McMillian, 2004).

2.2.8 Illness experience

Considering the above definition of disease, similarly, illnesses is the way in which the sick person and his/her significant others and community perceive, live with, and respond to symptoms and sometimes disability (Nettleton, 2013: 73). Therefore, illness experience is the way in which the illness is reflected in an individual's life. This reflection of illness includes both personal and social ideas about what is normal as well as the pathology behind it (Larsen, 2017).

2.2.9 Illness narrative

Illness narratives are defined as the "story-telling and accounting practices that occur in the face of illness" (Gabe, Bury, & Elston, 2004: 82). Nettleton (2013: 74) advances that illness narratives are stories told by the patient and significant others to give "coherence to the distinctive events and long-term course of suffering" (Nettleton, 2013: 74).

2.2.10 Patient

The medical dictionary defines a patient as "a person who is ill or is undergoing treatment for disease" and acknowledges that there is debate the appropriateness of this term as it "denotes a dependent relationship on the part of the person undergoing treatment" (Nursing, 2012). In this study the term patient is not used, for the above reason. Instead, people living with HIV are referred to as such and in the case of those interviewed for this research, and they are referred to as research participants or participants.

2.3 CONTEXTUALIZING THE HIV EPIDEMIC IN SOUTH AFRICA

The South African health care system, like many other systems and areas in the country, is deeply entrenched in the apartheid era characterised by racial and gender discrimination (Coovadia *et al*. 2009: 817). The country's history has had a significant impact on current day health policy and services, which subsequently has a direct effect on people's illness narratives. Prior to 1994, the beginning of a democratic South Africa, health services in the country were highly uneven both in the public and private health sectors. Apartheid policies divided society according to age-based hierarchies, gender, class, mobility and race. Furthermore, these policies influenced the organisation of social life, access to basic resources of health and health services (Tsampiras, 2012: 25). During the 1980s to the early 1990s health services in South Africa were managed by several statutory bodies which were organised along racial lines and led to immense disparities in funding such that by 1991 the country had "14 different departments of health, one national Department of Health (DoH), three 'own affairs' departments – six in the 'homelands' and four in the TBVC[9] 'states'" (Tsampiras, 2012: 28-29). During this period, the white minority had the highest government spending on health care, while the majority of races had minimal resources to share.

When the African National Congress (ANC) won the first democratic election in 1994 the party "inherited a health service that was indelibly marked with the inequities of the apartheid era, highly privatised and distorted toward the hospital needs of the urban whites" (Baker, 2010: 79; Wilson & Fairall, 2010: 504). Therefore, much work had to be done to dismantle the apartheid system and its policies and address its manifestations. In the process of tranforming the country, and specifically the health care system, a National Department of Health (NDOH) was formed (combining the administrations put in place in the apartheid era) (Coovadia *et al*., 2009: 828). The introduction of the NDOH resulted in more clinics being built and the existing ones being upgraded. Consequently, more people had access to public health care. Primary healthcare became free for all users and "essential drug lists and standard treatment guidelines were developed and issued for both primary healthcare and hospital levels" (Coovadia *et al*., 2009: 828). Among other successes, the party passed legislation to allow safe, legal termination of pregnancy and also introduced the *HIV and AIDS and STI Strategic Plan for South Africa* in 1994. In the same year, AIDS was also declared a 'presidential lead project', giving it

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[9] A collective name for the former 'independent' black states of Transkei, Bophuthatswana, Venda, and Ciskei.

preferential access to funds (Wouters, Van Rensburg, & Meulamans, 2010: 174). Since then, the fight against HIV and AIDS has undergone many trials and tribulations nationally.

The greatest HIV-related success for South Africa has been implementing the world's largest (ART) programme (WHO, 2020), which has also undergone further expansion with the implementation of the Universal Test and Treat (UTT)[10] guidelines (Avert, 2020). The ART programme in South Africa has been largely financed from the country's own domestic resources (Avert, 2020). In the 2019 National Health Budget (Treasury, 2019) a bulk of the *HIV, TB, malaria and community outreach grant* was allocated to HIV and AIDS to continue the implementation of the UTT policy for ART, and to provide services intended to prevent HIV. Additionally, R1 billion will be allocated to this component in 2021/22, resulting in an increase from R20 billion in 2019/20 to R24.5 billion in 2021/22. According to the budget, the total allocation in the HIV, AIDS and STIs subprogram in the Communicable and Non-communicable Diseases programme is R75.9 billion over the medium term. These 2019 Estimates of National Expenditure allocations are "expected to enable the department to increase the number of people receiving antiretroviral treatment from 4.3 million in October 2018 to 7 million in 2021/22, and to fund HIV-prevention interventions such as HIV counselling and testing, condom distribution and medical male circumcision" (Treasury, 2019: 4). Cleary and McIntyre (2010: 2) explain that due to the scale of the epidemic, HIV has a considerable cost, mainly because the treatment strategy intends to provide coverage for a high percentage of those in need. With that said, the cost of managing the epidemic has yielded positive results. The success of South Africa's ART programme is evident in the increase in national life expectancy from 56 years in 2010 to 63 years in 2018 (Avert, 2020).

In the year 2000, HIV and AIDS was identified as the number seven cause of death globally. 15 years later, in 2015, HIV and AIDS was no longer in the top ten global list (WHO, 2019). There has been a global decline in the number of deaths caused by HIV and AIDS, going from 1.5 million in 2000 to 1 million in 2016. While this decline shows a global improvement, low-income countries are still severely affected by the epidemic – as it is still in the top ten causes of death in those countries (WHO, 2018). South Africa is identified as having an upper-middle-income-economy (CFDC World Bank List, 2017). In terms of the World Health Organization's (WHO) 2015 top ten causes of death in the upper-middle-income-economies, HIV and AIDS is not on the list, meaning that even though the country has the largest burden of the epidemic

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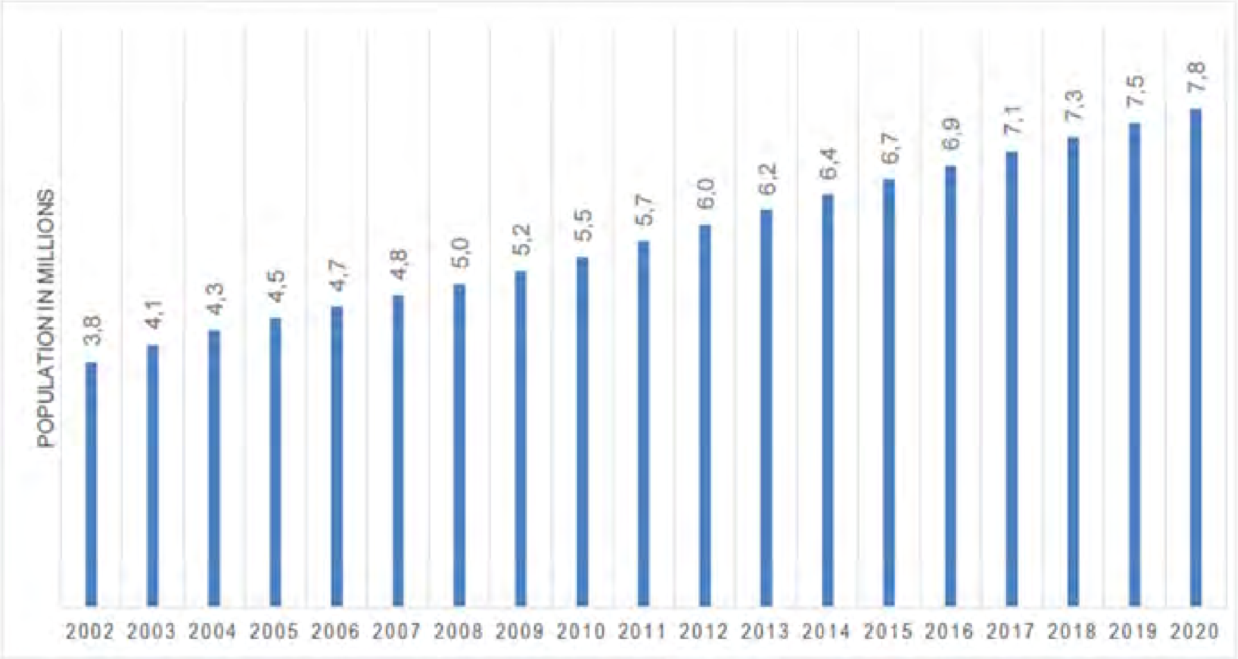
[10] Universal Test and Treat is a strategy in which all HIV infected individuals receive treatment whether in need or not. It is aimed at eliminating HIV as it reduces the rate of spreading the virus to other people.

in the world (Uebel, Timmerman, Ingle, & Van Rensburg, 2010), the disease is not killing as many people as it used to thus the number of HIV-related deaths have decreased. For example, there has been a 50% decrease in HIV-related deaths, from 140 000 deaths to 71 000 deaths between 2010 and 2019 (UNAIDS, 2020). The ART rollout of 2003 is largely a catalyst in this regard. Stats SA noted that "access to antiretroviral treatment has changed the historical patterns of mortality. Access to ART has thus extended the lifespan of many in South Africa, who would have otherwise died at an earlier age – as evidenced in the decline of AIDS deaths post-2006" (Stats SA, 2018).

According to Stats SA, the estimated overall HIV prevalence rate is approximately "13, 1% among the South African population. The total number of people living with HIV is estimated at approximately 7, 8 million in July 2020. For adults aged 15–49 years, an estimated 19, 0% of the population is HIV positive" (Stats SA, 2018). The current prevalence is an increase from 4.25 million in 2002. While there is an increase in new infections, the number of HIV-related deaths have decreased demonstrating on the one hand, the effectiveness of treatment in prolonging lives.

On the other hand, the increase in new infections suggests that more needs to be done to link those who test positive for HIV to care as soon as they are tested (HSRC, 2018). Furthermore, of those linked to care, an even greater effort is required to sustain adherence to treatment which will, in turn, result in more people being virologically suppressed; thus not transmitting the virus (Van Dyk, 2011: 5; Avert, 2020). In addition, health education and specifically HIV



and AIDS education is necessary both for people infected and those affected by HIV and AIDS (Tsope, 2018: 26).

FIGURE 2: HIV PREVALENCE IN SOUTH AFRICA SINCE 2002

As mentioned in Chapter One, the Higher Education HIV/AIDS programme conducted the *HIV Prevalence and Related Factors Sector Study* (HEAIDS, 2010) in South African HEIs between 2008 and 2009 which found that there is an estimate of 3.4% of students LWH in Higher Education Institutions. The HIV rate in institutions of higher education is in line with the HIV prevalence rate of young people nationally. The *Midyear population estimates 2020* reports that the HIV prevalence among the youth aged 15–24 has remained stable over time (StatsSA, 2020). Even though the prevalence of HIV among youth aged 15 – 24 (who can also be found in universities) has stabilised, Buldeo and Gilbert (2015: 209) caution that institutions cannot be complacent as the sexual and social behaviours of sections of university communities puts young people at risk. .

As mentioned above, the decline in AIDS related deaths has been due, for the most part, to the ART rollout. In 2003 calls were made by people living with HIV (PLWH), HIV and AIDS activists and groups and organisations such as the Treatment Action Campaign (TAC) to combat South Africa's burden of the HIV disease by providing antiretrovirals (ARVs) to people who needed them (Uebel *et al*., 2010: 598). As a result, the South African government officially approved a national programme that made ART available in the public sector as of 2004 (Van Dyk, 2011: 235). While the decision to dispense treatment at all public healthcare facilities demonstrated progress from the previous years, the limitation was that treatment was restricted to HIV positive people who had weaker immune systems stipulated by a CD4+ count of less than 500 cells per ml or a viral load bigger than 55 000 copies per ml. However, in August 2011 this was expanded to patients with CD4+ counts less than 350 cells per ml and 'allowing clinical judgement to be exercised at earlier stages of the disease' (Wood, 2010: 539).

Providentially, on 1 September 2016, in accordance with the World Health Organization's (WHO) guidelines on HIV treatment, South Africa became one of the first countries to adopt the Universal Test and Treat (UTT) policy which stipulated that every person who tested positive for HIV (including those already living with the disease) regardless of CD4+ count and viral load should be offered ART, prioritising those with a CD4+ of less than 350 per ml

(Department of Health, 2016: 1). Because of this, more people who know their status are now on treatment and are virally suppressed (UNAIDS, 2018; Bor *et al*., 2017: 3)

It is clear that for South Africa, the epidemic has experienced tremendous development in the biomedical arena. In fact, Bartlett and Finkbeiner (2006: 67) assert that the history of the treatment of HIV and AIDS is possibly one of the most remarkable success stories in the history of medicine. The authors add that ART is the most significant development in a widespread, serious disease in the last 30 years. Be that as it may, the social aspects of HIV still need to be debunked, particularly pertaining to stigma and discrimination which will be discussed, among other challenges, in Chapter Three.

2.4 THE HIV EPIDEMIC IN UNIVERSITY SETTINGS

HIV and AIDS influences all categories of people that make up the university community: students, academics staff, clinical staff, administrative staff and support staff (Phaswana-Mafuye & Peltzer, 2005: 278). For this reason, the *HIV Prevalence and Related Factors* (HEAIDS, 2010) report, based in South Africa, states that “all institutions should strive to become environments which are sensitive to and accommodating of the needs of HIV-positive people” (HEAIDS, 2010: xxii). The report then makes recommendations for the care and support of those living with HIV and AIDS: ART access, peer support, ‘buddy’ systems, and wellness programmes for HIV-positive people (all of which will be discussed in depth further in the chapter). The university context is important to help uncover the vulnerability of students and staff. As mention in Chapter One, Buldeo and Gilbert (2015: 210) assert that due to South Africa’s high prevalence of HIV there is a need for HIV and AIDS-related research to be centred on young people in universities, “particularly because they are the drivers of the future economy” and constitute a high-risk group for HIV infection (Buldeo & Gilbert, 2015: 210; Kelly, 2003: 9).

As mentioned above, the prevalence of HIV among students and staff at universities is lower than in the general population, however, a low prevalence does not mean that there are no people living with HIV (PLWH) in the areas, nor does it mean the particular area cannot be debunked; especially as “universities will remain fertile grounds for risky sexual behaviour” (Buldeo & Gilbert, 2015: 209). Buldeo and Gilbert (2015: 210) further recognize that even though university students might have a high chance of getting infected with HIV the level of risk in the setting i.e. university, does not compare to the level that is evident in the wider national community of South Africa. Hence university students are considered “differently vulnerable" within the institutional contexts they occupy. For this reason, Buldeo and Gilbert (2015: 209) maintain that university communities should continue to promote HIV and AIDS and Voluntary Counselling and Testing (VCT) awareness as a strategy in the fight against the epidemic. In the same light, the authors identify university communities to house the "most capable and promising members of all societies and constitute the next generation in terms of skills development and experience" (Buldeo & Gilbert, 2015: 209).

Due to its context, the university setting is deemed effective in relaying messages and encouraging change (Pieterse & Van Wyk, 2006: 1), therefore, Buldeo and Gilbert (2015: 210) see it as essential for universities to effectively respond to HIV and AIDS. Universities can do this by employing and evaluating policies and interventions to improve the existing programmes related to HIV and AIDS and to aid in the prevention of new infections (Buldeo & Gilbert, 2015: 210). While universities are academic spaces, they are also social spaces whereby students are exposed to new experiences which are essential to their personal development. The space creates an opportunity for freedom from authority, exposure to drugs, alcohol and peer pressure. There is also an increased chance of higher-risk sexual practices which Buldeo and Gilbert (2015: 210) claim are related to complex factors including "normative roles, power relations and othering discourses".

Buldeo and Gilbert's study highlights that institutions of higher education play a role in students' empowerment and agency over their health and sexual well-being and thus can use the platform to shape and change narratives around sexual and reproductive health. Moreover, the study advances that in the process, universities need to be cognisant of the "complexities of human behaviour and that university students are not a homogenous subpopulation for which one type of intervention will be effective" (Buldeo & Gilbert, 2015: 210)

In the same light as above, Mavhandu-Mudzusi (2014) highlights the importance of context specific models and interventions to addressing HIV and AIDS on university campuses. It is noteworthy that Mavhandu-Mudzusi does not position HIV and AIDS as the only condition affecting students and staff at university, but rather acknowledges the reality of the epidemic on campuses and the importance of healthy staff and students for both the institutions and the country.

Mavhandu-Mudzusi (2014: 209) claims that HIV and AIDS is taking its toll on South African institutions of higher learning; such that there have been reports of students and staff becoming ill and some dying from AIDS-related conditions. Even though there is a high level of knowledge and awareness of HIV and AIDS, university students “continue to engage in risky behaviours such as early multiple and unprotected sexual encounters, which increase their vulnerability to HIV”, hence the importance of VCT (Kelly, 2003: 10) and peer education (Kalunga, 2016) in combatting the epidemic. In agreement, Ndabarora and Mchunu (2014: 202) add that even though university students have been proved to have:

> “a higher degree of knowledge about HIV/AIDS and HIV modes of transmission, they are still not utilising existing HIV prevention methods and still engage in risky sexual practices favourable to HIV” (Ndabarora & Mchunu, 2014: 202).

Further, Mavhandu-Mudzusi (2014: 214) proposes that there is a need for contextually relevant planning for managing staff and students living with HIV and AIDS in universities, which will improve the quality of life of the staff and students. Additionally, there is a need for universities to establish the factors that influence utilisation of existing prevention methods and what the barriers to utilisation are, to ensure that relevant measures are put in place (Ndabarora & Mchunu, 2014: 203).

As discussed in Chapter One, the needs of students living with HIV in university institutions are often ignored and hidden from the burden of shame to a point where “students living with HIV find it difficult to stand up for their rights” (Kalu, 2015: 5). Additionally, Kalu (2015: 195) emphasizes that each university student living with HIV develops different meanings which also impact social health, physical health, emotional/mental health, future goals, knowledge and understandings of HIV and AIDS, and the process of transformation after testing positive for HIV (Kalu, 2015: 52).

Kelly (2003: 2) argues that HIV and AIDS awareness at universities is still only concentrated on during the brief period of orientation; other responses to the epidemic, if any, are rather uncoordinated and disorganized. The HEAIDS report (2010: xvi) found similar results whereby students and staff perceived a lack of visibility and voice from campus management and student leadership. Moreover, it was reported that HIV and AIDS were not seen as a strong priority on most campuses (2010; xvi). This reiterates Mavhandu’s (2014: 214) findings that there is inadequate planning for managing staff and students living with HIV and AIDS. In keeping with the above, Pieterse and Van Wyk (2003: 1) emphasize that an effective institutional response to HIV is one that ensures that the entire institution recognises both the:

> “threat of HIV/AIDS and the possibilities for a transformed institution and society, and to respond accordingly in a holistic way. This involves evaluating the essence, culture and power of the institution, and the institution’s relationship and interaction with its wider society is scrutinised.”

The *South Africa’s National Strategic Plan for HIV, TB and STIs 2017-2022* (NSP, 2017: 4) highlights that the national HIV burden varies widely by geography, key vulnerable populations, and age and sex; with more than 19% of adults in the country living with HIV. The needs of the key and vulnerable population continue to be addressed as well as the social and structural drivers of HIV, TB and STIs since 2012.

There has been exceptional progress made in the fight against HIV in the South African context (NSP, 2017: 4). However, more work needs to be done to address the pandemic. Institutions of higher education have a role to play in achieving the goals as they constitute of young people who are the drivers of the future economy. Kelly identifies reasons why every university in Africa must engage “dynamically and proactively” with the HIV and AIDS epidemic (Kelly, 2003: 3-6):

1. No university is immune from HIV and AIDS.
2. HIV and AIDS has the potential to weaken institutional functioning.
3. The long lead-time between initial HIV infection and the development of AIDS has major implications for universities.
4. The mandate of service to service demands the engagement of every university with HIV and AIDS.
5. Universities have a special responsibility for the development of human resources.
6. Universities are critical agents of change and providers of leadership for society.
7. Universities should be at the forefront in developing deeper understandings of HIV and AIDS.
8. The disease raises a host of complex moral, ethical, human rights, and legal issues that cry out for the kind of knowledge, understanding and insight that universities are especially well-equipped to provide.
9. “HIV and AIDS is not a passing phenomenon” (Kelly, 2003: 6) but one that is likely to affect society for the rest of the century.

Additionally, *The Report of the study on HIV prevalence and related factors at Rhodes University (2010)* states that the scale of the pandemic impends on the supply, demand and quality of education such that the debilitation of students and staff entering the higher education system:

> "impacts negatively on the sector's core business: teaching and learning, research, and community engagement. Moreover, the loss of qualified graduates impacts on national, regional and continental development, diminishing 'private and social returns to investment in higher education.'"

Pieterse and Van Wyk (2009: 2-3) also highlight that the disease "radically alters the core function and rationale of any university and the inimitable potential of a concerted, consolidated and integrated tertiary education sector response to HIV and AIDS in the SADC is thus obviously very crucial" (Pieterse & Van Wyk, 2006: 2-3).

According to Kelly (2003: 1), universities lack an institutional and consistent response to the epidemic. Rather, the epidemic is treated as a student or health issue and not an issue that must be integrated into a "university's core operations of reflecting on issues affecting society, teaching, research and community engagement" (Kelly, 2003: 1). Kelly further argues that institutions need to focus on developing high-level university leadership and total management commitment. In the same light, Cairns, Dickinson and Orr (2006: 159) suggest that the key failure of HIV and AIDS programmes at universities lies with the configuration of power within the universities and the "funding logic that militates against institutions of higher education" which then creates the high cost of HIV and AIDS programmes. Moreover, there is a need for health campaign initiatives to be inclusive of young people as their concerns, feelings and suggestions are barely considered despite the high rate of new infection among this age group (Maswanya, Brown, & Merriwan, 2009: 247).

Cairns *et al.,* (2006: 159) explain that although institutions of higher education are aware of the "moral imperative" of responding to the HIV epidemic, funding models in these institutions do not support this, hence they put forward four suggestions to tackle this "political economy configuration" – "changing funding formulas; securing direct funding from businesses as the primiary recipient of the human capital created; soliciting international donor funding and direct ring-fenced funding offered by government" (Cairns *et al*., 2006: 159). Following inaction after the launch of the HIV and AIDS policy, it was noted in 2002 that there were challenges within the institutional nature of a university that impeded policy implementation and these challenges had the following implications (Cairns *et al*., 2006: 160):

> "First, there appeared a need to broaden the scope of the proposed response to HIV/AIDS. Second, there was an increase in the expected cost of the programme since resource-constrained entities, necessary for aspects of implementation, resisted on the grounds of increased workloads. Third, mistiming of the programme start-up in relation to the university's budgetary cycle generated implementation difficulties."

As mentioned above, the critical issue facing institutions of higher education is the "cost-benefit relationship in funding HIV/AIDS programmes" which Cairns *et al.* emphasise are related to the way in which these programmes have little to no return on investment for the institutions (Cairns *et al*., 2006: 160). This is to say that, unlike the business sector, universities are unlikely to be faced with students whose HIV positive status develops into AIDS (assuming that most students are at the institution for 3-5 years) whereas this is more common in employees working at organisations. Consequently, the cost of expanding HIV and AIDS programmes for students at HEI represent a cost that does not have any "prospect of direct benefit accruing later" (Cairns *et al*., 2006: 160). Cairns *et al*. (2006: 160) assert that until the cost-benefit relationship is understood, higher education institutions are unlikely to respond vigorously and holistically to the epidemic.

According to Cairns *et al*, there are six categories identified by the Higher Education Programme for institutional responses to HIV/AIDS (Cairns *et al*., 2006: 160):

1. Effective policy, leadership, advocacy and management.
2. Effective HIV prevention (among employees and students).
3. Effective care and support (among employees and students).
4. Teaching appropriate to the HIV/AIDS era.
5. Appropriate research/knowledge creation.
6. Community outreach.

The above categories show that it is imperative for responses to HIV and AIDS by institutions of higher education to be multifaceted in the interest of the complex activities they run as educational institutions, workplaces, and agents of social development (Cairns *et al*., 2006: 160). In *Popular Responses to HIV/AIDS and Policy*, Leclerc-Madlala (2005: 845) contends that the gap between policy and implementation may not be the most formidable challenge to South Africa's fight against AIDS, but rather the "growing gap between government and an increasingly ill and enstranged populace" (Leclerc-Madlala, 2005: 845). Therefore, the most ideal response to HIV and AIDS is one that "seeks to meet the needs of people, both those infected and those affected by the disease, while promoting a culture of openness in treatment and of democratic values in policy responses" (Leclerc-Madlala, 2005: 845). Further, it has been highlighted that in order for there to be appropriate and relevant responses to the epidemic, policy-makers, programmers and planners need to "know your epidemic" (GNP+, 2012: 18). Phaswana-Mafuye and Peltzer (2005: 278) identify that a major gap in responses to HIV and AIDS by tertiary institutions is that they tend to concentrate on prevention, impact, and management only in students rather than including employees of the institutions as well.One of the key responses to the HIV epidemic in South African HEIs has been the establishment of Higher Health, which works with Universities South Africa (USAf) and the South African College and Principals Organisation (SACPO) on behalf of the Department of Higher Education and Training (DHET). Higher Health has reported steady growth of health promotion and clinical services at South African universities and colleges over the years (Health H. , 2021). This is seen in the following major developments since 2018 (Health, H., 2021):

1. Over 850 000 students participated in the campus-based-peer-to-peer education programme delivered through face-to-face enegagement with students via a wide range of campus activities set out to discuss health, wellness and other social challenges.
2. Peer education has increased with over 4000 student peer educators successfully enaging in health mobilisation and over 1000 university staff members serving as peer mentors.
3. Over 80 campus clinics have been established since 2018.
4. Through HIV campaigns such as the First Things First campaign, more than 220 000 HIV tests and screenings for TB and STIs were performed.
5. Distribution of condoms improved substantially, especially on TVET campuses, with overall students having accesss to 11.7 millions condoms including female condoms.

More and more health promotion activities and responses to the epiemic continue to be introduced on university campuses, including the establishment of HIV research centres and institutes on university campuses such as the Wits Reproductive Health and HIV Institute (WITS RHI) at the University of the Witwatersrand, HIV Mental Health Research Unit (HIV MHU) at the University of Cape Town and the HIV/AIDS, Tuberculosis and Health Promotion at the University of Kwa-Zulu Natal, to name a few.

2.5 THE HIV EPIDEMIC AT RHODES UNIVERSITY

According to *The Report of the Study on HIV Prevalence and Related Factors at Rhodes University (2010)*, in 2010 the overall prevalence of HIV among students and staff at Rhodes University was 1.5%. Of the 1.5%, 0.2% were students, and no academic staff were found to be HIV-positive in the sample. The prevalence of HIV among administrative and service staff was higher at 6.7% and 12.9% respectively. The statistics could possibly be attributed to the fact that the Rhodes University Health Care Centre, while accessible to all, is mainly used by students and grade 1-5 staff members who are predominantly support staff i.e. administrative and service staff. To that end, the numbers could be higher with the inclusion of those students and staff who access ART from private facilities or local public facilities outside the university. The figures in this study are to be treated with caution as the study was firstly voluntary, thus it is possible that it did not reach the whole Rhodes University community.

In 2006, the Rhodes University HIV and AIDS Plan was described, by HEAIDS, as “socially responsible” as it included “an informed definition of HIV and AIDS, consideration of models of transmission; support for condom distribution, counseling at a campus clinic, and consideration of education and changes to the curriculum” (Van Wyk & Pieterse, 2006: 1). *The Report of the Study on HIV Prevalence and Related Factors at Rhodes University (2010)* outlines both the qualitative and quantitative findings from the study. The qualitative findings reveal that – regarding HIV prevalence and susceptibility – there was a lack of experience, among first-year students, in relation to making good and informed decisions about alcohol and sexual liaisons and this was highlighted by the great risk of casual sexual intercourse in the context of alcohol intake. Further, students reported to using condoms in “casual, once-off, and new sexual relationships” – except when there was substance abuse (especially alcohol), then there was a drop in condom use (Rhodes University, 2010: 3). It was also noted that it was more socially acceptable for male students to have more than one sexual partner at a time.

The students reported a frequent pattern of intergenerational relationships with non-campus partners (Rhodes University, 2010: 3). HIV and AIDS management structures, as previously mentioned, were perceived to not regard HIV and AIDS as a priority. VCT was reported to be negatively affected by fears of stigma and discrimination related to the outcome of the HIV test. While the quantitative results show a low level of stigma,

> “…qualitative findings showed that profound levels of perceived stigma exist on campuses often in subtle forms, e.g. avoidance of shared toilets, distanced friendships,

> and extensive gossip and suspicion about people’s HIV status. Disclosure, even in the private settings, was deemed to be too risky for many HIV-positive people. Many fear rejection” (Rhodes University, 2010: 4).

Based on the findings, the report made recommendations in two areas specifically (for Rhodes University): HIV prevention and care and support for PLWH.

2.5.1 HIV prevention

While the university presented a low prevalence of HIV, the report encouraged it not to become complacent to a point where student and staff’s HIV-prevention motivation drops. In the same light, it was recommended that the university continues to work hard “to ensure it attains the goal of ‘no new infections’” and that “new students entering the institution must be encouraged to maintain the successful tradition of HIV prevention” (Rhodes University, 2010: 7). Furthermore, work towards prevention of the spread of HIV among students, student peer education, and condom distribution were advised to be officialised, systemised and supported, especially the university’s management and unions, who were seen to have done “little to support the implementation of prevention programmes” (Rhodes University, 2010: 7). An example of the above, was work done by those such as SHARC (Students HIV/AIDS Resistance Campaign). The report showed that there is value in introducing a peer-education programme, “a pivotal intervention on other campuses, for workplace education” (Rhodes University, 2010: 7). Rhodes University was reported to have lower levels of HIV testing in comparison to other universities included in the study, thus more work towards promoting HIV testing and knowing one’s HIV status was encouraged (Rhodes University, 2010: 8). As at 2020, in response to the HIV epidemic, Rhodes University had in place a campus clinic, student and staff peer educators, wellness leaders, and an HIV Office – all of which work collaboratively to address HIV and AIDS within the university.

2.6 HIV RELATED INTERVENTIONS AT UNIVERSITY CAMPUSES

It is clear that young people are at the centre of the global HIV and AIDS epidemic (Buldeo & Gilbert, 2015; GNP+, 2012; Kelly, 2003; Maswanya *et al.*, 2009; UNAIDS, 2018) both regarding new infections and opportunities for “halting the transmission of HIV” (Visser, 2007: 679). Visser asserts that evidence has shown that in the countries in which HIV prevalence is decreasing, young people have a big role in reversing the trends as they are the ones who are more likely to adopt new behaviours. For this reason, Visser argues that it is important to focus interventions on young people.

According to the *HIV Prevalence and Related Factors* (HEAIDS, 2010) report, campus management and student leadership have been perceived to not take HIV and AIDS seriously (HEAIDS, 2010: xvi). These perceptions are shaped by the inadequate or absence of HIV leadership whereby HIV and AIDS is not seen as a priority and there is minimal support for HIV related initiatives in the university space. This stance can arguably be attributed to the low prevalence of HIV in university campuses; however, it reinforces the notion of invisibility of PLWH which has profound impact on PLWH in terms of isolation and their (in)visibility. Additionally, "when low prevalence is also reflected in low priority, by default, responsibility for raising the issue of HIV falls to those most affected, i.e. PLWH" (GNP+, 2012: 16). The HEAIDS report further demonstrates that at the time there were questions on university campuses regarding the:

> "accountability and responsibility for managing infection prevention, seeing to the needs of HIV-positive people and ensuring the effectiveness of interventions were often vaguely responded to, even those most often centrally involved tended to not adequately talk about the apportionment of responsibilities and commitments to develop services" (HEAIDS, 2010: xvi).

The report argues that there was a need for a diversified and customized response to HIV and AIDS by all institutions rather than a generic approach (HEAIDS, 2010: xx). This is important because university communities and people living with HIV are not one homogenous group (Buldeo & Gilbert, 2015: 210, GNP+, 2012, HEAIDS, 2010: xx). According to Pieterse and Van Wyk (2006: 1), HEIs in the Southern African Development Community (SADC) need to move beyond prevention and work across a "continuum that includes prevention; treatment; care and support; research, innovation and thinking faster than the epidemic" (Pieterse & Van Wyk, 2006: 1). A critical issue for all HEIs to be cognizant of is that "trials designed for one particular group do not necessarily translate to other groups…[there is a] need to recognize that not every individual within a population needs the same intervention" (Hosek & Pettifor, 2019).

2.6.1 Care and support for PLWH

It was reported, by HEAIDS, that Rhodes University had at the time failed in its support of HIV-positive members (Rhodes University, 2010: 7). The university was advised to consider placing an HIV-positive peer educator to lead peer educators and convening a working group inclusive of PLWH. To ensure that PLWH receive treatment early into their diagnosis, the university's health service was implored to actively "reach out to HIV-positive students and staff and assist them to maintain and monitor their health" (Rhodes, 2010: 7). Additionally, it was recommended that VCT services should continue to be promoted, especially among couples.

At the time of the study, the Rhodes University HIV and AIDS programme was centred on the Dean of Students Office and the *HIV/AIDS Task Committee*. However, since HIV and AIDS was found to be more of a staff than a student problem at Rhodes University, the Human Resources division were encouraged to play a much stronger role than had been the case at the time. The report argued that a systematic institution-led programme of action involving all elements of HIV and AIDS response management and all role players - the campus health centre, the Dean of Students Office and the Human Resources Division - should be mounted.

The next section seeks to explore the most common HIV related interventions on university campuses.

2.7 HIV PREVENTION INITIATIVES ON UNIVERSITY CAMPUSES

According to Visser (2007: 679), several HIV preventive interventions that use diverse approaches have been implemented in the educational sector in South Africa, and they have had differing results. Many of these programmes, according to Visser (2007: 679), are often short-term and focus on raising awareness and providing information about the risk of HIV. Visser adds that it is important that "programmes should be specifically developed to match the culture, age and sexual experiences of participants and should address the underlying reasons for high-risk behaviour" as research has indicated that programmes that take into account the "social and contextual factors risk behaviour of the target population are more successful than programmes that do not" (Visser, 2007: 679). Understanding issues that influence and maintain high-risk behaviours plays a key role in designing and successfully implementing interventions aimed at "stemming the tide of infections among young people" (Visser, 2007: 680).

In the same light as Visser (2007), Hosek and Pettifor (2019) report that it is important for prevention approaches to consider the context of people's lives and to address the multiple levels of influence on their lives. Moreover, HIV prevention interventions must take an integrated approach to achieve maximum efficacy. Hosek and Pettifor (2019) note, however, that there are limited "rigorously evaluated combination prevention interventions" for young people. They argue that there are currently a range of “effective biomedical, behavioural and structural approaches that can be integrated into prevention packages to address prevention needs” (Hosek & Pettifor, 2019).

Behavioural interventions alone – which are the most common in university settings – have limited efficacy in reducing HIV incidence among young people, and other populations, therefore, there is a need for integrated approaches. Hosek and Pettifor (2019) advance that in contrast to a purely biomedical or behavioural model, a biopsychosocial approach “posits that health is best understood in terms of a combination of biological, psychological and social factors” (Hosek & Pettifor, 2019). They define biomedical HIV interventions in relation to the Centres for Diseases Control definition, according to which these are medical, clinical and public health approaches that moderate biological and psychological factors to prevent HIV infection, reduce vulnerability to HIV and decrease the infectiousness of HIV (Hosek & Pettifor, 2019).

Factors such as poverty, unemployment, violence, limited education, food security, stigma and discrimination not only increase the risk of acquiring HIV, but are also crucial structural drivers that limit access to prevention and care interventions thus increasing HIV risk (Hosek & Pettifor, 2019). While there is still a great need for larger evidence base and effective structural interventions for HIV prevention, Hosek and Pettifor (2019) argue that there has been some progress made in the areas of social protection and gender-based violence (GBV).

Ndabarora and Mchunu (2014: 202) put forward that for interventions aiming to improve the utilisation of HIV and AIDS prevention methods among students at universities to be effective, the institutions should equally focus on eliminating identified barriers, promoting HIV and AIDS prevention services and providing appropriate resources such programmes.

2.7.1 Voluntary Counselling and Testing (VCT)

VCT has been identified as a key entry point into HIV care and a critical stage of wellness for PLWHA as this stage is one of the determining factors of how one accesses care and support, if at all, should one test positive for HIV (Worley *et al*., 2009: 369; Maswanya *et al*., 2009: 247). This stage also sets the tone for how many people view HIV, testing and LWHV; therefore, the coverage and quality of the counselling and testing is important. HIV testing, and counselling is also the gateway to accessing biomedical prevention (Hosek & Pettifor, 2019). Maswanya *et al*. (2009: 247) note that not all population groups have an equal likelihood of accepting VCT thus “public health interventions on HIV counselling and testing should be specifically targeted for each population group" (Maswanya *et al*., 2009: 247). Moreover, there is a need for health campaign initiatives, VCT included, to particularly address the concerns and feelings of young people as they are the age group with the highest rate of new HIV infections (Maswanya *et al*., 2009: 247; Buldeo & Gilbert, 2015: 209).

Hosek and Pettifor (2019) highlight that testing modalities should go beyond the traditional clinic setting to reach those who are at highest risk of infection. Modalities such as mobile testing, household testing, venue-based testing and self-testing should be encouraged more as these provide a private and convenient way to access HIV (Mesemwa, 2011: 21).

Worley *et al*. (2009: 369) assert that there are several challenges in providing VCT and post-test support. In agreement, HEAIDS found that students and staff fear the outcome of testing thus they find ways to delay testing, preferring to "wait until their studies are completed, they decide to marry or begin to feel sick" (HEAIDS, 2010: xvi). Mesemwa (2011: 20-21) adds that while VCT was understood to be beneficial in the university setting the main barriers to uptake included feelings of shame, embarrassment, fear, rejection, and denial.

2.7.2 Peer Support and Education

Peer education and support have been widely advocated as alternative or complementary to interventions presented by adults, and are becoming an increasingly popular method for promoting behavioural change in prevention programmes (Visser, 2007: 680). Brack, Millard and Shah (2008: 566) explain that the role of peer education programmes of college campuses is to train students to provide educational programming to other students through counselling, providing information and conducting outreach programmes with the aim of more organised, accurate and influential support by peers. Furthermore, these programmes operate in conjunction with existing systems of social support at the institutions.

According to Worley *et al*. (2009: 369), health literacy and psychosocial support through peer education have a positive effect both on those who are infected and those who are affected by HIV and AIDS; thus they are important intervention strategies in communities. Worley *et al*.(2009: 369) assert that peer education encompasses different areas, for example: advocacy, counselling, distributing materials and service referrals. Furthermore, peer education "involves using members of a group to effect change among other members of the same group" (Worley *et al*., 2009: 370). This intervention method is based on the assumption that behaviour is "socially influenced and that behavioural norms are developed through interaction" (Visser, 2007: 680).

In the university context then, peer educators should ideally be at the forefront of effecting change in the university. HEAIDS (2010: xxii) asserts that it is important for every HEI to establish a support programme led by HIV-positive people for PLWH. It is claimed that these programmes have shown to be effective on some campuses. In agreement, Worley *et al*. (2009: 370) argue that the involvement of PLWH in peer support and education recognises the significant contributions they can make and create a space for this. As a prevention method, Visser (2007: 678) suggests that peer education can contribute to “a delayed onset of sexual activity”.

2.7.3 Oral Pre-Exposure Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PEP)

The word “prophylaxis” means “to prevent or control the spread of an infection or disease” (NIH.gov, 2020). Thus, Pre-Exposure Prophylaxis (PrEP) is a prevention method used by people who are HIV-negative and at a high risk of exposure to HIV through sexual contact or injection. These drugs are most efficient when taken *prior* to possible exposure as they work to keep the virus from establishing an infection (CDC, 2019). Similarly, Post-Exposure Prophylaxis (PEP) is a type of antiretroviral drug for people who are HIV-negative taken *following* a single high-risk exposure to the virus to stop HIV infection. To be effective, PEP must be started within the first 72 hours of exposure to the virus and continued for 28 days (CDC, 2019).

Both PrEP and PEP are safe to use for all age groups and have been recorded to be of interest especially to young people; however, inattention and inability to adhere may have harsh consequences on effectiveness, particularly for those groups of people who are most vulnerable to HIV infection (Hosek & Pettifor, 2019). According to Hosek and Pettifor (2019), for these interventions to be fully effective, amongst other things, the programmes must include other actors in the lives of those most vulnerable to HIV infection, such as partners, parents, family members and the community at large. Lack of support and continued stigma around PrEP and PEP are major barriers to accessing the necessary prevention. Because of the stigma, discrimination and lack of support, those vulnerable to HIV infection have discontinued use. Other reasons for discontinuation include: “trouble getting to doctor’s appointments, issues related to insurance coverage or loss and not feeling at risk of HIV” (Hosek & Pettifor, 2019); lack of awareness and education on these methods and how they can be accessed is also a barrier to prevention.

2.8 WELLNESS PROGRAMMES FOR PEOPLE LIVING WITH HIV IN UNIVERSITIES

In *Positive Learning: Meeting the Needs of Young People Living with HIV (YPLWH) in the Education Sector* (2012) the authors highlight that there is a need for greater attention to services that meet the needs of young people "for greater protection and promotion of human rights and for better involvement of young people including those living with HIV in the programmes that affect them" (GNP+, 2012: 6). It has is that in the context of education and the HIV epidemiology, PLWH, and specifically young people LWH, tend to be discussed "primarily in terms of education for HIV prevention" which is a narrow and exclusionary focus. Undoubtedly, HIV prevention is important; however, focusing on this one dimension obscures the fact that approximately 36.9 million people worldwide are living with HIV and AIDS (HIVGov, 2019) and that more children born with HIV are surviving reaching adolescence and adulthood, in part, making it to HEIs; making it even more critical and necessary to:

> "broaden conceptualisations of the needs of YPLWH... consideration also needs to be given to the implications of this expanded conceptualisation in terms of 'joining up' the links between different age-related services in order to ensure continuity, as individuals transition from one group (e.g. infants) to another (e.g. children)" (GNP+, 2012: 14).

The above study (GNP+, 2012: 14) includes the following recommendations to ensure that educational spaces become supportive and conducive learning environments for YPLWH:

1. Recognition, from the education sector, of the presence of HIV-positive learners [students] and support "actions that eliminate stigma and discrimination and provide a safe and enabling environment for all" (GNP+, 2012: 6).
2. Protecting the right to confidentiality to enable YPLWH to reach their educational potential.
3. "Concerted and sustained efforts" need to be made to eradicate stigma and discrimination "throughout the education sector, from the policy level to the schools" (GNP+, 2012: 7).
4. The school community (including management, staff, learners, and parents) need to be "HIV-literate' and sensitised to issues relating to prevention, care, and treatment as well as the rights of YPLWH" (GNP+, 2012: 7).
5. Implementing social protection measures that meet the needs of YPLWH and connects schools, health services, and the community.

Including YPLWH and PLWH in general is critical in interventions and wellness programmes for PLWH as the infected individuals will ensure that the real issues faced by those living with HIV can be understood and mitigated accordingly (GNP+, 2012: 7).

2.8.1 Individual Counselling

Counselling in HIV and AIDS treatment and prevention has become a primary element in a holistic model of health care whereby psychological issues are recognised as integral to patient management (Chippindale & French, 2001: 1533). HIV and AIDS counselling has two core goals: the prevention of HIV transmission and the support of those affected by HIV, directly and indirectly (Chippindale & French, 2001: 1533, Kanekar, 2011: 3). The former type of HIV and AIDS counselling follows that an early step in HIV prevention and reduction is behavioural risk assessment, especially with high-risk individuals, particularly given the absence of an effective vaccine or a cure to the disease (Kanekar, 2011: 3). This type of HIV and AIDS counselling involves risk-reduction counselling, pre-test counselling, and post-test counselling. Chippindale and French (2001: 1533-1534) explain that during pre-test counselling, also known as VCT (as discussed in section 2.5.1 above), the individual is oriented to the disease and implications should one test positive. The individual also undergoes a "realistic assessment of the risk of testing positive for HIV" (Chippindale & French, 2001: 1533). Post-test counselling serves two purposes: for the individual who has tested negative for HIV, this is an opportunity to reinforce risk-reduction informative and interventions. For the individual who tests positive, this is a crucial step for induction to ART, coping procedures and linkage to care and support (Horta *et al.* 2017: 54; Stinson & Myer 2012: 68).

The latter form of HIV and AIDS counselling is specifically for the individual who tests positive HIV; this type of counselling follows that when someone tests positive for HIV they are faced with numerous psychological issues related to personal and social relationships which often affect self-esteem and how they view treatment; additionally the new diagnosis raises financial worries and could be met with denial (Rohleder, 2008: 280). The person also experiences a change from crisis care to managed medical care, which brings with it "a need for ongoing psychological support" (Rohleder, 2008: 280). Hence the need for counselling, which is regarded as a key element in the prevention and treatment of HIV infection (Rohleder, 2008: 278). According to UNAIDS, HIV counselling is defined as "a confidential dialogue between a client and a counsellor aimed at enabling the client to cope with stress and take personal decisions related to HIV and AIDS" (Rohleder, 2008: 280, UNAIDS, 2020). While virology tests are a key indicator of adherence to ART, HIV counselling is an important tool in determining a realistic assessment of factors impacting adherence, especially for those with low adherence or default on medication (Chippindale & French, 2001:1535; Kanekar, 2011: 4).

2.8.2 Support Groups/Buddy programmes

Another form of counselling, which as mentioned above, plays an important role in HIV treatment, is a support group. Support groups, according to Rohleder (2008: 278), provide essential supportive counselling for HIV-positive individuals struggling to cope. An HIV diagnosis has far-reaching psychological consequences (Aulette-Root *et al.*, 2014: 29). Individuals living with HIV have identified rejection, lack of intimacy, social isolation, lack of acceptance, stigma and discrimination as the main psychological stressors experienced (Collins, 2006: 110; Geary *et al.*, 2014: 419; Charmaz, 1983: 168). According to Marino, Simoni and Silverstein (2007: 68) a common method of addressing the above-mentioned psychological stressors involves "training peers, who share a diagnosis with the patient to provide social support and other assistance". This method capitalizes on the peers' potentially influential relationships and their ability to relate on a personal level to the needs and concerns of those in the group.

Marino *et al*. (2007: 68) explain that research on the peer approach in other chronically ill populations has suggested that peer support groups are mutually beneficial for the peers providing the support and the individuals receiving the support. Furthermore, five main benefits of peer support/support groups/buddy programmes are identified as follows (Marino *et al*., 2007: 68; Walch *et al*., 2006: 284):

1. Access to a role model who reinforces benefits of behaviours.
2. A resource for coping techniques and experiential knowledge.
3. "A sounding board for strong effect that may be burdensome to family members" (Marino *et al*., 2007: 68).
4. Training and guidance in how to normalise required behaviour.
5. Low-key behavioural monitoring.

Aulette-Root *et al.* (2014: 30) add that because HIV is a long-term illness that is relieved by staying as healthy as possible, support groups also provide a forum for teaching and learning about health and positive living. Furthemore, the assertion is that being surrounded by people with similar problems alleviates the feelings of isolation and loneliness that can accompany an illness that carries with it such stigma as HIV(Aulette-Root *et al*., 2014: 30).

2.9 CONCLUSION

This chapter has demonstrated that while much has been done in relation to HIV and AIDS, much of the work, particularly in university settings, focuses on preventative measures because universities arguably have lower prevalence of HIV therefore low priority however, using the scale and distribution of the epidemic negatively affects experiences of those living with HIV, especially in settings where prevalence is low. GNP+ (2012: 16) states that it is important that "irrespective of the prevalence in the country, all nation government have a responsibility to understand the dynamics of the epidemics in their own country". The same can be said for HEIs, health sectors and other sectors and services because understanding the nuances and changes in the epidemiology is a "critical first step to knowing what kind of scenarios of YPLWH are living and how to provide adequate and appropriate support" (GNP+, 2012: 15). The next chapter critically analyses existing literature on the challenges of living with HIV and offers a discussion on illness experiences and illness narratives.

CHAPTER THREE: CHALLENGES OF LIVING WITH HIV

“We live in a completely interdependent world, which simply means we cannot escape each other. How we respond to AIDS depends, in part, on whether we understand this interdependence. It is not someone else's problem. This is everybody's problem.”

Bill Clinton

3.1 INTRODUCTION

As a continuation of Chapter Two, this chapter expands on the synthesis and discussion of literature by illuminating some of the key challenges of living with HIV (LWH). The chapter broadly discusses the psychosocial, practical and medical challenges of LWH. Additionally, this chapter will offer a discussion on illness experiences as well as illness narratives and how these two concepts play out in the lives of people living with HIV (PLWH).

As mentioned in Chapter One and Two, the HIV epidemic has undergone tremendous development in the biomedical arena through the treatment (ARVs) possibly being one of the most remarkable success stories in the history of medicine (Bartlett & Finkbeiner, 2006: 67). The success of the antiretroviral therapy (ART) being the most significant development in a widespread, severe disease in the last 30 years has not eradicated the psychosocial, emotional, mental, physical, and psychological challenges faced by PLWH. Moyo and Perumal (2019: 1) state that “as the most stigmatised epidemic in history, HIV and AIDS has proven to be a fierce challenge to humanity”. In the same light, Hsiung and Thomas (2001: 749) explain that it is this negative discourse around the epidemic that continues to perpetuate a “pervasive hostility and attitude” towards HIV and PLWH.

Every individual’s experience of LWH is different and shaped by racial, gender, class, and sexual inequities at different levels. These inequities at macro-structural, meso-institutional, and micro-interpersonal levels also significantly influence the probability of exposure to the virus, the medical, programmatic, political and socio-scientific responses (Watkins-Hayes, 2014: 431). This chapter advances Bor *et al.*’s (1993: 6) assertion that while the HIV disease is primarily a medical problem, it presents psychological, social, political, economic and legal consequences for the individual. For the purpose of this chapter, however, as mentioned above, the focus is on the psychosocial, practical and medical challenges. This chapter is set to outline the various multi-layered challenges PLWH experience. An important consideration is that these challenges are interlinked and interwoven; thus, none are more important than others, particularly because individuals' experiences and circumstances vary. Additionally, Kyakuwa (2009: 367) explains that the impacts of HIV and AIDS "transcends socioeconomic status, gender, social situation, age, and cultural background, irrespective of one's economic status, social situation or geographical setting, an HIV diagnosis can carry the psychosocial burden". Moreover, the challenges are not limited to those discussed in this chapter.

3.2 CHALLENGES OF LIVING WITH HIV

Humans are complex and have multiple and diverse needs such as a sense of belonging, emotional, psychological, socio-economic, physical and health needs, among others (Kalipa & Bereda-Thakhathi, 2014: 1324) – all of which can be interrupted and exacerbated by the additional burden of living with HIV. According to Kalipa and Bereda-Thakhathi (2014: 1325), PLWH suffer a lot of complex emotional and social challenges that ultimately affect their physical well-being (Ofovwe & Ofovwe, 2013: 180 and Kyakuwa, 2009: 367). An HIV-positive diagnosis, even for individuals who live in the comfort of home support, presents a shift in one's view of life and often also results in trauma. Kalipa and Bereda-Thakhathi (2014: 1327) explain that "besides the usual challenges faced by PLWHA, HIV-positive students in university, in particular, are even more burdened because of their unique settings on university campuses and campus-life related challenges". For this reason, university students become uniquely affected by the disease and its treatment.

According to Marino *et al.* (2007: 68) an HIV infection has far-reaching psychosocial consequences. The authors identify the following psychosocial stressors: rejection, lack of intimacy, social isolation, social stigma, and lack of acceptance (Marino *et al*., 2007: 68; Mesemwa, 2011: 1 and Moyo & Perumal, 2019: 2). Additionally, Reif *et al.* (2011: 152) highlight that there is a history of traumatic and or stressful experiences prevalent in PLWH which have been consistently associated with proper health outcomes, however, it is put forward that there is little knowledge about the factors that predict these experiences among HIV-positive individuals (Reif *et al*., 2011: 152). Consequently, there is a need for efforts to identify individuals at risk for traumatic events and substantial stressors and to address the challenges – which speaks to the care and support element of HIV more than the prevention element. Without discrediting the positive experiences of LWHV, Hsiung and Thomas (2001), address the negative challenges associated with health care services, which are among the key factors affecting illness experiences – these will be explored further below.

The GNP+ report (GNP+, 2012) outlines how HIV can impact individuals' educational experiences. One of these (which is relatively unexplored) is regarding the effects of HIV and HIV-related drugs on cognitive development and capacity. In addition to the often unseen personal and internal changes and challenges that an HIV-positive diagnosis presents an individual, PLWH are often subjected to the seen social issues such as blame, fear, and avoidance. Especially if they are perceived as personally responsible for their infection based on their risky behaviour or lifestyle choices (Houtsonen *et al*., 2014: 535), or they are perceived to "know better". The consequences and effects of LWH transcend beyond individuals' personal lives and alter individuals' careers and public life. Phaswana-Mafuye and Pietzer (2005: 277) explore the consequences of HIV and AIDS in the workplace by investigating how duties, staff morale, job satisfaction and workload are impacted. The study's findings show that HIV and AIDS is a threat to South Africa's economic, social and political development – all of which reveal that the epidemic does not only affect those who are infected but all of society bears the brunt.

Similarly, Pieterse and Van Vyk (2006: 1) assert that Higher Education Institutions (HEIs) do not have adequate responses and interventions in place to address the HIV epidemic and the challenges and impacts thereof. As a result, there is a lack of data and pervasive stigma associated with the epidemic. Pieterse and Van Vyk (2006: 1) emphasize that universities are an ideal platform to disseminate an institutional response to the epidemic as they are expected to provide intellectual leadership in society. As mentioned in Chapter Two, universities are deemed effective in relaying messages and encouraging change in their immediate context that will influence wider society. For this reason, a focus on HIV at university level has the potential to effect change widely.

To understand the complexity of an epidemic such as HIV, it is essential to acknowledge all the aspects that make it, rather than limiting it to one focus. Mack's book, *In Time of Plague: The History and Social Consequences of Lethal Epidemic Diseases,* (1991: 2) emphasises that

> "diseases are not simple biological entities which belong to the exclusive domain of scientists and physicians; [rather] they are socio-cultural events as much as biological and medical ones, and so coming to terms with them cannot simply be a matter of waving the scientists' magic wand".

The holistic approach emphasized by Mack (1991: 2) speaks to how people experience disease or illness as a phenomenon that extends far beyond the medical and biomedical domain. More specifically, HIV and AIDS has shown how epidemics are complex and multi-layered. As mentioned above, epidemics take place in various ways: as a biological event, social perception, collective response, the existential, the moral and the individual (Mack, 1991: 5). Because of this complexity, an understanding of the interactions between the constituent aspects of the epidemic is essential.

3.3 PSYCHOSOCIAL CHALLENGES OF LIVING WITH HIV

Like any chronic condition, HIV has long term consequences for the individual, especially longer because there is no cure for the disease, yet. Much of the burden of LWH is the emotional burden whereby the individual must live with the emotional cost of long-term treatment and the long-term "medical surveillance" involved (Turner & Kelly, 2000: 124). Turner and Kelly (2001: 124) explain that individuals living with chronic conditions must cope with the condition itself and the emotional dimensions of the conditions which are "frequently overlooked when medical care is considered" (Turner & Kelly, 2000: 124). The emotional dimensions of LWH are an area often neglected in the epidemic, as more attention is on ensuring that individuals have access to and adhere to treatment (Turner & Kelly, 2000: 124). Living with a chronic condition, according to Turner and Kelly (2000: 124) results in the individual having to make adjustments in their lives and often before the adjustments have been made, individuals grieve the new condition they are faced with.

The ways in which individuals reconstruct their narratives due to illness will be discussed in a different section below. For purposes of this section, only the psychosocial aspects affecting PLWH will be discussed.

3.3.1 Identity Crisis

In addition to the physical impacts of HIV and AIDS, an individual – following a positive HIV diagnosis – goes through a process of narrative reconstruction whereby a different outlook of self, life, and illness in general is shaped (Nettleton, 2006: 81). For many, this is often a long and ongoing process that is within the context of the individual's biography, and in turn, invariably influenced by and meshed with, cultural values of the society in which they live (Nettleton, 2006: 81). Due to these changes, an individual also undergoes a mental shift where there is a rift created in their identity. Kalu (2015: 19) explains that commonly this rift is perpetuated by popular narratives that ascribe categories and characterises for the diseases, for instance, that PLWH are commonly homosexual, immoral, sex workers, promiscuous, drug users etc. For individuals who do not identify with the ascribed categories, or who live in societies where these categories are shunned, Kalu (2015: 19) explains that it becomes difficult to identify with the disease. Individuals then face an identity crisis of either a) secretly LWH in fear of the associations attached, or b) identifying with the disease but refusing to be associated with the categories or c) accepting the disease and the shame that comes with the associated categories.

A second part of the identity crisis is attributed to another popular narrative in society about HIV and AIDS – that one is going to die following a diagnosis. According to Kalu (2015: 19) no one, except some of those who are psychiatrically ill, wants to die. Therefore, PLWH would rather not identify with the disease to not "wish death upon themselves" (Kalu: 2015: 19). Largely, the mental consequence of the identity crises, and sometimes the disease itself, is that of denial.

3.3.2 HIV denial (ism)

Denial has been recognised as one of the factors that contribute to the HIV epidemic and the increasing number of HIV and AIDS-related deaths. For the purpose of this section, denial will be discussed in two parts: AIDS denialism and denial of an HIV-positive diagnosis. One of the Treatment Action Campaign's (TAC) missions was to fight against AIDS denialism. In the pursuit to do so, AIDS denialism was extensively debunked. The movement (TAC, 2012) defined AIDS denialism as follows:

> "It is the promotion of one or more of the following pseudo-scientific views: firstly, that HIV does not cause AIDS; secondly, that the risks of ARVs outweigh their benefits and lastly that there is not a large AIDS epidemic in sub-Saharan Africa".

This followed after the former President, Thabo Mbeki, embraced and reinforced denialist beliefs and gave credibility to AIDS denialists by delaying HIV testing and efforts to distribute ARVs (Kalichman *et al*., 2010: 436). AIDS denialism and denialists, such as former President Thabo Mbeki and former Minister of Health Manto-Tshabalala Msimang, offered false hope to PLWH by asserting that HIV is harmless and that it can be cured with natural remedies (Kalichman *et al*., 2010: 436). The results of this stance were devastating for those LWH, with over "330 000 South Africans dying earlier than necessary from AIDS and more than over 35 000 babies needlessly HIV infected". Some of these babies were orphaned because medications that could have prevented mother-to-child transmission (MTCT) were not made available (Kalichman *et al*., 2010: 436). Kalichman *et al.* (2010: 432) found that AIDS denialism beliefs were also common among PLWH and that these beliefs were associated with poor health outcomes. Moreover, AIDS denialism "intersects with AIDS conspiracy theories and may impede HIV prevention and treatment" (Kalichman *et al*., 2010: 436).

According to Petros, Airhihenbuwa, Simbayi, Ramlagan and Brown (2006: 68), denial causes those LWH to hide their condition. As such, the silence and denial of HIV and AIDS are identified as dangerous as it prevents individuals from accurately assessing their personal risk of infection as well from accessing or seeking and adhering to treatment once diagnosed (Petros *et al*., 2006: 68 and Horta et *al*., 2017: 52). Horta *et al.* (2017: 54) and Stinson and Myer (2012: 68) explain that how an individual processes an HIV-positive diagnosis influences their engagement with HIV treatment and care. The key themes that were evident following an HIV-positive diagnosis include shock, doubt and disbelief. Horta *et al.* (2017: 54) describe periods of non-acceptance or denial as ranging from months to years and marked consequences for many individuals' mental and physical health.

For some PLWH the persistent denial of their status is as a result of "feeling overwhelmed by the life-long requirement of clinic attendance" (Wringe *et al*., 2009: 635) and commitment to ARVs for the rest of their lives (Stinson & Myer, 2012: 67 and Ofovwe & Ofovwe, 2013: 180). In line with this, Ben-zur (2003) claims that while denial is an obstacle, it is also a potential mechanism in coping with health threats related to LWH. This, however, does not mean that it is a positive coping mechanism. Kamen, Tanguchi, Student, Keinitz, Giles, Khan, Lee, Gore-Felton, Koopman (2011: 1328) emphasize that denial is a "specific and complex form of avoidance coping" with both cognitive and behavioural aspects. Kamen *et al.* (2011: 1330) reveal that research participants who reported use of denial coping at baseline were more likely to demonstrate delayed reductions in depressed mood and denial as an outcome. Lower social support, higher perceived stress, and poorer medication adherence were factors found to be linked with denial coping, which in turn impacted on the quality of life of PLWH.

In a study conducted at an HIV treatment programme in Tanzania (Wringe *et al*., 2003: 632) it was found that denial of HIV status was commonly associated with the use of alternative healers and was found to occur at any stage of the HIV illness experience. For some, the denial occurred before, during, or after using ART. Moreover, it was found that doubt over HIV status was sometimes associated with having no symptoms consistent with HIV infection (Horta *et al*., 2017: 55). The above factors, among others, have a detrimental effect not only on the health of PLWH (knowingly or unknowingly) but also on clinic attendance and adherence for those who know their positive HIV status. Wringe *et al.* (2009: 635) also found that those who were in denial of their positive HIV status reflected claims of being cured by God.

3.3.3 Depression and anxiety

As mentioned before, there are substantial interventions and efforts in place to control the spread of HIV. However, the number of new infections is increasing, and the effects of the virus are still prevalent for both those infected and those affected. Mental illness, especially depression and anxiety, are additional burdens faced by PLWH and show up at different stages and altitudes following the diagnosis. Ofovwe and Ofovwe (2013: 177) assert that PLWH have been reported to be more at risk of developing mental illness than the general population. Additionally, it is argued that the psychopathological proportion of symptoms reported by PLWH in the study is a cause for concern (Ofovwe & Ofovwe, 2013: 177).

According to Krumme *et al*. (2015: 284), for there to be effective support and treatment of PLWH and depression, there is a critical need for a better understanding of the relationship between depression and HIV-related outcomes, especially relating to adherence to treatment. Krumme *et al*. (2015: 284) conducted a study set out to examine whether depression was associated with attrition from care among adults LWH in Rwanda and whether any relationship between depression and attrition was mediated through suboptimal adherence to treatment. The findings revealed that the high prevalence of baseline depression in PLWH highlights the need for effective and accessible mental health services for HIV-infected individuals. Moreover, it was concluded that promptly identifying and effectively treating depression in PLWH may improve not only individuals' mental health but also ARV intended outcomes (Krumme *et al*., 2015: 286). In this way, it is emphasised that adherence support on its own is not enough to avert the adverse HIV-related outcomes among individuals LWH and depression.

According to Ofovwe and Ofovwe (2013: 178), there is a complex and bidirectional relationship between mental illness and HIV and AIDS such that even though there is a significant amount of research carried out in high income countries, less is known about HIV and mental health, especially in Sub-Saharan Africa. Ofovwe and Ofovwe (2013: 177) report that PLWH meet the criteria for generalised anxiety disorder, and some additionally present symptoms of depression. Because of their HIV-positive status, some individuals have also shown and expressed "feelings of self-doubt, self-consciousness, and negative expectations about interpersonal interaction and feelings of helplessness and despair" (Ofovwe & Ofovwe, 2013: 178). Depression and anxiety have been reported as significant co-morbidities in HIV and AIDS. Both have far-reaching implications as they have been found to correlate with lower adherence to ART, which in turn results in poorer health, social isolation, and faster progression from HIV to AIDS (Ofovwe & Ofovwe, 2013: 180).

In the same light, Prinsloo, Greef, Kruger and Ellis (2016: 262) found that there is a meaningful relationship between HIV and depression. The assertion is that on the one hand, individuals with depression could be more vulnerable to HIV as they tend to engage in risky behaviour. On the other hand, HIV infection may increase the risk of depressive symptoms. HIV stigma has been described as a key factor in the development of psychological distress like depression and anxiety in PLWH.

3.3.4 Stigma and Discrimination

As previously mentioned, stigma and discrimination are the greatest challenges to the progress made in the HIV epidemic (Kyakuwa, 2009: 367 and Stein, 2003: 95). Not only does stigma and discrimination undermine the biomedical developments of the disease, but it also influences individuals' illness experiences and constructions of self when LWH. Setlhare, Wright and Couper (2014: 309) assert that the stigma related to HIV and LWH often leads to psycho-emotional disturbances, which affect other areas of individuals' lives. Gillet and Parr (2011: 337) explain that fear of blame, violence, and abandonment by a partner also contribute to why PLWHA do not disclose. Consequently, stigma and discrimination have developed into barriers to HIV and AIDS prevention and care (Makoae *et al*., 2009: 1357). According to Moyo and Perumal (2019: 2), the stigmas around the pandemic and PLWH are perpetuated by the social constructions of what LWH looks like – certain identifiable characteristics are assigned to the pandemic so that PLWH can be recognized and labeled. It is markers such as weight loss, skin rashes, etc. which for some people are side effects of illness and treatment (Aulette-Root *et al*., 2014: 26). Makoae *et al*. (2009: 1360) assert that treatment side effects and stigma have a negative impact on an individual's ability to access care and support and to adhere to treatment. For some, the side effects of ARVs are not only short term and minimally bothersome, but they also cause visible markers or 'stigma symbols'.

According to Smith *et al*. (2008: 1267) stigma is

> "a simplified and standardised image held by a community towards certain people; this image is frequently of disgrace. Essentially, it is a social construction shared by a group. Thus, stigma is an attribute applied to those who do not meet the definition of "normal" in a given social context."

HIV stigmas, then, according to Aulette-Root *et al.* (2014: 44) are the negative ideas about PLWH, while discrimination are the actions that are taken to disadvantage those identified to be LWH. Similarly, Smith *et al*. (2008: 1266) define stigma as a "simplified, standardised image of the disgrace of certain people that is held in common by the community at large". Additionally, AIDS stigma is defined as "prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, their loved ones and associates and the groups or communities with which they are affiliated" (Smith *et al*., 2008: 1268).

Aulette-Root *et al*. (2014: 26) emphasize the role of stigma in the lives of those LWH by explaining how inescapable it is. All PLWH experience stigma to some extent, and these experiences are dependent on many variables, including class, gender, sexuality, race, location, age, etc. It is important to note that while stigma is a social construct, it is not exclusively an external phenomenon; rather, that it can also manifest internally. To explain this, Staggs (2007: 12) asserts that labels are not only external – individuals can internalize labels and then enact those labels. Once the label is embedded in an individual's self-concept, the individual may self-stigmatize and assume behaviour in line with the label, which is directly linked to the concept of role-playing that Blumer (1969: 13), Charmaz (1990: 1161) and Crooks (2010: 15) demonstrate. These labels mentioned above illustrate the way in which stigma cannot take place in a vacuum. Rather, as Aulette-Root *et al*. (2014: 44) states, stigma occurs "within social contexts that include political relationships, inequalities and tensions" therefore, "[stigma] serves to maintain existing power relations, ensuring that those who are perceived as 'others' are kept in that position". Aulette-Root *et al*. (2014: 44) extend this notion by stating that it is "not just relationships of inequality but systems themselves [that] are retained in part by the use of stigma".

Prinsloo *et al*. (2016: 262) identify three types of stigma: received stigma, internalised stigma, and associated stigma – all of which result in psychological and social HIV stigma outcomes for PLWH, those close them, and the community at large. According to Prinsloo *et al*. (2016: 262), on the one hand internal stigma "correlated significantly with indicators of affective (depression and helplessness) and behavioural (medical non-adherence) well-being". Received stigma and anticipated stigma, on the other hand, were associated with "indicators of physical health and well-being (low CD4 counts and chronic illness morbidity)". This emphasises the way, as discussed in Section 3.3.3 (Hwang *et al*., 2019), in which depression and stigma have a negative impact on the quality of life of PLWH.

Similar to received stigma, is the notion of perceived stigma, which according to Kyakuwa (2009: 369) involves shame, secrecy, and withdrawal triggered by applying negative stereotypes to oneself or the fear of being discriminated against.

The GNP+ report (2012: 23) upholds that HIV-related stigma, as much as it can be perceived (felt stigma), is also likely to be internalised (self-stigma) with the result that PLWH come to share the negative perceptions of others. In the case of HIV-related stigma, felt stigma refers to the awareness of stereotypes attached to HIV and LWH. It provides the "foundation for other related phenomena, including stereotype threat, which occurs among stigmatised individuals whose task performance is impaired in situations that make stereotypes about their group salient" (Herek, Saha & Burack, 2013: 41). Furthermore, it can refer to real or imagined fear of societal attitudes and potential discrimination resulting from particular attributes, diseases or associations of a certain group or behaviour which have been constructed to be undesirable (Hasan, Nath, Khan, Akram, Gomes, 2012: 22).

In contrast, self-stigma is revealed in a negative effect toward and beliefs about the self (Herek *et al*., 2013: 41). The stigmatised individual then, goes beyond a state of awareness of the stereotypes and stigmas to the point of accepting these as legitimate. Hasan *et al*., (2012: 23) explain that self-stigma is the process of internalising "shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive…[internalised stigma] discourages PLWH from seeking care and may increase the levels of their loneliness" (Hasan *et al*., 2012: 23). Felt stigma and self-stigma, according to Herek *et al.* (2013: 41) are significantly interrelated with symptoms of depression and anxiety; however, management of felt stigma reduced self-stigma's association with depressive symptoms to non-significance.

Moyo and Perumal, (2019: 5) demonstrate that HIV stigma results in feelings of anger, fear and uncertainty about the future, which leads to strained relationships with colleagues and family. In this way, fear and uncertainty, among other feelings, become a hindrance to disclosure.

3.3.5 Disclosure

Several studies (GNP+, 2012: 22; Van Dyk, 2011 and Gillett & Parr, 2011) have revealed that for some people LWH, there is "greater safety in silence" about their status because of the many, often unpredictable, consequences of disclosure. For most individuals, these consequences are in addition to the challenges and changes they go through at a personal level. The GNP+ report highlights that some challenges such as stigma and discrimination thrive through "the application of ill-considered or poorly planned policies on health and safety, or school-based testing or treatment that breach confidentiality or require disclosure" (GNP+, 2012: 23). In the same light, Aulette-Root *et al*. (2014: 29) claim that government policies are not always accommodative and supportive of PLWH in the most efficient manner. For example, in South Africa there are individuals who are compelled to choose between social disability grants and ARVs.

Just as the way in which an individual processes an HIV-positive diagnosis influences their engagement with HIV treatment and care, the disclosure also determines whether an individual seeks treatment and care. Disclosure, particularly to healthcare workers, must take place in order for an individual to seek and receive ART. Furthermore, disclosure must take place in order for an individual to receive social, emotional, and adherence and treatment support (Aulette-Root *et al*., 2014: 52). Horta *et al*. (2017: 56) and Stinson and Myer (2012) found that disclosure was helpful in the process of HIV status acceptance which enabled a better quality of life and linkage to treatment and care.

While disclosure can be helpful, it can also result in negative consequences. Hutton, Masijon, and Collins (2013: 66) describe how disclosure may result in negative social responses in family, friends, and colleagues such as blame, arguments, embarrassment and sometimes actual or perceived changes in affection, support and treatment. For some PLWH, the fear of shame and discrimination following disclosure promotes negative effects such as feelings of social isolation and damaged self-image for the PLWH (Houtsonen *et al*., 2014). These negative social interactions and consequences often lead to psychological issues. In agreement with the above, Holt, Court, Vedhara, Nott, Holmes and Snow (1998: 50) add that disclosure is a potent stressor for many PLWH, particularly in the early stages following diagnosis, regardless of whether an individual chooses to disclose or not. Meanwhile, disclosure serves as a means of accessing practical and emotional support which may sequentially promote healthier coping mechanisms and psychological adjustment (Holt *et al*., 1998: 52).

In their study, Holt *et al*. (2013: 54) found that non-disclosure – even though as discussed above has negative consequences for the individual – appeared to allow those LWH to exercise some control over their condition. It is argued that non-disclosure enabled the newly diagnosed HIV-positive individual to "focus on themselves and their own immediate condition, without having to contend with the added uncertainties associated with the reactions of others" (Holt *et al*., 1998: 54). The assertion is that once an individual has gone through this temporary phase of non-disclosure, they appeared to have achieved some form of emotional adaptation and somewhat become confident in dealing with disclosing and the reactions thereof (Holt *et al*., 1998: 54).

3.4 PRACTICAL AND MEDICAL CHALLENGES OF LIVING WITH HIV

The reality in South Africa, and globally, is that not all who are living with HIV have access to ARVs. Affecting public health facilities is the issue of stock-outs as well as a lack of adherence from the patients, among other issues; which affect the whole treatment programme and patients' illness experiences. The World Health Organisation (WHO) defines stock-outs as the complete absence of required medicine for at least one day at a storage or delivery point (WHO, World Health Organization, 2017). Drug supply issues have been identified to be among the issues threatening the country's ART programme severely (Odendal, 2013: 1). Lack of early warning systems for public health facilities has been a major problem in drug supply. Moreover, there are faults in systems that report "potential shortages, drug suppliers failing to meet tender quotes; government failing to pay suppliers and poor ordering practices at health facilities and medicine depots" (Odendal, 2013: 1).

In 2015 between October and December, Hwang *et al*., 2019 conducted a cross-sectional telephonic survey of public health facilities in South Africa. In this survey, the facilities were asked about the prevalence of stock-outs (of ARVs and TB medicines) on the day of the survey and in the preceding three months, both in terms of their duration as well as impact. Of the 2370 facilities included:

> "20% (485) reported a stock-out of at least 1 ARV and/or TB-related medicine on the day of the contact and 36% (846) during the three months prior to contact, ranging from 74% (163/220) of health facilities in Mpumalanga to 12% (32/261) in the Western Cape Province. These 864 facilities reported 1475 individual stock-outs, with one to fourteen different medicines out of stock per facility. Information on impact was provided in 98% (1449/1475) of the stock-outs: 25% (366) resulted in a high impact outcome, where patients left the facility without medicine or were provided with an incomplete regimen. Of the 757 stock-outs that were resolved, 70% lasted longer than one month" (Hwang *et al*., 2019: 1).

Stock-outs in South Africa have been reported every year throughout the years, in South Africa (Veenstra *et al*., 2010; Hwang *et al*., 2019; Monama, 2020). In 2020, the fight against COVID-

19 was the main disruptor to the ART programme (Stats SA, 2020) (WHO, World Health Organization, 2020). Access to HIV medicines has been severly imapcted by COVID-19. The WHO reported that 73 countries had warned about having been at risk of stock-outs and 24 countries reported having either a "critically low stock of ARVs or disruptions in the supply of these life-saving medicines" (WHO, World Health Organization, 2020). South Africa is one of the countries identified as experiencing a disruption in ARV supply. Some of the reasons for the shortages in supply include failure of suppliers to deliver on time; courier services shut down due to Covid-19 restrictions and governments having to make upfront payments in order for some suppliers to process orders (Monama, 2020). The unplanned interruptions of the ART programme directly affect individuals as they are exposed to an increased risk for opportunistic infections, virological failure and drug resistance (Hwang *et al*., 2019: 2). Furthermore, PLWH may be subjected to stress due to the uncertainty and, the significant financial burden due to additional transport costs thereof. As a result, individuals may be potentially discouraged from optimally adhering to treatment. Hwang *et al*. (2019: 2) adds that stock-outs have a negative impact on retention in care and patient survival.

Hannaford *et al*. (2020: 1) assert that even though South Africa has expanded access to ART and has the largest global ART programme, challenges with retention to care appear to increase as the pandemic matures. Retention in HIV care is an imperative aspect of sustaining viral load and reducing transmission; however, Hannaford *et al*. (2020: 1) have identified that loss to follow-up remains substantial in South Africa. Disengagement from the ART programme threatens individual outcomes and increases transmission, which in turn, negative affects the progress from ART expansion. Hannaford *et al*. (2020, 5) reveal that mobility and structural barriers are significant contributors to disengagement, notwithstanding high motivation to continue ART. Mobility, especially in rural populations, is a barrier to successful long-term retention. Additionally, difficulties (perceived or actual) in obtaining formal transfer letters from one facility to another affect adherence and retention to HIV care.

The South African government and communities are continuously working towards improving ART programmes and accessibility. However, issues such as cost of services, lack of skills [development], capacity, stigma and discrimination, lack of adequate and updated information create barriers of accessibility of services (Mokomane *et al*., 2017: 125). Furthermore, inequity issues also strengthen the barriers between people and antiretroviral treatment (Fairall & Wilson, 2010: 507). Practical factors such as lack of training of service providers, lack of resources, long waiting times, and poor quality of care directly affect provider, facility and programme design (Mokomane *et al.,* 2017: 126).

According to Aulette-Root *et al*. (2014: 26), taking ARVs can be difficult in itself because individuals experience fear and uncertainty about what the pills do to their bodies. Furthermore, side effects (that can last up to months) can get in the way of day to day activities. Aulette-Root *et al*. (2014: 30) explain that ARVs do not only cause suffering and pain; they are also debilitating, which prevents individuals from carrying out some tasks in their daily lives.

Additionally, Simoni, Aunon, Kemp, Kutner, Ramaiya, Velloza, and Yung (2017: 564) assert that another practical obstacle to achieving the best outcomes for individuals receiving treatment is adherence. The researchers claim that while there are improvements in the availability and affordability of antiretroviral therapy, the UNAIDS' goal of 90 percent viral suppression is derailed by poor adherence by patients. Even when there has been funding allocated to interventions to promote adherence in both high-income and low-income resource settings, adherence is a challenge (Simoni *et al*., 2017: 564). The issue of adherence is multifaceted as there are various reasons for which individuals cannot religiously adhere to treatment.

Treatment regimen prescriptions affect adherence, most notably for those who have larger prescriptions, i.e., people who must take more than the one standard pill at different times of the day. Moreover, the larger doses involve more side effects, which in turn affect adherence (Van Dyk, 2011: 8). Hannaford *et al*., (2020: 1), as mentioned above, add that another significant challenge in South Africa is retention to care.

In 2014 the Joint United Nations Programme on HIV and AIDS (UNAIDS) launched the UNAIDS Fast-Track stategy which set out to step up the HIV response in low and middle income countries to meet one of the Sustainable Development Goals (SDG) to end AIDS in 2030 (Avert, Avert, 2020). The strategy was in response to the increase in new HIV infections and AIDS related deaths, thus the stragey outlines the need to reduce HIV infections and AIDS related deaths by 90% by 2020. To achieve this, the Fast Track strategy set out targets for prevention and treatment, known as the 90-90-90 targets (UNAIDS, 2020). In other words, by the end of 2020, 90% of PWLH should know their HIV-positive status, 90% of those who know their HIV-positive status should be initiated on ART and of those initiated on ART, 90% should be virally suppressed (see figure 4 below). Another target of the Fast Track strategy was to achieve fewer than 500,000 new HIV infections annually (a 75% reduction since 2010) (UNAIDS, 2020; Avert, 2020).

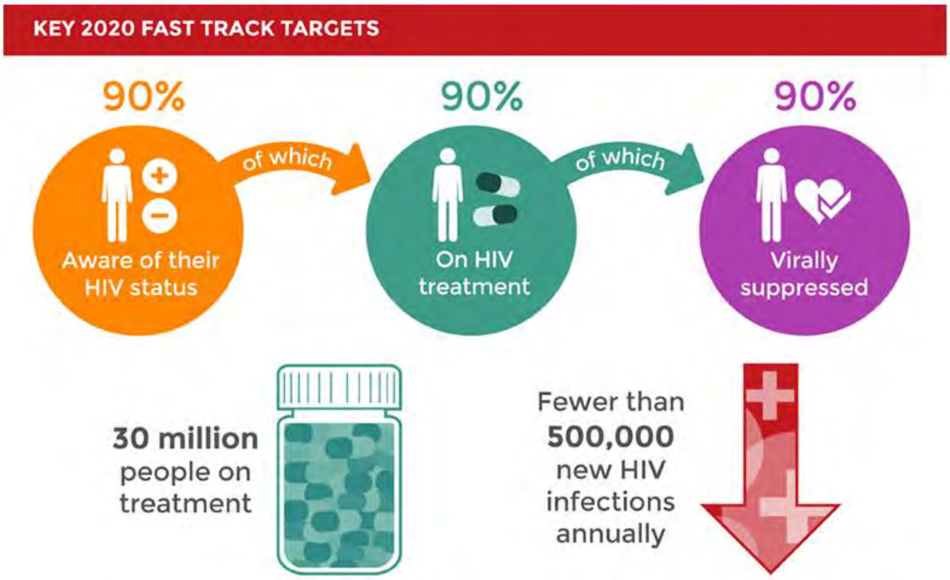
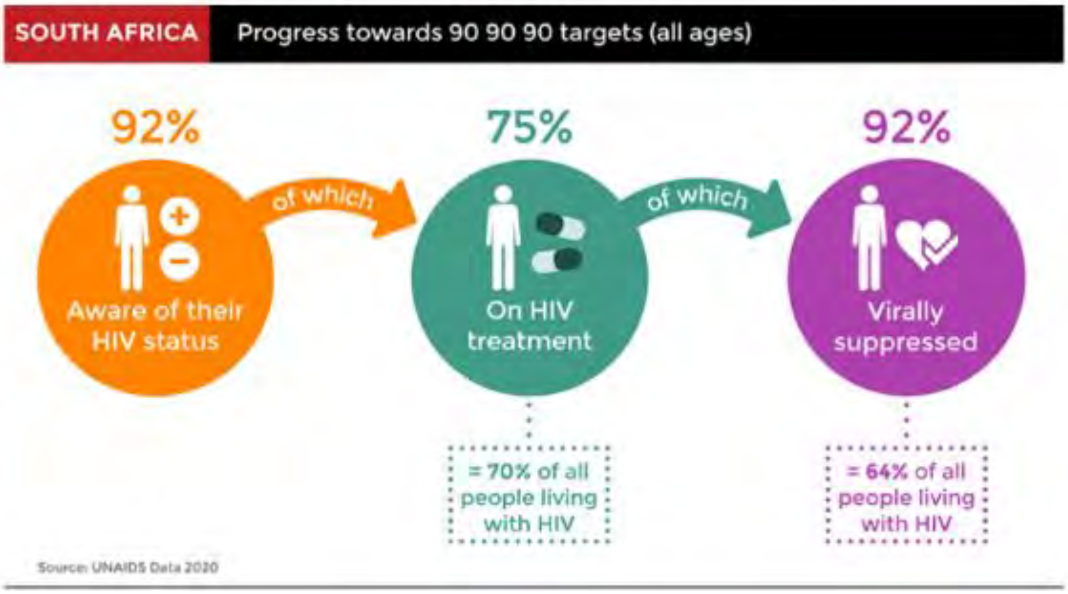


FIGURE 3: 90-90-90 TREATMENT TARGETS

South Africa is making steady progress towards the 90-90-90 targets, more especially when it comes to testing and viral suppression. At the end of 2019, 90% of people living with HIV were aware of their status, of which 68% were on treatment. Of those diagnosed and on treatment, 87% were virally suppressed. This equates to 62% of all people living with HIV in South Africa on treatment and 54% virally suppressed. In 2020, the numbers have increased with 92% of those infected knowing their status; 75% of which were initiated on treatment and of those initiated on treatment 92% were virologically suppressed. This equates to 70% of all PLWH initiated on art and 64% of all PLWH being virologically suppressed.



Source: UNAIDS Data 2020

FIGURE 4: SOUTH AFRICA'S PROGRESS TOWARDS 90-90-90 TARGETS (ALL AGES)

While accessing treatment is free in South Africa, there are hidden costs involved in being on ARVs, such as money for food and transportation to collect ARVs. The service-related problems identified are, unfortunately, beyond the control of patients. For example, healthcare workers going on strike or holiday without backup plans in place for patients and stock-outs affect adherence (Mokomane *et al*., 2017: 127). The lack of infrastructural, institutional, and human resource capacity in most developing countries influences the way in which HIV and AIDS is responded to (Auerbach & Mulhern-Pearson, 2008: 176).

3.5 ILLNESS EXPERIENCE AND ILLNESS NARRATIVES

Morrall (2001: 49) defines health as an ideal state and the absence of disease; therefore, illness is the subjective experience of not feeling well. Moreover, illness encompasses the "experiences of diseases, including the feelings relating to changes in bodily states and the consequences of having to bear that ailment". Illness then relays a 'way of being' for the individual (Morrall, 2001: 49).

According to Bury (1982: 169), illness does not only affect the individual, it also involves families and wider social networks, and it disrupts the ways in which these networks relate to the individual as well as to the illness itself. Individuals faced with an illness, and their loved ones, undergo a process of accommodating the manifestations of the disease (Brashers *et al*., 1998: 67). When someone gets sick, their views of illness change, and the relationship between the body and the person is disrupted, resulting in a different outlook on life and illness in general (Nettleton, 2006: 81). When an individual is faced with an illness, a difference between illness and disease is made clearer. Nettleton (2006: 81) distinguishes that a disease is a biophysical event and the most important aspect to medical professionals, while illness is the way in which the sick person and her/his social network perceive and lives with the new experience (Nettleton, 2006: 81).

How people make sense of their illnesses is "within the context of their biographies, and in turn must invariably be influenced by, and meshed with, cultural values of the society in which they live" (Nettleton, 2006: 81). Morrall (2011: 50) adds that the meanings attached to the illness, the reactions that are a result of the illness as well as how medical professionals and society frame and respond to the individual are all dependant on social context, thus are socially constructed.

The introduction of the *HIV and AIDS and STI Strategic Plan for South Africa* (2007-2011) created a new outlook on the infection, both for medical professionals and society as a whole. This consequently influenced people's construction of their illness experience. Coovadia *et al*. (2009: 828) acknowledge that there has also been progress in the redistribution of resources between geographic areas and levels of care, which is an attempt at making services equal for all. For a long time, the HIV illness trajectory had been viewed as a predominantly downward course characterised by primary infection, clinical latency, and AIDS-defining illness; however, this narrative has changed (Brashers *et al*., 1998: 76). With the success of ART being the most significant development, the progression of the disease is slowed and sometimes halted.

Once an individual's life has been disrupted by an illness such as HIV and AIDS, the individual goes through a process where their "narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose" (Williams, 1984: 179 & Brashers *et al*., 1998: 68). In agreement, Lorig *et al.* (2013) assert that any illness requires that the individual does new things and incorporates more frequent interactions with the doctor and the healthcare system. In addition to that, the individual also learns new skills to deal with the illness and continue with life. This process helps the individual deal with the disruption and create a new 'identity' in relation to her/his illness as some illnesses do change almost everything in the individual's life. During this process, the individual interacts with his/her environment and significant others. Williams (1984: 181) further explains that one's narrative about one's illness has to revolve around the medical world within which the illness is defined. One's demographics do not only determine how one will experience the illness but also go further to affect whether or not one gets a medical diagnosis. Therefore, the role of the doctor varies in different situations, confirming Williams' claim that "both illness, and the response of professionals to it, suggests a world of power inequality" (Williams, 1984: 185). This links to medicine and social justice in South Africa, where the health of the nation is dependent upon more than just wealth and having the right to healthcare (Daniels, 2002: 7). This, in turn, affects the way one places a sense of identity with the new illness.

The emergence of a chronic illness or illness in general results in a lot of suffering for the individual. Charmaz (1983: 168) identified the following four key areas from which individuals suffer: leading restricted lives; experiencing social isolation; being discredited and burdening others. For some, there is also an element of denial at the initial stages of diagnosis; the denial can act as a form of a defence mechanism (Royer, 1998: 22). Furthermore, Charmaz explains that serious chronic illness also results in "spiralling consequences such as loss of productive function, financial crises, family strain, stigma, and a restricted existence" (Charmaz, 1983: 169). This process takes a different form for different individuals; therefore, the period of such experiences will also differ. The above areas are more internal and personal than those that Williams (1984) and Bury (1982) identified. Charmaz explores the ways in which the individuals lose themselves due to illness, "as they suffer losses of self from the consequences of chronic illness and experience diminished control over their lives and their failures, affected individuals commonly not only lose self-esteem but even self-identity…diminished self" (Charmaz, 1983: 169). Even though there are individuals who do not recognise themselves as active authors of their narratives and therefore having nothing to reconstruct (Williams, 1984: 179), they still undergo suffering.

Another significant facet of the HIV experience, and other acute and chronic illnesses, is uncertainty (Brashers *et al*., 1998: 67). Kuang (2018: 10) explains that uncertainty exists in the "form of ambiguity, vagueness, unpredictability, and lack of information in the illness context and serves as a crucial variable influencing patients' experiences in illness, treatment, and hospitalisation" (Kuang, 2018: 10 & Mishel, 1990: 256). Brashers *et al*. (1998: 66) describe uncertainty as a chronic and pervasive root of psychological distress for PWH. Uncertainty, according to Brashers *et al.* (1998: 61), is heightened by several factors such as complex changes in treatment, ambiguous symptom patterns, and fear of negative responses to disclosure. These factors affect an individual's illness experience and are linked with negative perceptions of quality of life and poor psychological adjustment. Therefore, uncertainty is recognised as a "problematic aspect of illness experience across acute and chronic disease activities" (Brashers *et al*., 1998: 61).

According to Brashers *et al*. (1998: 67), an individual's educational level, trust and confidence in health care providers, social support as well as cognitive wellness play a role in how individuals experience illness-related uncertainty. Depending on whether an individual views uncertainty as danger or opportunity, "emotion or problem-focused styles of coping are used" toward adaptation and narrative construction (Brashers *et al*., 1998: 67; Williams, 1984: 81; Kuang, 2018: 16 and Mishel, 1990: 256). For those who view uncertainty as an opportunity, Brashers *et al*. (1998: 67) explains that uncertainty becomes a tool for a personal sense of control over the illness and the narrative thereof. Contrarily, Kuang (1998: 16) describes how individuals may avoid information in hopes of preventing heightening uncertainty and confusion.

Uncertainty in illness is not only relating to medical issues. Kuang (2018: 16) explains that personal and social forms of uncertainty are equally critical in illness experiences. Personal forms of uncertainty refer to an individual's "doubts and questions about their valued identities, personal and professional roles, financial stability, and life plans" (Kuang, 2018: 16). Social forms of uncertainty, meanwhile, refer to "the distinct questions that people have about their intimate and professional interactions and relationships as a result of living with a serious illness" (Kuang, 2018: 16).

Mishel (1990: 256) demonstrates that there are two appraisal processes in the theory of uncertainty, which are useful in determining the value an individual places on uncertainty: inferences and illusions. The former process refers to the assessment of uncertainty based on examples of related situations. For instance, if inferences are favourable, then the uncertainty will be viewed as an opportunity, and if inferences are threatening or harmful, the uncertainty will be viewed as a danger (Mishel, 1990: 256). The latter process refers to the "construction of beliefs that have a generally positive outlook" (Mishel, 1990: 256). Illusions then allow uncertainty to be viewed as indicating the potential for a positive outcome. These processes can be fostered by the person living with the chronic condition, their social networks, and care providers.

Illness experience is how the illness is reflected in an individual's life. Illness narratives are then defined as the "story-telling and accounting practices that occur in the face of illness" (Gabe, Bury, & Elston, 2004: 82). Nettleton (2013: 74) advances that illness narratives are stories told by the patient and significant others to give "coherence to the distinctive events and long-term course of suffering" (Nettleton, 2013: 74).

Further than reflecting illness experience, illness narratives also contribute to the experience of symptoms and suffering. As emphasised previously, all narratives are context dependant such that the narrative a patient shares with the doctors, nurses, family and friends will vary – sometimes complementary and other times contradictory (Nettleton, 2013: 74). According to Kleinman (1988), illness narratives serve two primary purposes: to provide patients living with chronic conditions a "witness to suffering" and to address their existential fears. Illness narratives are also important outside the clinical situation. Nettleton (2013: 74) supports:

> "Illness narratives not only provide insights into the experiences and views of the narrator, such as the practical consequences of living with symptoms and how illness influences social relationships but more than this, they also afford insights into the cultural and social factors that shape, or give rise to people's experiences."

As mentioned before, illness disrupts an individual's life; illness narratives are central to experience because they help individuals deal with the altered situation and disruption caused by a disease. Gabe *et al.* (2004: 83) add that illness narratives play a role in the integration and reintegration of individuals into their social worlds.

3.6 CONCLUSION

This chapter has demonstrated some of the complexities of the HIV disease and the difficulties many PLWH experience in the process of coming to terms with their HIV-positive diagnosis.

Community-based organisations have played a significant role in aiding the minimisation of challenges faced by PLWH. Cain, Collins, Bereket, George, Jackson, Li, Prentice and Travers (2014) show that the involvement of PWLHA in community-based organisations has reduced, among PLWHA, stigma, shame, feelings of guilt and social isolation which in turn has had a positive effect on treatment adherence and overall illness experience. This chapter has also demonstrated that in addition to the physical burden of infection, PLWH have to carry the burden of psychosocial, practical, and medical challenges associated with the disease. The GNP+ report (2012: 22) highlights that it is unacceptable to place responsibility for challenging prejudice and championing rights solely upon those LWH. The report states that "education institutes and their managers have responsibility for ensuring that school environments are supportive and protective of privacy and dignity" (GNP+, 2012: 22) of all in their community. The same can be said about every other community, workplace, and environment. Lastly, this chapter has also demonstrated how, as former President Nelson Mandela pointed out, this disease is a "war against humanity. We need to break the silence, banish the stigma and discrimination, and ensure total inclusiveness within the struggle against AIDS. If we discard the PLWHA, we can no longer call ourselves human" (Aulette-Root *et al*., 2014: 43).

CHAPTER FOUR: RESEARCH METHODOLOGY

"Like no other illness, AIDS tests our ability to put ourselves in someone else's shoes – to empathise with the plight of our fellow man. While most would agree that the AIDS orphan or the transfusion victim or the wronged wife contracted the disease through no fault of their own, it has too often been easy to for some to point to the unfaithful husband or the promiscuous youth or gay man and day "This is your fault. You have sinned". I don't think that's a satisfactory response. My faith reminds me that we are all sinners."

Barack Obama

4.1 INTRODUCTION

This chapter sets out to present how the research was conducted. In so doing, the chapter describes the method and methodology employed to answer the research question and achieve the goals of the study. As mentioned in Chapter One, the central question of this thesis is: *What are the experiences of living with HIV in the Rhodes University context*? To answer this question the study classified a primary goal and secondary goals, as follows:

4.1.1 Primary goals

The main aim of this study was to explore HIV-positive staff and students' experiences and perceptions of living with HIV at Rhodes University.

4.1.2 Secondary goals:

- To explore strategies to address HIV and AIDS at Rhodes University, specifically relating to support, management, prevention, and education of the disease.
- To understand how staff and students living with HIV and AIDS experience the university's policies, practices, and responses.
- To investigate Rhodes University's institutional practices and responses to HIV and AIDS and PLWHA.
- To explore whether and how stigma is prevalent in the participants' communities and how these affect them.
- To uncover whether and how participants have to reconstruct their narratives when they are at the institution.

It is clear from the above mentioned central question and goals of the research that subjective meanings and everyday experiences and practices shape the contemplation of the narratives of the research participants. Therefore, the qualitative research paradigm was the best suited in conducting this study. The choice to employ this paradigm was in line with Flick's (2009: 16) explanation that qualitative research demonstrates the "variety of perspectives (those of the patient, his or her relatives, of professionals) on the object and starts from the subjective and social meanings related to it".

4.2 EMPLOYING A QUALITATIVE FRAMEWORK

The nature of the information and evidence required in this study led to the qualitative research approach alone being the choice of design. As mentioned in Chapter One, due to the continually changing nature of HIV narratives in South Africa and globally, the intention of the study was to focus on the personal and social symbolisms and meanings attached to living with HIV by members of the Rhodes University community. The design was appropriate as it emphasizes the insider perspective and the understanding of the worldview of research participants (Greenstein *et al*., 2003: 49 & Babbie & Mouton, 2001: 270). The design was also most appropriate because of the central motif of understanding the way in which participants interpret and understand their social reality (Ritchie & Lewis, 2003: 1; Ely *et al*., 1991: 4).

In terms of research design, Greenstein (2003: 52) recognizes that "in any social context, it is possible that people may occupy different socially constructed realities and may therefore have different ways of interpreting their actions and the actions of others" (Greenstein *et al*., 2003: 52). For this reason, it was not the intention of this research study to make inferences or generalizations. Furthermore, I, as the researcher, acknowledge that the experiences of the participants interviewed may be significantly different from the rest of the Rhodes University population of PWLH and shaped by many differing factors. While qualitative research procedures seek patterns among cases, these cases are not reduced to their averages. Instead, qualitative research procedures provide a means to "generalize to theory rather than populations" (Bryman, 2012: 406). In other words, the quality of the theoretical inferences made out of qualitative data is what is crucial.

Laher, Fynn and Kramer (2019) highlight that the research process is not linear, as has historically been regarded in the global North, especially in South Africa where there is a "range of culturally diverse communities that are in constant flux and are dynamic in nature". Moreover, in South Africa, there are "typified racialised tensions, gender inequalities, socioeconomic disparities and high levels of violence" (Laher, Fynn, & Kramer, 2019) – all of which affect the way in which individuals make meanings of their circumstances. These factors influencing the process of meaning-making subsequently have implications on research conducted in South African contexts (Laher, Fynn, & Kramer, 2019).

This study emphasizes individual meanings and renders the complexity of each participant's narrative to be necessary. Furthermore, this study acknowledges and emphasizes that every day lived experiences and narratives of participants are shaped by the recognition that being HIV-positive is a "complex ongoing process" and not just a single crisis moment (Skhosana *et al*., 2006: 18). Thus, the way in which individuals deal with an HIV-positive diagnosis involves manoeuvres, negotiations, adaptation and growth (Skhosana *et al*., 2006: 18). The qualitative research design offers the most appropriate and effective way of understanding the abovementioned processes, experiences and narratives.

Qualitative researchers study people in their natural or social settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them (Marshall & Rossman, 1999: 106 & Babbie & Mouton, 2001: 270). Qualitative research is a multimethod and multifaceted field of inquiry that incorporates different orientations and methodologies, which enable the researcher to conduct in-depth studies about broad arrays of topics; consequentially obtaining an understanding of underlying reasons, opinions, and motivations (Yin, 2011: 1). This design explores phenomena under scrutiny by focusing on the participants. Researchers within this framework are drawn to "how individuals arrange themselves and their settings and how inhabitants of these settings makes sense of their surroundings through symbols, rituals, social structures, social roles and so forth" (Lune & Berg, 2017: 15). Furthermore, the qualitative framework endeavours to understand the social world, human experiences and social meanings (Judgeo & Moalusi, 2014: 77) which is in line with the chosen theoretical frameworks of the study.

As noted in Chapter One, much of the literature on HIV, while vital, presents PLWHA as passive individuals who are studied, yet not given much room to speak of their experiences of living with HIV and AIDS and responding to the different strategies and policies put in place to address a condition that they are living with. Therefore, this research sought to give participants the autonomy and opportunity to speak. According to Ely *et al*. (1991: 4), the qualitative research paradigm presents participants with the opportunity to "speak for themselves, to provide their perspectives in words and other actions". This is in alignment with the claim by Ritchie and Lewis (2003: 1) that the way in which researchers carry out research is informed by a myriad of factors including their beliefs about the nature of the social world. Liamputtong (2007: 8) asserts that qualitative research methods are especially appropriate to the study of vulnerable people as they allow the researcher to "hear the voices of those who are silenced, othered, and marginalised by the dominant social order" (Liamputtong, 2007: 8). Furthermore, the research design is suitable because it allows the researcher and the participant to unpack complex issues and realities such as LWH.

4.3 THE NATURE OF DATA COLLECTION

This study follows Lune and Berg's (2017: 15) view that researchers do not conduct research solely for the purpose of amassing data. Instead, the purpose of research is to "discover answers to questions through the application of systemic procedures" (Berg, 2017: 15). Thus, this research is predominantly reliant on the participants' perceptions and voices (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991: 4) and, therefore, incorporates in-depth interviews and purposive sampling aimed directly at PLWHA. The participants were recruited through the Rhodes University Health Care Centre[11] and the Rhodes University HIV Office[12] – who both agreed to be gatekeepers of the study. The use of these channels was to reach as many students and staff members as possible who access ARVs through the university clinic. While participants could have been sought in other ways such as the university mailing lists or social media, reaching participants through the university system legitimised the research process and minimised the risk of the researcher not being trusted. Additionally, this choice was more ethical and avoided the possibility of an individual LWH accidently responding 'to all' or publicly in some way and thus divulging their status and their private communication in general.

These gatekeepers were entrusted with communicating the study's aim to potential participants and to give them a letter from the researcher explaining the study process in writing as well as an agreement form which the participants, upon agreeing to participate in the study, submitted to the gatekeepers to give to the researcher. Following that, the researcher directly made contact based on the agreement forms. This process eliminated the possibility of the health practitioners breaking the confidentiality of their clients and minimised pressure on participants to join the

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[11] The Rhodes University Health Care Centre, popularly known as the San (Sanatorium) is the primary health care service on campus which, among other services, offers HIV testing and counselling services to all students and staff as well as distributes ARVs to those LWH.

[12] The Rhodes University HIV Office, now known as the Wellness Office, offers free, strictly confidential HIV counselling and HIV-related workshops.

study. Furthermore, the Health Care Centre staff agreed to provide a space for interviews to take place in the facility to ensure neutrality and privacy for the participants, should participants wish to use the space.

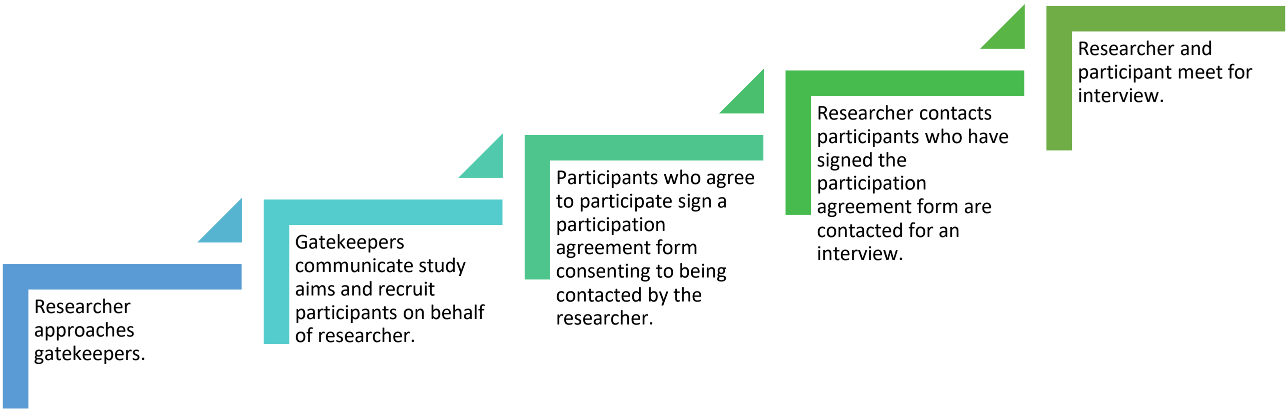

FIGURE 5: PARTICIPANT RECRUITMENT PROCESS

Having been a student at the university for eight years, I had an advantage regarding the proximity of the setting – I am an insider and familiar with the institution, its structures and its culture. Ely *et al*. (1991: 16) explain that researcher proximity has an advantage in that there is little or no resistance to “entering the field”. However, the authors caution that there can be risks in this kind of proximity to the potential participants. Due to the nature of the study, as the researcher, I was aware of the potential challenges that would arise in recruiting study participants; especially student participants (who had not publicly disclosed their HIV-positive status). I was prepared to encounter individuals who could be reluctant to have another student (in the case of students LWH) or a student (in the case of staff members LWH) knowing such confidential information. I shared the same views as Liamputtong (2007: 4) who argues that participants may be distrustful of non-members (to the participants HIV community or circle of healthcare workers, friends, family etc.). Me being a non-member of the participants circle was a potential challenge as it could result in participants potentially avoiding revealing their identities and/or participating in the study because of a myriad of reasons including their “marginality, lack of opportunity to voice their concerns, fear of their identity being disrespected, stigma attached to their social conditions, heavy responsibilities and scepticism about being involved in research" (Liamputtong, 2007: 4). Fortunately, my being a non-member was not an issue to the participants who agreed to partake. Instead, it encouraged a much more honest interaction.

4.3.1 Choice of participants

As mentioned above, in line with the study's purpose, the study adopted purposive sampling aimed at PLWH at Rhodes University and three key informants (the HIV Officer, Head Professional Nurse, Chairperson of Peer Educators) central to the study. I, as the researcher, was granted access through the Rhodes University Ethics Committee to reach participants through the Rhodes University Health Care Centre and the HIV Office (now called the Wellness Office). I worked hand in hand with the three departments as gatekeepers, to gain access to individuals who either access ART or HIV-counselling services through them. As is the case for purposive sampling, the research specifically targeted individuals either studying or working at Rhodes University and who are LWH.

Because the Health Care Centre and the HIV Office each comprise more than one staff member, I met with each department and its staff to explain the purpose and aims of the study as well as the role of the staff members in assisting with the recruitment of participants. In the case of the Health Care Centre, all six permanent nurses (who all regularly interact with clients) were present at the meeting and were given all the documentation necessary in order to be acquainted with the study, i.e. the research proposal, the letter to the potential participant from the researcher, a consent form to be signed by the participant following the agreement to participate in the study.

The recruitment of participants took place privately during the participants' regular consultations or check-up at the Health Care Centre or HIV Office. After that, I directly made contact based on the signatures of participants given via the agreement forms. As mentioned above, this eliminated the health practitioners breaking the confidentiality of patients and minimised pressure on participants to join the study. Potential participants were specifically assured that should they not wish to participate or show no interest in the study; the researcher would not have access to their confidential information, i.e. their names.

These gatekeepers were chosen because they already have a relationship with participants and because I, as the researcher, was mindful of the confidentiality and anonymity in the patient-health practitioner relationship. The Health Care Centre staff specifically reached participants accessing their treatment from their facilities. At the same time, the HIV Officer had access to both those participants accessing treatment at the Health Care Centre as well as from other facilities outside of the University. As an HIV Officer, Mr Mzizi, leads the university's HIV programmes such as the Peer Educators and HIV-related campaigns and events (workshops, discussions etc.). In this capacity, he interacts with students and staff LWH.

The gatekeeper also gave the potential participants a brief personal and academic background about the researcher which highlights that I am a mature student, sub-warden[13], wellness leader and HIV Peer Educator at the university with prior research in conducting research with HIV positive participants. This was done to highlight that I respect and understand the sensitivity of the topic and each individual's experiences. Even though I am not a qualified psychologist or therapist, I do have experience with basic counselling where training was conducted at the University at different capacities over the years that I have been a student at the university. The participant was also be given a letter from the researcher (see Appendix 1) which explains the research study, the goals, the type of questions that the participants can expect, the consent form (see Appendix 7) and the agreement form (see Appendix 2). The gatekeeper was also expected to highlight that the participant is not expected to speak about the way in which they contracted the virus, rather, about the experience of living with the virus, especially in the university setting.

4.3.2 The interview method

As the researcher, I went into the field viewing social life in terms of processes rather than in static terms and seeks to bring out as much of a holistic perspective as participants would share (Ritchie & Lewis, 2003: 4& & Rabbie & Mouton, 2001: 271). For this reason, I conducted in-depth face to face interviews with each participant. Face-to-face interviews offer the participant an opportunity to present their narratives as they experience them, thus giving the researcher the chance to view "events and the social world through the people that they study" (Bryman, 2012: 399). Bryman (2012: 469) explains that what makes the interview an attractive qualitative method of conducting research is the flexibility involved. Thus, the method was appropriate as it allowed the researcher and the participants to interact in a way that was most comfortable for the participant and without other people present, which enhanced confidentiality and privacy. Although the study was finalised amidst the COVID-19 pandemic,

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[13] "Sub-wardens are selected from within the student body of the residences. While assisting the House Warden with essential operational tasks, the Sub-Warden is the conduit between fellow students and the House Warden. Sub-wardens are usually second or third year students." (Rhodes University, 2016)

all face-to-face interviews with students and staff were conducted before March 11, 2020 when the WHO declared COVID-19 a pandemic. Thus, it was unnecessary at the time to practice COVID-19 guidelines. However, face-to-face interviews with all gatekeepers took place following the official announcement of the South African national state of disaster under Section 27(1) and Section 27(2) of the Disaster Management Act on 15 March 2020 in response to the coronavirus pandemic. In line with curbing the spread of the coronavirus, the face-to-face interviews strictly adhered to all health protocols such as wearing of masks during interviews, sanitizing before and after interviews as well as maintaining a distance of more than one meter. The interviews took place in well ventilated rooms (DPSA, 2020).

I was aware and acknowledged that this method had the potential to "pose a threat or risk to actors who fear exposure and sanctions" (Liamputtong, 2007: 2). Disclosing one's HIV status to an unknown person may be a challenge for the participants. Hence the I tried to mitigate this potential challenge by providing background information and assurance to the participants of the importance of confidentiality. The participants were also familiarised with the ethical process that the study was guided by.

4.3.3 The interview setting

The research study in no way intended to deceive participants. From the beginning to the end of the research process, there was transparency between the researcher and the participant. All the information regarding the study, research process, role of the interviewer and participant as well as the intended outcomes of the study were provided before, during and after the research had been conducted. As an individual who values honesty and trustworthiness I ensured that I highlighted this to each participant.

The initial proposal was to conduct all interviews at the Health Care Centre where no attention could be drawn to either the participant or the researcher. The Health Care Centre staff agreed to create a space for me to sit and wait for participants for interviewing. This method eliminated any questions that could have aroused should participants be seen with the me, and it ensured that privacy and confidentiality were prioritised as the Health Care Centre is a neutral space that many Rhodes University staff and students access without explaining purpose for access or any physical markers in the property. The plan was that participants would access the interview room as they would a nurse at the facility and only the Health Care Centre staff, researcher and participant would know that the researcher was in one of the consultation rooms.

Participants who preferred a different interview setting were encouraged to choose a place where they would be most comfortable. Elmir *et al.* (2011: 14) advance that when research participants are in a comfortable interview setting, they are more likely to disclose information and reveal the nature of their lived experience. All ten participants opted for the second option – a place of their choice. Each interview happened at different locations, including the local Botanical Gardens, the researcher's office, participant's staff room, residence garden and a student's room. One participant initially invited me to their place of work, but when the I arrived at the agreed time, it turned out that the staff member's colleagues had not left for lunch as she had hoped, which made the participant uncomfortable. I then suggested a different venue, and the staff member agreed. Once at a different area from their workplace, the participant relaxed and shared that she was worried that we would be overheard. The change in setting helped ease her concerns. The interview took place in my office.

4.3.4 The interview questions

As is the nature of semi-structured interviews (Bryman, 2012: 471), I went into the field with a list of questions (see Appendix 8). Even though an interview guide was used and the purpose of the interview was highlighted, the nature of the questions gave participants room to discuss other areas that were not directly posed by the researcher.

According to Liamputtong (2007: 4), researching sensitive/vulnerable/hidden/hard-to-reach participants requires special care from the researcher as these groups of people are often "hard to reach, they are the silent, the hidden, the deviant, the tabooed, the marginalised and hence 'invisible'". Because of the above reasons, the questions asked did not reinforce the status quo or the stigmatisation of the participants. In this study I specifically ensured that the participants were aware that how they contracted the virus was not a focal area of the interview; instead, the focus was on the processes after the diagnosis and navigating the disease at Rhodes University. Furthermore, I emphasized that some questions may be sensitive; and gave the participant a choice not to answer such questions. Moreover, in line with Ritchie & Lewis views, as the researcher, I showed appreciation of the importance of "sustaining empathic neutrality whereby the researcher uses personal insight while maintaining a non-judgmental stance" (Ritchie & Lewis, 2003: 4 & Downey *et al*., 2007: 736).

4.3.5 The role of the researcher and participant

As discussed earlier, the study sought to take an emic perspective with a focus on penetrating the participants' frames of meanings (Ritchie & Lewis, 2003: 4). To gain insider perspective, Babbie and Mouton (2001: 271) encourage researchers to make a deliberate attempt to put themselves in the shoes of the participants' and try to "understand their actions, decisions, behaviour, practices, rituals and so on from their perspective". My views of the respective roles is inspired by Ely *et al.*'s idea that qualitative research is an interactive process in which the participants teach the readers about their lives (Ely *et al.*, 1991: 4). Further, it is emphasized that reciprocity involves "a mutual exchange of information and contributes to establishing rapport" (Elmir, Schmied, Jackson, & Wilkes, 2011: 14). With this is mind, the aim was to mitigate the power differentials (as discussed by Laher *et al.*, 2019: 4 and Elmir *et al.*, 2011: 14) between the two roles and in the process empower the research participant.

While it is important to mitigate power differentials and to develop good rapport with participants, this may result in the researcher developing a closeness to participants which may confuse the role of friend and researcher. Thurairajah (2019: 134) explains that the relationship between the qualitative researcher and their participant is perhaps the most important as it determines the kind of data that is gathered thus affecting the outcome of the research. However, Thurairajah (2019: 135) highlights the importance of creating and respecting boundaries to maintain professionalism. A few days after an interview, a participant invited me to be a speaker at an event they were hosting as a "friend". To ensure that the researcher-participant boundary would not be crossed, especially during the research process, I politely declined the invitation.

According to Liamputtong (2007: 6), researchers working with vulnerable groups must make judgements on the impact of their research on both the participant and the researcher themselves. Because of the sensitive nature of the research topic, both the participant and the researcher have the potential to be emotionally involved in the narratives shared. The interaction requires disclosure of behaviours, views, and attitudes which would usually be kept private and personal; therefore, a certain level of trust and rapport must be established between the two parties (Elmir *et al.*, 2011: 13; Thurairajah, 2019: 134). In accordance with this, I first introduced myself to the participants and gave them information about me that the participant would not have known simply by reading the recruitment letter. I also explained why I feel the study is necessary in society and in the school of knowledge. By doing this, I wanted to show the participant that while the study is for academic purposes (obtaining a Doctoral Degree) I also have stronger feelings towards advocacy for and education about LWH and PLWH. Bryman (2012: 664) explains that such engagement between the researcher and participants has positive consequences for the research – participants respond more positively when the researcher reveals something about themselves in the early stages or during the interview process.

4.3.6 Sampling technique

As previously mentioned, the study used purposive sampling aimed directly at PLWH. The plan was to interview a minimum of six students and six staff members for each category; however, only four students and six staff members were questioned due to unforeseen circumstances. The participants were recruited through the Rhodes University Health Care Centre and the HIV Office – both of which, as mentioned above, agreed to be gatekeepers of the study and strategic informants. The use of these channels was to reach as many students and staff as possible. As the researcher, I was conscious of the challenges associated with the study and getting participants due to its sensitive nature. Goode (2000) emphasizes that the more sensitive or threatening the study is, the more difficult it is likely to be to contact the research sample because of the greater need for potential participants to hide their involvement.

Through the gatekeepers, I identified and selected participants who are especially knowledgeable about and who have first-hand experiences of LWH at Rhodes University. Palinkas *et al*. (2015: 534) adds that while the selection of information-rich cases is essential, there is also the importance of availability and willingness to participate and the ability to "communicate experiences, and opinions in an articulate, expressive and reflective manner" (Palinkas *et al*., 2015: 534). The issue of availability and willingness were some of the challenges encountered in the study. On the one hand, due to COVID-19 Rhodes University had to unexpectedly migrate teaching and learning to remote and digital delivery platforms. The university halted all face-to-face interactions and sent all students and staff home. This had a direct impact on the recruitment and sampling of participants. On the other hand, some participants withdrew from the study. Furthermore, plans to conduct more than one interview with each participant had to be changed. Fortunately, enough data had been gathered from the individual interviews.

As mentioned above, the researcher had minimal control over the selection of the sample, thus a wider and more racially diverse group of participants could not have been targeted to reflect the diversity of experiences. The predominantly African black and female sample in this study was in part due to the high number of African black women LWH accessing treatment at the university clinic.

4.3.7 Method of analysis

The study and its aims called for a method of analysis which reflects the complexity, detail and context of data. Therefore, emergent themes and categories from the data collected were identified. Ritchie and Lewis (2003: 3) assert that in the process of analysis, it is important for the researcher to respect the uniqueness of each individual's narrative and to develop explanations at the level of meaning rather than the cause. In line with this, the study produced "detailed descriptions and rounded understandings" (Ritchie & Lewis, 2003: 4) and "thick descriptions" (Babbie & Mouton, 2001: 272) emanating from the participants' interpretations and perspectives of their experiences. I was the sole collector, transcriber, translator and analyser of the data – this gave me a deeper understanding of the data.

Lune and Berg (2017: 15) posit that when humans are studies in a "symbolically reduced, statistically aggregated fashion, there is a danger that conclusions – although arithmetically precise – may misrepresent the people or circumstances studied". In line with this notion, the researcher was aware that research on human beings affects how the persons studied will be viewed, therefore, in analysing and presenting the data, the researcher omitted any identifying information about the participants.

In line with the assertion in Section 4.2, that qualitative research procedures seek patterns among cases, this study employed a thematic analysis. The process of identifying themes in this study was guided by the central goals of the research, therefore, during this process the researcher systematically identified themes and subthemes which were recurring in the participants' narratives for each of the questions asked. The themes and patterns are a "product of a thorough reading and rereading of the transcripts or field notes that make up the data" (Bryman, 2012: 579). The themes and subthemes identified were then applied to the data and linked to the literature and theoretical frameworks employed. It is worth noting that in presenting the findings, outlying themes were also highlighted so as to explore how research participants may have had differing perceptions from each other (Bryman, 2012: 580) and how participants' views are in line with or differ from existing literature.

4.4 RESEARCHER VULNERABILITY

According to Downey, Hamilton and Catterall (2007: 724), researcher vulnerability as a result of researching vulnerable groups is an often-uncharted area in research. The assertion is that the potential impact, predominantly negative, of studying vulnerable groups on the researcher is often overlooked. Discussions of power differentials in the research process correctly emphasize the power of the researcher and address ways in which the research participant can and should be protected. While this is incontrovertible, Downey *et al*. (2007: 735) also draw attention to the vulnerability of the researcher. Methodological concerns surrounding the research of vulnerable populations rightfully and commonly focus on the participants – ensuring that they are unharmed or further disadvantaged by the research.

For Downey *et al*. (2007: 735) the relationship between the researcher and the participant is one of "shifting boundaries" where the researcher does not always assume the dominant role but is "susceptible to changing positions of vulnerability throughout the research process" (Downey, Hamilton, & Catterall, 2007: 735). The premise of the argument is that researchers also become vulnerable when entering the social world of the vulnerable subject of study; thus, researchers need to be prepared for this role. During the research process, the researcher encounters ethical dilemmas linked to proximity and personal involvement which draws upon intuition and empathy as well as feelings and emotions. Downey *et al*. (2007: 735) contend that assuming the role of the researcher does not negate the potential to feel isolated, vulnerable and distressed.

The role of a qualitative researcher especially comes with responsibilities: being trusted with sensitive information, managing privacy and confidentiality, maintaining a non-condemnatory attitude and environment etcetera (Downey, Hamilton, & Catterall, 2007: 736). Due to the role of the researcher and the kind of environment within which the researcher will find themselves, the researcher needs to be aware that feelings of vulnerability may be reflected back to them. Part of this researcher vulnerability may be in the form of self-disclosure, which Elmir *et al*. (2011: 14) describe as the process of revealing information about the self [researcher] to the participant. Even though Elmir *et al*. (2011: 14) advocate this, as it enhances the possibility for greater engagement from participants and makes the process less intimidating, it is cautioned that self-disclosure can potentially lead to scrutiny and digression from the interview, depending on the information divulged by the researcher (Elmir *et al*. 2011: 14; Thurairajah, 2019: 135). Further, self-disclosure may contribute to the confusion about the role of the researcher. This speaks to the earlier example regarding a participant inviting me to speak at an event they were hosting.

In a different interview with a staff member, the participant had their friends over, and at the end of the interview they said it was "their turn to interview me" – this particularly lightened the mood as the participant had ended the interview with a story that put them in distress. After my self-disclosure, we were able to return to the interview with the participant.

Downey *et al*. (2007: 738) explain that while it is possible for the researcher to anticipate certain aspects of the risks associated with the role of researcher researching vulnerable populations, it is during the research process that "hidden risks emerge". Subsequently, "every eventuality cannot be addressed in the context of training" (Downey, Hamilton, & Catterall, 2007: 738). In the same breath, partly due to the focus mainly on participants, it is often difficult to predict in advance the impact the research process will have on the researcher and what vulnerabilities will be encountered.

4.5 ETHICAL CONSIDERATIONS

In terms of the Rhodes University Ethics Standards Committee, the study's sample has been classified (for their vulnerability) as level two of three. This level stipulates that the "project involves standard social and/or psychological studies of individual or groups of human subjects considered 'vulnerable' or with potential to cause distress, embarrassment or offence. In such studies, fairly standard ethical procedures might contain mild risk" (RUESC, 2018: 8). Liamputtong (2007: 2) explains that a precise definition of the term 'vulnerable' is problematic because the term itself is socially constructed. Due to this, there are varying definitions for the term. From Liamputtong's findings, the researcher identified with two definitions of 'vulnerable' that are aligned to this study:

> "A vulnerable person is an individual who experiences diminished autonomy due to physiological or psychological factors or status inequalities" and "vulnerable populations are social groups who have an increased reactive risk or susceptibility to adverse health outcomes" therefore " these vulnerable people then will include those who are impoverished, disenfranchised, and/or subject to discrimination, intolerance, subordination and stigma" (Liamputtong, 2007: 2).

In conducting this study, the researcher recognized that the interview process may trigger negative feelings regarding living with the disease. Thus, I consulted with the Rhodes University Counselling Centre[14] to provide counselling should student participants require it. Staff members who needed counselling services would be directed to the HIV Office. Furthermore, disclosing their HIV-positive status to the researcher may be of concern to the

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[14] The Rhodes University Counselling Centre only offers free counselling services to students registered at the institution.

participant in terms of trust and confidentiality hence the researcher ensured that participants are aware that only the researcher would know and have access to the raw data. The supervisor and readers of the study would not be able to identify the participants.

As the researcher, I acknowledge that not all risks are reversible – the researcher cannot reverse triggering emotions but will have remedial measures in place should there be harm to the participant (Dube *et al*., 2017: 5). In partnership with the RU Counselling Centre, we ensured that student participants were aware of the services offered at the university's Counselling Centre and that these could be accessed if needed. Staff member participants were aware that the HIV Office would offer counselling services. I was also sensitive and cognizant throughout the interview process that participants could, if they wished, withdraw from the study or choose not to discuss certain aspects of their experiences. If the participant felt that their participation in the study was causing harm or distress and they wished to withdraw they were aware that it would be acceptable and should be communicated. The participant was also given time to process questions, and when there was a need to discontinue the interview, this was be respected, as was the case with the participant who was with friend.

Participants were aware, as mentioned in Section 4.2 above, of the researcher's previous experiences with the topic of discussion both academically as a researcher and also as wellness leader, sub-warden and Peer Educator. The participants were informed that the researcher had conducted similar research with participants LWH and had previously mitigated all possible harm to participants. Additionally, the researcher ensured both in a previous study (Tsope, 2018) and the current study that participants were aware of their role, the researcher's role, risks, and benefits of participating in the study. Further, the researcher emphasized to all participants that the study is not focused on how participants contracted the virus, instead, their experiences following the diagnosis. Lastly, the researcher ensured that the interviews did not coincide with any significant event in the participants' lives that may trigger negative emotions such as the date in which they were diagnosed, exam period, the Silent Protest[15](in the case of gender-based violence), or any other dates on which participants would not be willing to have interviews.

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[15] The Silent Protest is a Rhodes University movement that takes place annually. It is a protest against rape and sexual violence of women and non-conforming bodies. The main idea around the silent protest is to challenge the culture of silencing women and non-conforming bodies around sexual and gender based violence. The silent protest also highlights the difficulty of reporting these crimes often times leaving the victims silenced, there are too many rape cases that go unreported and this movement seeks to break this silence

Regarding benefits, I communicated that it was my hope that the participants would see value in their contribution to academic research and potentially influence change in the university setting. Furthermore, I hoped that participants would also see value in contributing to the way in which the HIV-narrative is constructed, mainly because I embrace the notion of "nothing about us, without us" (Charlton, 2000). In the same breath, as the researcher, I hoped that the study would enhance participants' knowledge; following Ritchie and Lewis' (2003: 6) claim that "our knowledge of the world is based on 'understanding' which arises from thinking about what happens to us, not just simply from having had particular experiences".

This study is in agreement with Liamputtong (2007: 29 and Elmir *et al*., 2011: 12), that sharing sensitive or personal information is not always a negative experience. Instead, that participants may find the experience cathartic and that they would be able to talk about issues that they otherwise would not or have not had the platform to discuss. Liamputtong (2007: 29) adds that the confidential nature of the research process may present an opportunity for participants to open up and raise concerns and even be a therapeutic and empowering experience.

4.6 CHALLENGES ASSOCIATED WITH THE QUALITATIVE RESEARCH DESIGN

Due to the range of culturally diverse communities that are dynamic, constantly changing and are "typified by racialized tensions, gender inequities, socioeconomic disparities and high levels of violence" in South Africa, conducting research is likely to be challenging (Laher, Fynn, & Kramer: 2019: 4). According to Laher *et al*. (2019: 4), the challenge is likely to involve access to spaces and resources for data collection and relate to power differentials between researcher and participants.

As discussed in Section 4.2 of this chapter, the researcher is already a member of the studied setting thus having an advantage in entering the setting. The challenge with proximity, according to Ely *et al*. (1991: 16), is that, on the one hand, the researcher can be familiar; on the other hand, it is argued that "being familiar is less a function of our [researchers] actual involvement in the setting than it is of the research stance we [researchers] are able to adapt within it" (Ely *et al*., 1991:16). Moreover, the concept of familiarity is unpacked as follows:

> "…we are too familiar when we 'know' the answers ahead of time or when we feel too close, too distressed, too disinterested, or too biased to study the situation, or when we realise that the people in it did not accept us in our researcher roles. We are too familiar when we cannot make the familiar unfamiliar" (Ely *et al*., 1991:16-17).

While it is important to study the familiar, Ely *et al*. (1991: 17) encourage an awareness of the blinders that come with it and thereafter addressing these blinders accordingly. In the same light, Elmir *et al*. (2011: 15) express the difficulty in researchers distancing themselves and remaining "faceless" during the study of subjective experiences. Researching sensitive topics and vulnerable populations has the potential to pose a threat to the wellbeing of the researcher, particularly if "they have strong feelings or have lived experiences of the phenomena under investigation" (Elmir *et al*., 2011:15). To avoid the negative impact on the wellbeing of the researcher or what Elmir *et al*. (2011: 15) call "researcher burnout", reflection between interviews helps. Reflection after each interview proved to be useful for me as a researcher as I did find some interviews to be very emotionally charged, which in turn left me upset and feeling sorry for the participant. Even though I maintained composure during the interviews, I did respond to the feeling in the room and expressed empathy to the participant. In one interview particularly, with Staff member 2, while sharing an experience, she cried, and I allowed her to have the moment. Only to realise that I had shed a tear while listening. I cannot recall whether I was triggered by her experience in the sense that I understood what she was telling me, or I was deeply was attached to the participant's story. At the end of the interview, we had a conversation about that moment and she interestingly found that my response to her crying was validating because she said: "it [crying] is not something you see in counselling – the therapist usually sits and blankly stares at you [the client]".

Another factor that has previously been discussed in this chapter, which presents unique opportunities but also has the potential to be challenging to the design and the researcher is undertaking research with vulnerable people (Liamputtong, 2007: 2). Certainly, qualitative research methods are especially appropriate to the study of vulnerable people as they allow the researcher to interact and learn from those who are silenced, othered, and marginalised by the dominant social order (Liamputtong, 2007: 8). However, the researching of the abovementioned groups of people commonly involves behaviours and experiences that are "intimate, discreditable, or incriminating" (Liamputtong, 2007: 2), making it risky for potential participants to show interest. Liamputtong (2007: 2) refers to these sensitive areas as "back regions": private spaces where personal activities take place, and only "insiders" participate. Gaining access to these "back regions" entails jumping through some hoops; as such, these spaces render the need for the researcher to be sensitive to the "confidences and intimacies of others" (Liamputtong, 2007: 5). Liamputtong (2007: 27) further prompts researchers to be cautious and aware that their studies, especially with vulnerable groups, have the potential to reinforce stereotypes and contribute to discrimination against participants.

Laher *et al*. (2019: 4) explain that the data collection process starts with the practice of ethical procedures such as obtaining informed consent. In South Africa, for example, where there is linguistic diversity, this stage is already met the linguistic barriers between the researcher and the participant where participants may not fully understand what they are consenting to. Moreover, Laher *et al*. (2019: 4) highlight the high level of uneducated people in South Africa and the African regions which "implies that some participants may be illiterate and thus unable to read an information sheet or give written consent" - which affects the objectivity of the ethical imperatives in research. In this study, the researcher has minimised the aforementioned effects by ensuring that the gatekeepers give the potential participants both a written and verbal explanation of the study and its purposes.

4.7 CONCLUSION

It is clear from the above discussion that the qualitative research paradigm is the most appropriate to capture the experiences of PLWH. The chapter has demonstrated that the research process is not linear and that research involving vulnerable populations requires careful considerations of the holistic process to mitigate potential risks for all those involved in the research. The chapter highlights that the choice of methodology stems from the epistemological and ontological view that knowledge and reality are best sought from those who experience it.

CHAPTER FIVE: THEORETICAL UNDERPINNINGS

"History will surely judge us harshly if we do not respond with all the energy and resources that we can bring to bear in the fight against HIV/AIDS"

Nelson Mandela

5.1 INTRODUCTION

In alignment with the goal of understanding participants' experiences and narratives and the chosen methodology of the research, this study seeks to integrate three theories, namely: social constructionism, symbolic interactionism and the biographical disruption theory. It is worth noting, however, that the focal theoretical framework is the social constructivist theory. The chosen approaches are interlinked and best suited because of their shared goal of understanding how individuals create meaning for themselves and others. While they have different intellectual backgrounds and emphasis, in practice, the strength of the theories is their value in a study of meaning creation (Leeds-Hurwitz, 2006: 229). Social constructionism broadly focuses on "making sense of the nature and structure of the social world"; symbolic interactionism emphasises "making of self, and social roles" (Leeds-Hurwitz, 2006: 238) and the biographical disruption theory highlights the processes which people living with chronic illnesses go through to adapt their lives to accommodate their illnesses in pursuit of continuity. The study follows the symbolic interactionist view that the individual and society are inseparable units, therefore, mutually interdependent. Thus for a complete understanding of the one, there needs to be a comprehensive understanding of the other (Meltzer, Petras & Reynolds, 1975: 2). Russell (2009: 100) explains that broader inequalities such as class, gender, ethnicity and age shape an individual's perceptions and experience of health, health care and illness; as such this study views these variables as intersectional. The assertion is that, in all these determinants, "biological and socio-cultural influences work in complex ways to influence health outcomes" (Russell, 2009: 100).

The chosen theories are essential to the study as the aim is to delve into how individuals create or recreate a sense of self personally and in their social worlds, especially within the Rhodes University community, due to living with HIV and AIDS. The study follows that "meanings allow people to produce various realities that constitute the sensory world (the so-called real world), but because these realities are related to how people create meanings, reality becomes an interpretation of various definitional options" (Lune & Berg, 2017: 17). Most importantly, the theories also follow the approach that the individual can shape and reshape his or her environment (Meltzer *et al*., 1975: 57).

This chapter seeks to review social constructionism, symbolic interactionism and the biographical disruption theory by highlighting how these theoretical frameworks relate to the qualitative research paradigm and how illness, with a focus on HIV and AIDS, can be understood from these lenses.

5.2 SYMBOLIC INTERACTIONISM AND ILLNESS

The guiding principle of symbolic interactionism as a theoretical framework (rooted in evolutionism) is that on one end, social life is a process of interaction between the social environment and the natural environment and on another end, it is a process of interaction between human beings within these spaces (Reynolds & Herman-Kinney, 2003: 40). Furthermore, human beings behave in ways that adapt to these environments and the individuals mutually influence one another. (Reynolds & Herman-Kinney, 2003: 40; Reynolds & Herman, 1994: 1). Through social interaction, human beings are constantly changing, as is the society within which they find themselves.

According to Benzies and Allen (2000: 544), symbolic interactionism provides a theoretical perspective for how individuals interpret actions, people and objects they encounter. Additionationally, Reynolds and Herman (1994: 2) assert that understanding human behaviour requires the researcher to learn the participants' meanings, as the framework emphasises that humans act towards things based on their symbolic meanings. Moreover, 'sympathetic interaction' or 'verstehen' is required to get a deeper understanding of the participants' lived experiences and symbolic worlds. 'Sympathetic interaction/introspection' or 'verstehen' promotes the notion of thoroughly investigating meanings and definitions held by people and not just relying on observations of external behaviour (Benzies & Allen, 2000: 543).

Goffman (1963) explains how individuals actively participate in the construction of their social worlds, and this process includes the construction of individual selfhood through social interaction. Concerning illness, symbolic interactionists effectively explore, in detail, the experience of illness within the context of individuals' daily social interactions which consequently shape the performance of self (Conrad & Barker, 2010: 568). In this way, symbolic interactionists, as mentioned above, focus on the micro-level to supplement the macro-level view of life (Schwartz & Rutter, 2000: 17).

The actor, the object, the meaning, the act and joint or social action are central concepts to symbolic interactionism. Each of these concepts is highlighted in the premises within which symbolic interactionism rests: firstly, humans live, in part, in a symbolic world of learned meanings. Secondly, through social processes and social interaction, symbols develop and are shared. Thirdly, the symbols that arise have motivational significance whereby “meanings and symbols allow individuals to carry out distinctively human action and interaction” (Reynolds & Herman, 1994: 1). The fourth assumption is that the mind is a “functional, volitional, teleological entity” (Reynolds & Herman, 1994: 1) which operates in the interest of the individual, therefore, unlike other species, human beings can critically and creatively think and the capacity of this is moulded by social interaction. The fifth assumption follows that the self is a social construct whereby social interaction aids in creating the self. Lastly, Reynolds and Herman (1994: 1) add that social processes and social interaction create a symbolic society within which individuals interact. The central concepts will be discussed below, incorporating a demonstration of how the theoretical framework can be used to understand an individual’s illness experiences – the personal and social symbolism and meanings.

Within this framework, the main focus of the research entails seeking an understanding of the meanings of a situation from the perspective of the individual and societal groups. Consequently, it is imperative to gain an understanding of what individuals know about their world and what they deem essential (Benzies & Allen, 2000: 545).

5.2.1 The Actor

According to Blumer (1969: 12), the human being is an acting organism, meaning that the individual is not only a recipient of others on a non-symbolic level; instead, the individual also acts, makes indications to others, and interprets their indications. In other words, the individual also actively participates in the process of meaning-making as an object of his or her actions. Here then, the individual is aware of themselves; for example, one knows that one is a student, a mother, a person living with HIV and AIDS etc. This awareness of being an object to oneself determines how individuals act toward themselves and how they present themselves in actions to others. Blumer (1969: 12) asserts that this self-objectification, ‘self-object', emerges from the process of social interaction where outsiders define the person to themselves. Therefore, for an individual to see themselves as an object, the individual must see herself or himself from the outside, through role-playing – "we see ourselves through the way in which others see or define us" (Blumer, 1969: 13; Charmaz, 1990: 161). Crooks (2010: 15) furthers this by stating that role-playing, social interaction, reflection and self-objectifying also helps individuals get to know themselves better.

Individuals do not only interact with others as a ‘self’, but they also interact with themselves as a ‘self’. This interaction, Blumer explains, is social – like any other interaction with others would occur. It is a process of making indications. It is a daily process of continually communicating with oneself as though one is communicating with another person. For example, noting that one is angry with oneself, or reminding oneself to do daily tasks, or talking oneself through a plan of action (Blumer, 1969: 13). Symbolic interactionists assert that this process is continuous throughout one's life, showing that human activity is both individual and collective (Crooks, 2010: 14). The process is vital because the consciousness of the individual is “equivalent to his indicating the thing to himself – he is identifying it as a given kind of object and considering its relevance or importance to his line of action” (Blumer, 1969: 13). Interaction within the self and with others allows people to understand a situation better, and then make choices. Individuals living with HIV and AIDS then, in this context, are not only organisms who respond to a diagnosis, but they are organisms which must deal with the diagnosis and act accordingly after that. Thus, giving meaning to what they perceive their disease to be and then using the purpose provided as a basis for directing their actions as active beings.

5.2.2 Objects

The assertion is that “human beings live in a world or environment of objects, and their activities are formed around objects” (Blumer, 1969: 68). These objects, according to symbolic interactionists, are not self-existing with intrinsic natures; instead, they are constructed by humans through social processes and interaction. The quality of these objects is determined by the orientation and the way people act toward them (Charon, 2001: 29). George Mead defines an object as “anything that can be designated or referred to” (Blumer, 1969: 68). Blumer (1969: 68-69) identifies the following five features of objects:

1. The nature of an object is established by the meaning it has to the individuals who see it as such.
2. The meaning of an object is not intrinsic; it arises from how an individual is prepared to act toward it.
3. All objects are socially constructed.
4. People act toward objects based on the meanings they give them.

5. There is no one way of responding to objects, and the response is relative.

This perspective views human beings as living in a world of meaningful objects. Moreover, the world is socially produced, and meanings emanate from social interactions. As interactions change, so too do meanings attached to objects change. In this research, it is the ARVs and the individual consuming them that are the objects. ARVs can be viewed in varying perspectives depending on who is seeing them. Antiretrovirals carry different meanings to different people in different worlds. For those living with HIV and AIDS and consuming ARVs, the ARVs mean a completely different thing than to those who are living with HIV and AIDS and not consuming them. Furthermore, to medical practitioners and laypersons, the meanings of ARVs will be different. In the same way, the individual LWH carries a different role in different contexts, for example, in the clinic or hospital context they are considered patients whereas in their households or social circles they are a friend, sister, mother etc.

5.2.3 Meaning

While meaning is central to symbolic interactionism (as outlined in the five premises of symbolic interactionism listed above), the social sciences have generally downplayed the role of meaning by solely attributing human behaviour to the external factors and the factors producing them. Blumer (1969: 3) explains that factors such as "social position, status demands, social roles, cultural prescriptions, norms and values, social pressures and group affiliation" are given more attention than the "meanings of things for the human beings who are acting". Symbolic interactionism, however, values the meanings that things have for human beings to such an extent that undervaluing them is considered a falsification of the behaviour (Charon, 2001: 1). Meaning is an essential part of the formation of behaviour. Symbolic interactionism views meaning as deriving from two sources: first, the object itself – here the belief is that every object has a meaning whether individuals perceive it or not. Second, the "psychical accretion brought to the thing by the person for whom the thing has meaning" (Blumer, 1969: 4). The above two origins of meaning do not focus on a one-sided view of the creation of meaning. Instead, they appreciate that meanings are social products, created in and through people's defining actions as they interact with one another and themselves (Charon, 2001: 1).

5.2.4 The Act

According to Blumer (1969: 64), "action is seen as conduct which is constructed by the actor instead of a response elicited from some kind of performed organisation in him". As emphasised above, symbolic interactionists see humans as active organisms whose actions are inspired by the way they face, deal with and act toward objects. Individuals are constantly in a process of learning, unlearning and relearning meanings through interaction, which then determines how they view objects, acts, and themselves as actors. Blumer (1969: 64) explains that it is this consciousness by individuals that allows them to act as they see fit. In this regard, the narratives of people living with HIV and AIDS incorporate a whole process of understanding the diagnosis and the medical meaning of it and then coming to terms with the treatment of and the reality of living with the disease. Furthermore, individuals have to then define for themselves, after the whole process, what being HIV-positive means.

4.2.4 Joint action/social action

Joint action, or social action, highlights the interlinks in social interaction. Individuals find themselves belonging to more than one group or society, for example, one can be a part of an organisation, the mothers in a society, the working, those living with HIV and AIDS etc. In each of these groups there are different individuals with different positions and acting differently based on their perspectives, therefore, their ability to fit all these acts together is what makes the joint action, not their commonalities. Additionally, Watkins-Hayes (2014: 432) contends that HIV and AIDS "intersects with long standing social heirachies that seemingly render some groups more expandable than others". Therefore, the different group categories that exist and interesect as well as social meaning and resources historically and presently assigned to them are crucial to understanding HIV and AIDS (Watkins-Hayes, 2014: 432). Blumer (1969: 70) illustrates this joint action as follows:

> "Their alignment does not occur through sheer mechanical juggling, as in the shaking of walnuts in a jar or through unwitting adaptation, as in an ecological arrangement in a plant community. Instead, the participants fit their acts together, first by identifying the social act in which they are about to engage and, second, by interpreting and defining each other's acts as informing the joint act"

It is clear that while each participant in the group has different roles, the entirety of the group shares a goal and as society evolves so too do the goals and the actions of members in these societies (Charon, 2001: 30). The course of action in these groups is guided by the way the members construct meanings and use symbols (Crooks, 2010: 11). For Charon (2001: 3), as the action unfolds, individuals get a sense of their environment and then define situations. So, the group acts according to their definitions of situations. Moreover, as individuals manoeuvre their social worlds and "encounter privileges and disadvantages by virtue of their various social group memberships, they affirm, acquiesce to, resist or create alternatives to dominate ways of thinking and behaving" (Watkins-Hayes, 2014: 433).

The symbolic interactionist approach probes deeper than surface level understanding of objects or symbols and what Staggs calls 'sufferer images' (Staggs, 2007: 3).The person living with HIV and AIDS, the disease and the treatment of the disease are essential symbols or objects which in turn act as signifiers of HIV and AIDS. Chapter Three (and later in this chapter) illustrates that once an individual is diagnosed with HIV and AIDS there is a disruption that takes place which eventually leads to a narrative change. The individual's life, sense of being and the world around them is recast in a different light where they have a 'before' and 'after' in the way they view themselves (Staggs, 2007: 4). This 'before' and 'after' consists of new meanings, objects, actors and acts which lead the individual to interact with the jargon of HIV and AIDS. The transformation into this new narrative also means new social actions because the individual now belongs to a new group in society – that of PLWH.

PLWH are continuously defining and redefining themselves because of the developing nature of the disease, treatment of the disease and emerging research about the disease. As the biomedical and scientific aspect of HIV and AIDS develops, so too do the social perceptions of the disease and treatment develop. Thus, individuals go through the continuous reconstruction and redefining of self and their illness narrative (Kerr, Deane, & Crowe, 2019: 3). In line with this, Watkins-Hayes (2014: 432) asserts that the transformation of HIV and AIDS from an inevitable death sentence to a chronic illness has presented new social and cultural realities. Staggs (2007: 10) explains that some narratives of people living with HIV and AIDS are oriented toward the future, and others are present-oriented. This orientation determines the meanings individuals give to their lives. Their views of the possibility or impossibility of hope transform their narratives, their identities, and their social action. The organisations that some individuals join affect their identity, "based on the type of orientation, a patient can come to see himself [or herself] as empowered or as simply a 'manager of illness'" (Staggs, 2007: 10) The symbolic interactionist perspective applies to the study because it "supplements the macro-level view of life" (Schwartz & Rutter, 2000: 17) by looking at the micro-level, as is the intention of the study through its focus on specific individual narratives which shed light on the broader community of Rhodes University and its responses to PLWHA.

5.3 THE SOCIAL CONSTRUCTIONIST APPROACH

The social constructionist framework emphasises the social, cultural and historical aspects of a phenomenon “widely thought to be exclusively natural” (Conrad & Barker, 2010: 567). This theoretical framework proclaims that meanings of phenomena do not necessarily exist in the phenomena themselves, instead that meanings develop in a social context. The theory, therefore, explores how individuals and groups contribute to producing “perceived social reality and knowledge” (Conrad & Barker, 2010: 567). According to Leavy (2014: 85), the idea of social constructionism is that people create their reality through social interactions, relationships, and experiences. Social constructionists then, as mentioned above, are primarily concerned with the meaning-making process and how individuals' understandings and experiences come about, and how these meanings then feed into the larger discourse (Blanche *et al*., 1999: 278). Social constructionism values the complexities of human experiences and the idea that “any one facet of someone’s life intertwines with (contributes to) some other facet” (Roller & Lavrakas, 2015).

At the core of the theory is the emphasis on the extent to which human beings creatively and actively produce and construct society. Social constructionists assert that the world is “portrayed as made or invented – rather than as given or taken for granted” (Barry & Yuill, 2002: 21), as such, society or social worlds are interpretive nets woven by individuals and groups. Lock and Strong (2010: 4) summarise that in social constructionism, experience, or subjectivity, is at the core root of things. In this way, humans are not “individually encapsulated information processors” instead humans are inherently social beings who engage in the process of becoming “encultured” humans who then experience the world (Lock & Strong, 2010: 4; Williams, 2016). Our realities as humans then are constructed through our immersion in a shared experiential world with other people. The theory does not deny that explanations of the social are grounded in individual subjective understandings. However, the theory advances that these personal understandings are better understood in their social contexts (Williams, 2016: 204).

Several authors (Lock and Strong 2010: 6; Houston, 2001: 846-847; Burr, 1995: 3-6) agree that the five tenants that hold social constructionism are as follows:

1. The theory is concerned with meaning and understanding as the fundamental feature of human activities.

2. Meaning and understanding are rooted in social interactions and shared agreements about what these symbolic forms are to be taken to be.
3. The socio-cultural processes of meaning-making are specific to particular times and places.
4. The theory distances itself from essentialism and realism.
5. The theory adopts a critical perspective. It is concerned with “revealing the operations of the social world, and the political opportuning of power that is often accomplished unawares, so as to change these operations and replace them with something more just” (Lock & Strong, 2010: 6).

Rather than essentialism and realism, social constructionism has its origins in idealism. Idealism maintains that all knowledge and all that humans experience as reality is constructed through interaction with other humans as well as the natural world (Williams, 2016: 203). Having said that, there is a meeting point between realism and the interpretive aspect of social constructionism. For example, it could be argued that there is an actual reality but that it is known to us through our experiences and perceptions

As stated above, the theoretical perspective encourages the questioning of our assumptions about how the world appears to be. Burr (1995: 4) and Gergen (2001: 8) add that what is regarded as “truth”, which varies historically and cross-culturally, is not a product of objective observation but of the social processes and interactions in which people are constantly engaged with each other. Because of this, the idea is that there is a wide range of understandings of the world and we can, therefore, “talk of numerous possible social constructions of the world” (Burr, 1995: 5).

Charmaz (1990: 1161) asserts that chronically ill people, like other people, experience their constructions as reality, “their constructions are neither convenient fabrications, nor idiosyncratic inventions” but rather, their constructions reflect their understandings of their experiences as well as the diverse situations these experiences take place. Social constructionists appreciate that outcomes are a result of social interactions, negotiations, and power. For constructionists, illness is not just a physical state; it is a social phenomenon (Lober & More, 2002: 1). Weitz (2004: 2) advances this notion by highlighting that to the ill individual, an illness is both an internal and personal experience as well as a social phenomenon with social roots and consequences.

According to Lober and More (2002: 1) and Gergen (2001: 1), every society, through cultural and moral values, shapes what being ‘sick’ means – through interaction with members of the individual's immediate social circle and relationship(s) with healthcare professionals – and is influenced by the shared beliefs about health and illness. Therefore, meanings attached to behaviour or experience viewed as a sign or symbols of illness are aligned with social norms, cultural values and culturally shared rules of interpretation. Mishier *et al*. (2002: 142) note that social constructionists do not regard diagnosis as “the measurement and assessment of specific deviations from biological norms” but rather, as a process whereby signs are “evaluated as having cultural significance and in particular, as having the meaning of disease”.

5.3.1 Social constructionism and illness

Conrad and Barker (2010: 567) claim that a social constructionist approach to illness is rooted in the widely recognised conceptual distinction between disease (which is the biological condition) and illness (which is the social meaning of the condition). Unlike the medical model, which declares that diseases are “universal and invariant” to time or space, social constructionists emphasise how the meaning and experience of illness is shaped by cultural and social systems. The perspective highlights explicitly that these culturally and socially embedded meanings are not directly “derived from the nature of the condition” (Conrad & Barker, 2010: 567), instead that cultural and social meanings influence how society responds to those afflicted, which in turn affects the way in which individuals experience that illness. Thus illness is not merely “present in nature, waiting to be discovered by scientists or physicians” instead, Conrad and Barker (2010: 57) claim that all illnesses are socially constructed at the experiential level, based on how individuals come to understand and live with their condition. Illness then is a social designation which is not inherent in the nature of the medical fact. The social constructionist framework posits that illness is more than the medical truth. In line with the above, Martin and Peterson (2009: 578) argue that chronic diseases, such as HIV and AIDS, are socially constructed, notwithstanding widely accepted disease classification systems.

Martin and Peterson (2009: 578) assert that for those who experience the treatment for and live with chronic disease, the process of constructing the experience and assigning meanings to the condition is hugely personal and influenced by the different social contexts in which the individuals find themselves. Moreover, for those who suffer pain and debilitation from the chronic disease, or treatment thereof, “the process of social construction is even more relevant as it provides a set of meanings and explanations that simply cannot be accounted for by the biomedical model by which many health care professionals interpret the illness experience" (Martin & Peterson, 2009: 578). Medical knowledge about illness and disease is not given by nature; it is rather constructed and developed by claim-makers and experts within the medical field (Conrad & Barker, 2010: 57). Counter to these medical approaches to illness and disease, there is social constructionism, which provides an approach which is useful in broadening policy deliberations and decisions and also accentuates understandings of the social and personal dimensions of illness.

According to Martin and Peterson (2009: 579), social constructionists view health, chronic illness, chronic disease and medical care as social facts with "greater or lesser degrees of consensus". The perspective endorses that there is a process that takes place: experiences or behaviours are interpreted as signs or symptoms of disease or illness, depending on cultural values, social norms, and culturally shared rules of interpretation. In this way, further than diagnosis, which is a given medical fact, there is "a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience and power relations" (Martin & Peterson, 2009: 580). Social constructionists go as far as to claim that a diagnosis is used to construct an illness and in turn, cast specific individuals into the role of patients. In this light then, it can be argued that being diagnosed with HIV and AIDS has implications of labelling which in turn has consequences that exclude the individual from 'normal' social groups – for example, individuals will immediately be labelled as patients which removes them from the "healthy" group in society, further, more and more labels will relocate farther from their immediate circles into new ones. Weitz (2004: 118) explains that through defining cancer, polio and diabetes, for example, the bodily changes that these conditions produced are judged as abnormal and undesirable instead of seeing them as normal variations in functioning, abilities and life experiences. In the same way, when a condition is defined as healthy, it is in turn, viewed and judged as usual and desirable (Weitz, 2004: 118). In this way, constructivists follow that managing an illness involves active interpretive work beyond diagnosis and biomedical labelling (Martin & Peterson, 2009: 581 & Mishler *et al*., 1981: 142). By asserting that a diagnosis is a social process, and illness a social category, Mishier *et al*. (2002: 148) emphasise that there will be variation across cultures and times.

As mentioned above, the ways in which societies define illnesses reflect cultural, historical and economic interests and values rather than solely biological reality. In this way then, Weitz (2004: 119) and Williams (2016: 204-205) claim that illness is a social construction; it is something that exists in the world, not as an "objective condition". This does not mean, however, for example, that the virus that causes HIV does not exist or does not have symptoms. Instead, it means that in talking about HIV and AIDS as an illness, societal ideas about the virus and its symptoms are organised in one of many possible ways (Mishler *et al*., 1981: 141). Furthermore, in a different place or time the same conditions and symptoms identified with HIV and AIDS above, may be seen as manifestations of witchcraft, as healthy response to the presence of microbes or viewed under a different illness rubric (Weitz, 2004: 119). Weitz (2004: 119) concludes that much like sin or crime, illness refers to “biological, psychological or social conditions subjectively defined as undesirable by those within a given culture who have the power to create such definitions” (Weitz, 2004: 119).

Collins (2006: 110) maintains that HIV and AIDS' complexity is found in the notion that while the disease is fundamentally mostly sexually transmitted, it delves into individuals’ behaviours that are irrational and ignore warning signs, cautions, and dangers of general sexual behaviour. The disease also encapsulates "myths, stereotypes, lies, and taboos related to our sexual life, our sexuality, and our social-psychological beliefs…" (Collins, 2006: 110) – all of which are influenced by social interactions, structures and dynamics. Herek, Capitanio and Widaman (2003: 533) describe the way in which illness is socially constructed: symptoms are identified, and the disease is named; theories of the origin of diseases, transmission, prevention and cure, are “formulated, promulgated, criticised, and revised”; responsibility and blame are often assigned; labelling takes place and then the policy is created and implemented within this context. Following these stages is the effort to track, treat and prevent the said disease. This process is not necessarily sequential; instead, it is more circular.

In the view of Mishler *et al*., (1981: 141), the social constructionist approach is in contradistinction with the biomedical model of diseases as defined by reference to universal, culture-free criteria. In addition, a related implication of the constructionist approach stems from its “denial of the assumption of genetic disease”. Mishler *et al*. (1981: 142) argue that following that illnesses are culturally defined, cultural variation in the specifications of behaviours as signs of illness and in taxonomies of disease would be expected. As it stands, biosciences in modern Western medicine provide definitions that represent only such culturally set based set of definitions (Mishler *et al*., 1981: 142). Even though the same biological processes would be observed in different cultures, the meanings given to them would differ; hence Mishler *et al*. (1981: 142) explain that a sharper distinction in the biomedical model between biological signs and diagnosis is made. Consistent with this emphasis is the view outlined earlier in this section, of diagnosis as active interpretive work rather than solely as a technical procedure.

Mishler *et al*. (1981: 142) explain that instead of viewing "diagnosis as a measurement and assessment of specific deviations from biological norms", social constructionists view diagnosis in its entirety: as a process whereby certain signs are evaluated as having cultural significance and particularly having a meaning of disease. By separating signs and their meaning as disease, a distinction is made between the experience of those diagnosed and the definition of their condition by health professionals, more specifically the physicians. Critics of the traditional biomedical model have argued for the use of different terms to emphasise the difference. For example, it is argued that patients suffer "illnesses" while physicians diagnose and treat "disease" (Mishler *et al*., 1981: 142). Furthermore, the social constructionist approach to illness shifts attention away from the medically defined signs seen to be representing the condition of the patient to the "processes, that is socially organised activities of health professionals and others, through which these signs come to be defined, interpreted and responded to as having the 'meaning' of illness" (Mishler *et al*., 1981: 143). Thus the constructionist approach shifts from the biomedical model and proposes alternative definitions of health and illness which take into account a wider range of information and interests in making medical decisions than is required by the biomedical model.

5.4 THEORY OF BIOGRAPHICAL DISRUPTION

As discussed in Chapter Two, the emergence of a chronic illness can result in a lot of suffering for the individual (Turner & Kelly, 2000: 124). Charmaz (1983: 168) identified four key areas that individuals suffer from: leading restricted lives, experiencing social isolation, being discredited, and burdening others. In addition to the abovementioned, PLWHA also deal with stigmatisation which, combined with the progression of the disease, can lead to psycho-emotional disturbances and the strain or disturbance of relationships and painful bodily symptoms (Setlhare, Wright, & Couper, 2014: 309; Worley *et al*., 2009: 369). Moreover, the stigmatisation subjects PLWHA to blame, fear and avoidance (Houtsonen *et al*., 2014: 534; Reif *et al*., 2011). The above factors contribute to biographical disruption. This section contends that the concept of biographical disruption has utility for the understanding of experiences of LWH.

According to Reeve *et al*. (2010: 178) biographical accounts of illness are essential because they offer useful insights into the social and adaptive processes of living with chronic illness especially in the late modern Western societies where there is an increasing burden of chronic, non-life-threatening illness. Reeve *et al*. (2010: 178) explain that this increase in chronic illnesses, medicine is "shifting from a focus on the cure of acute disease to management of chronic impairment and disability", hence the rich literature recounting the biographical impact of illness. These biographical narratives include consequences of the challenges brought about by illness, and the subsequent adaptive processes individuals go through, including biographical reconstruction and biographical reinforcement.

Kelly and Field (2004: 256) contend that illness is a multi-phenomenal experience and a multi-layered object of analysis. To those experiencing the disease and its physical and psychological pathology, there are a variety of ways in which they will feel the experience. Illnesses may include intrusive symptoms, interruptions to customary physical and social routines; cognitive disorientation and confusion as well as a change in behaviour patterns (Kelly & Field, 2004: 256). For asymptomatic conditions, individuals may have less of a subjective or experiential dimension; but discomfort, disruption and distress may be unavoidable. Kelly and Field (2004: 258) assert that there are very few accounts of, especially, a chronic illness, which do not acknowledge the "disruption of the normal and usually desired routines of everyday life". In line with this, Carricaburu and Pierret (2004: 291) explain that in the case of HIV, the medical prognosis cannot predict when an individual will fall sick; therefore, asymptomatic PLWH have to manage a healthy life in the face of uncertainty.

Central to the process of coping with an illness is dealing with the manifestations thereof. Bury (1991: 461) claims that coping refers to a cognitive process where the individual learns to tolerate their illness and also involves "maintaining a sense of value and meaning in life, despite symptoms and their effects". For Hubbard *et al*. (2010: 133), coping includes normalisation of illness and bracketing of the impact of illness, which in turn minimizes the effects of the illness on an individual's identity. Normalisation entails individuals retaining their pre-illness lifestyle and identity intact by maintaining as many pre-illness activities as possible or through disguising symptoms, not to affect their pre-illness identity and activities (Bury 1991: 450). Other ill individuals normalise illness by finding ways to incorporate their condition into an altered lifestyle. By merging the disease into their lifestyles, Hubbard *et al*. (2010: 133) explain that individuals re-designate their everyday lives as containing the illness.

In some cases, the coping with the physical body comes before one has to cope with relationships, disruptions and any form of reconstruction. The reconstruction one goes through may also include reconstruction of self and identity. In the case of HIV, specifically, Watkins-Hayes (2014: 444) explains that coping with the disease entails simultaneously managing the physical demands and experiencing a social status that has the potential to diminish connections, existing resources as well as one's social standing. Kelly and Field explain that feelings about self-conceptions and identities applied externally (i.e. by others) "fluctuate and vary…they do not change in a coterminous, simultaneous or deterministic way" (Kelly & Field, 2004: 259). Here then an interconnection between symbolic interactionism, social constructionism and the theory of biographical disruption is highlighted as far as identity is concerned; because in the symbolic interactionist framework, identity is conceived as "a means of defining and differentiating self from others and takes into account people's preferred identities and identity goals that they desire, hope and plan for in future" (Hubbard *et al.*, 2010: 133).

For those LWH, a disease commonly constructed as a social phenomenon, there is also a process of self-conceptualisation within public discourses about HIV and AIDS (Carricaburu & Pierret, 2004: 292). Carricaburu and Pierret (2004: 292) point out that illness can be experienced at a personal and collective level; particularly for those LWH whose private experiences have to be merged with the collective experience of "an infectious illness associated with ideas of contagious diseases and epidemics".

In agreement with Bury (1982), Carricaburu and Pierret (2004: 294) assert that chronic illness disrupts the daily lives of individuals. Furthermore, Carricaburu and Pierret extend this narrative by claiming that a chronic illness "wreaks havoc in people's daily lives and their forms of knowledge" (Carricaburu & Pierret, 2004: 294). Bury (1982: 169) details the three ways in which chronic illness disrupts an individual's life as follows:

1. The disruption of taken-for-granted assumptions and behaviours. At this level, an individual goes through a process where parts of their lives, which otherwise wouldn't be, are brought into consciousness.
2. The disruption of explanatory systems usually used by people. This stage requires an individual to rethink and reconceptualise their biography and self-concept.
3. The response to disruption; in this stage, the individual needs to readjust their lives to accommodate the disruption and mobilise resources for the change.

Several factors will influence the way in which an individual experiences the three identified ways in which disruption unfolds; which reflects the intersectionality of HIV and AIDS. In line with this, Watkins-Hayes (2014: 432) argues that HIV and AIDS is an “epidemic of intersectional inequality that is fueled by racial, gender, class, and sexual inequities at the macro-structural, meso-institutional and micro interpersonal levels”; all of which significantly influence the likelihood of “exposure to the virus, the realities of living with the infection; and the medical, programmatic, political and socio-scientific responses” thereof. Additionally, Bredstrom (2006: 310) found that the above mentioned variables, with the addition of disability, all have a significant impact on the social construction of AIDS, and on an individual’s ability to respond to the epidemic, to protect themselves from HIV infection or to get the necessary care should they become infected with HIV, on the policy and agenda, and lastly on who dies and who survives an HIV diagnosis and the disruption thereof.

In a study conducted by Carricaburu and Pierret, *From Biographical Disruption to Biography Reinforcement: The Case of HIV-positive Men*, research participants had to organise their everyday lives around three issues (Carricaburu & Pierret, 2004: 295). Firstly, participants had to reorganise their lives around managing the secret of their positive HIV status. Secondly, participants had to deal with constraints and self-constraints surrounding the uncertainty of the future. Lastly, navigating resources (medical, personal, and social) to build up hope. It is clear from the above that for PLWH, disruption takes place at different levels and varies. Moreover, despite the disruption of diagnosis, individuals have to find a sense of continuity for their lives (Carricaburu & Pierret, 2004: 297).

According to Bury (1982: 168), even though people living with chronic illnesses adapt their lives to accommodate their illnesses in pursuit of continuity, such people still experience “periods of classic sick-role behaviour when such events as surgical intervention or sudden exacerbations of symptoms occur”. This is evident in asymptomatic PLWH who, at times, experience intense symptoms, side effects (from ARVs), or even the development from HIV to AIDS. Bury (1982: 170) further highlights that the transition from trivial symptoms to a developing and persisting disability, from HIV to AIDS in the case of LWH, affects the individuals who have to be initiated (by self and others) into a new social and medical arena where guidelines of the previous stage of illness may or may not be sufficient.

Carricaburu and Pierret (2004: 294) contend that meaning and context are intertwined in the notion of biography. The claim is that through placing chronic illness in its social context, meaning can be established. This process of meaning-making is long and often not linear; Bury (1982: 174) contends that the process includes merging knowledge gained from specialists with personal biographies. For some, this process of searching for the meaning of events and answers to the questions – why me? why now? “incidents from the past are set against persuaded knowledge about the disease and the disease’s causation,” i.e. an overlap between moral concerns and scientific-based knowledge. Bury (1982: 177) and Carricaburu & Pierret (2004: 294) claim that of importance throughout the process of disruption, to those experiencing the illness, is maintaining normality.

5.5 CONCLUSION

It is clear that symbolic interactionism and social constructionism speak to similar principles, and in some ways that the symbolic interactionist perspective contributes to a social constructionist approach to illness. The biographical disruption theory contributes in the same light by explaining the processes individuals go through following a diagnosis. Conrad and Barker (2010) demonstrate that there is no exhaustive history of the intellectual contributions which lead to and continues to inform the social constructionist approach to illness. Further, this chapter showed that these contributions and strands are not mutually exclusive. The critical theoretical framework of this study centres around the way in which illness is shaped by “social interactions, shared cultural traditions, shifting frameworks of knowledge and relations of power” (Conrad & Barker, 2010: 569).

CHAPTER SIX:
RESULTS: SETTING THE SCENE

6.1 INTRODUCTION

Using thematic analysis as outlined in Chapter Four, in line with the theoretical foundations outlined in Chapter Five, a total of four broad themes emerged from the analysis, namely: interventions and responses to HIV at Rhodes University; adherence and disclosure;, stigma and discrimination; and, as well as disruption and reconstruction of narratives – all of which are addressed in depth in the respective chapters to follow. In setting the scene for the upcoming empirical chapters, it is worth noting that the critical instrument for data analysis was the researcher; who made judgments about coding, theming, decontextualizing and decontextualizing the data (Nowell *et al*., 2017: 2). The themes identified in this thesis were generated inductively from the raw information gathered from the in-depth interviews. The empirical chapters in this thesis follow Boyatzis' (1998: 4) view that themes are patterns found in "information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon". Guest *et al*., (2012: 3) assert that while theoretical or philosophical foundations offer a framework for inquiry, it is the data collection and analysis processes as well as the outcomes thereof that are most important in research because what is known at the end of the research process is determined by the methods by which it came to be known. Thus, in Guest *et al*.'s (2012: 11) view, thematic analysis is still the most useful approach to "capturing the complexities of meaning within a textual data set" (Guest *et al*., 2012: 11).

The interpretation of the key themes, emerging from participants experiences, is guided by the social constructionism, symbolic interactionism and the theory of biographical disruption. The themes capture the participants' experiences of living with HIV at the university, their perceptions about the way in which the university addresses HIV-related issues, their experiences of adherence, disclosure and stigma, and lastly, how each participant's life was disrupted by an HIV-positive diagnosis and the reconstruction that took place as a result. The key themes discussed in this thesis do not cover all aspects of the participants' experiences that were shared by the participants; instead, these themes were chosen due to their relevance to the study's goals. While the key themes, and the sub-themes within them (to be discussed in the respective chapters to follow), were common amongst the participants in the study, there were differences in narratives, as will be seen in the discussion. It is also important to note that the narratives shared in this research do not capture the participants' illness experiences entirely, as the focus in this study was precisely in the university context. Having said that, aspects of participants' experiences outside the university context that directly affect their experiences in the university context are incorporated.

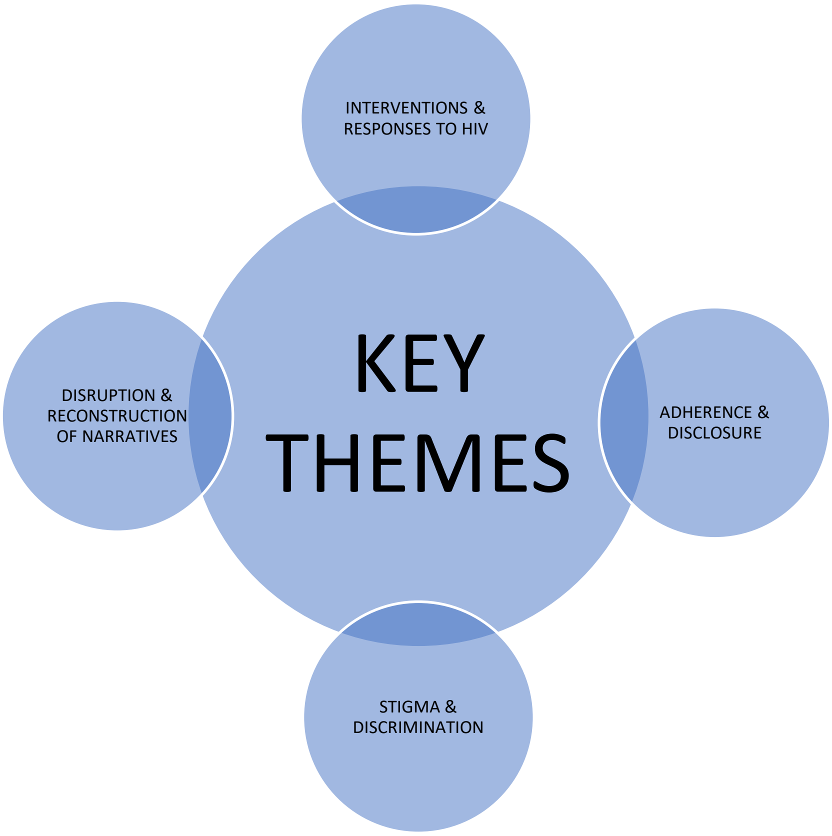

FIGURE 6: KEY THEMES

6.2 THE PARTICIPANTS

The participants of this study comprised six female black staff members and four black students (one male and three female) who accessed ARVs from the Rhodes University Health Care Centre. Accordingly, the study is made up of their experiences and perceptions. It is worth noting that due to the size of the university and the sensitive nature of this study, the participants are not referred to by name or pseudonyms. Instead, they are referred to as "Student X" or "Staff member Y" and where connections need to be made about a said participant's narrative they are made based on the information already offered in this thesis, if and when necessary. Where I use the term "the participants", I refer to the collective participants in the study. As mentioned in Chapter Two, the participants in this study are deliberately not referred to as patients.

The following section will offer a summary of each participant to provide insight into the participants' lives beyond their HIV-positive status. The introduction of the participants seeks to demonstrate and echo Bor *et al*'s (1993: 445) claim that HIV-lived experiences cannot be talked about without considering the multiple identities that "inform social experience and that certain categories are likely to dominate in specific contexts, spaces and moments" and that "race will likely continue to be a critical category of analysis in the Sociology of HIV/AIDS" (Bor, Miller, & Goldman, 1993: 445).

Student 1:

Student 1 is a 20 year old single undergraduate male pursuing his first degree. He lives in one of the campus residences, where he is also a student leader. This student was diagnosed at the university campus, during the *First Things First* HIV campaign, at 19 years. How he contracted the virus is still unknown to him, and he shares that he struggled with the confusion the most, following diagnosis. He has disclosed to his closest friends, sister and mother only. He is the last of two children and lives with both parents. He enjoys going out with friends, and he is a social and environmental activist. He is very friendly, articulate and well-read. At the beginning of the interview, he shared that he knew he could trust me because he had done his research about me. Therefore he had prior knowledge.

Student 2:

Student 2 is a 24-year-old postgraduate female student, pursuing her second degree. During her undergraduate years, she lived on campus and has since moved off-campus at the beginning of her postgraduate degree. Student 2 student was diagnosed at the university campus, at 19, during a campaign by the South African National Blood Services (SANBS). She was told at the campaign station that she could not donate blood and was given a referral letter to open with her General Practitioner (GP). Only later, once the GP had seen the letter was she officially diagnosed following another HIV test. She shared that she later learned that she contracted the virus through a rape inflicted by an older family member when she was a child. She has disclosed to all her friends, family and boyfriend. She is in a loving relationship and is the first of two children. She comes from a big family and shared how close they all are in the family. Student 2 had disclosed her HIV-positive status to me a while before this research was even considered, in my capacity as Sub-Warden.

Student 3:

Student 2 is a 21 year old single female final year undergraduate student, pursuing her second degree. She lives in at the university residence and is a member of a student society. She was diagnosed at the university campus during the *First Things First Campaign* a year before the interview was conducted, at 20 years. She is the last of three children and lives with their single mother. She is very soft-spoken and enjoys anime. She shared that one of her concerns about leaving Rhodes University at the end of the year is that she has to disclose to her family and initate antiretroviral therapy at a public facility. Only the nurses and myself know her status, no one else knows.

Student 4:

Student 4 is a 24-year-old single female postgraduate student, pursuing her third degree. She lives off-campus with her friends. She was diagnosed at 16 during a school trip and later found out that she was born with HIV. She is an only child, living with her aunts who took her in following the death of her parents at age 5 and 6 respectively. She is an athletic person, with a bubbly personality and shared that while she has not disclosed to anyone (except the aunts and family members who knew before she did) she does not hide her status, it has just never been necessary for her to disclose. She shared her love for sports and exploring new places.

Staff member 1:

Staff member 1 is a 36 year old female with no children. She lives with her mother and her two sisters, who are also her best friends. She works in the university as a gardener. She was diagnosed in a local clinic following symptoms she could not make sense of. Her then-boyfriend, whom she believes she contracted the virus from, denied knowing his status even though she later found his antiretroviral medication. She later broke up with him and was at the time of the interview pursuing a new relationship. She finished her matric and due to lack of funds could not pursue tertiary education. She shared that she has a handful of friends but doesn't trust friends because "one moment they are laughing with you, the next they are laughing at you". Hence the only people she had disclosed her status to are her immediate family members, boyfriends and myself. When I asked her how she knew she could trust me she said "we don't know the same people and I don't see why you would go around talking about me". She is an introvert and very shy, however very funny. She became more and more comfortable as the interview proceeded and at the end of the interview we walked together and she was telling me about her township.

Staff member 2:

Staff member 2 is a 41 year old single woman with two children. She works as a cook in one of the student residence dining halls. She lives with her two children in her family home which she shared with her brother following their parents’ passing. The brother has also recently passed on. She was diagnosed when she was pregnant with her daughter. She shared that her diagnosis has taken a lot from her. She broke up with the father of her children who showed no remorse when she confronted him, as she is sure she contracted the virus from him. She also shared that the diagnosis has restricted her life and made her see things differently. She now has no social life. She is “just alive for my children”, whom she loves very dearly. Our conversation was very emotionally loaded. Staff member 2 was holding back at first but became more and more comfortable as the interview went. At the end of the interview, she was grateful and said that it was her first time talking about her diagnosis and how it really affected her. She also considered my suggestion to try counselling.

Staff member 3:

Staff member 3 is a 52 year old widowed woman, who at the time of the interview had recently lost her only son in a tragic car accident. She is a grandmother to a boy whom she says is “the reason I have to stay healthy and alive”. She has been living with HIV for 16 years. Staff member 3 learned of her diagnosis when she heard rumours in her neighbourhood about her late husband having an affair with a woman who was alleged to be HIV-positive. She shares that she immediately had to test to make sure before she could confront the husband, who later revealed no knowledge of his status and refused to test. This resulted in him succumbing to the disease a few years later. Staff member 3 is a very bubbly, stylish and beautiful woman who is vocal about her HIV-positive status and says she shares it with others to show them that HIV is not a death sentence and “you can be beautiful and happy with this disease”. She is a cleaner at the university. Her interview took place in a residence staff room, where she invited her two closest friends to join us. The women shared how proud they are of the impact Staff 3 has had with changing the negative HIV-narrative both at work and at home, where they all live in the same street.

Staff member 4:

Staff member 4 is a 34 year old single mother of two daughters. She is very shy and soft-spoken. She was diagnosed when she was pregnant with her first child whom she is very grateful for because if it were not for the pregnancy, she would have never tested. She also proudly shared that both her daughters are HIV-negative and that alone is the reason why she trusts that ARVs work. Staff member 4 is a gardener in the university. On the day of the interview, it was her birthday, and she shared how excited she was to have lived to see the age as she had lost friends and neighbours to HIV. She shared that she had an on and off relationship with the father of her children, who is also the breadwinner, even when they are separated as they were at the time of the interview. Staff member 4 shared how fortunate she has been to have boyfriends who are not bothered by her HIV-positive status and that she has become an HIV activist over the years.

Staff member 5:

Staff member is a 45 year old married woman with two children. She works in the university as a cleaner. She has been living with HIV for 3 years and shared that she went for an HIV-test because of her gut feeling. She shared that it had been on her mind for about a year before she finally tested, and she thinks it is because of the husband's infidelity that she was always thinking about it. She shared that she resents her husband but can not leave the marriage because she doesn't want to rob her children of their father as she knows what it is like to grow up without one. She has an infectious laugh and always cracks a joke at the end of sharing anything that upsets her. She says she enjoys comedy and watching rugby as those are the two things that she and her children bond over.

Staff member 6:

Staff member 6 is a 32 year old female working as a cleaner in the university. She has been living with HIV for 14 years. At the time of the interview, she shared that she was excited that she and her boyfriend were trying to conceive. This was exciting because for her as being a mother was something she had always wanted to be, but her diagnosis forced her to put the dream on halt. However, she has recently learned that with an undetectable viral load, she can conceive with minimal to no risk of infecting her unborn child; hence they were trying for a baby. She shared how close she is with her friends and family but felt that they didn't need to know about her status. For her, her HIV-positive status was personal and only shared with her boyfriend and brother. She also shared that she wants to further her studies in the near future and working at Rhodes University has been a great inspiration as she frequently sees women in her age group studying.

Participant	Age	Years LWH	Race	Marital Status	Occupation	Children
Student 1	20	1	Black	Single	Student	0
Student 2	24	5	Black	Single	Student	0
Student 3	21	1	Black	Single	Student	0
Student 4	24	24	Black	Single	Student	0
Staff member 1	36	10	Black	Single	Gardener	0
Staff member 2	42	6	Black	Single	Cook	2
Staff member 3	52	16	Black	Single	Cleaner	1
Staff member 4	34	8	Black	Single	Gardener	3
Staff member 5	45	3	Black	Married	Gardener	2
Staff member 6	32	14	Black	Single	Cleaner	0

FIGURE 7: PARTICIPANTS SUMMARY

6.3 CONCLUSION

This chapter has, in conjunction with Chapter Four, provided the reader with a broader view into who the participants are, beyond their HIV-positive status. It has also demonstrated the intersectionality of HIV and AIDS (Watkins-Hayes, 2014: 432; Bor *et al.*, 1993: 445). Furthermore, it has mirrored the South African HIV-prevalence statistics, showing the age group, race and sex with the highest prevalence. I hope that in reading the preceding chapters, these demographics will be kept in mind as they have a direct impact on illness experience. The way in which an individual makes sense of their illness is within the context of their personal biographies, thus will be continuously influenced by and meshed with cultural values of the societies they live in and the constructions of the disease and living with it both by medical professionals and society (Nettleton, 2006: 81; Morrall, 2011: 50).

CHAPTER SEVEN: INTERVENTIONS AND RESPONSES TO HIV AT RHODES UNIVERSITY

"…We must remember: One of the biggest hurdles for our global response to AIDS is psychological. That is the stigma factor. To greater or lesser degrees, almost everywhere in the world, discrimination remains a fact of daily life for people living with HIV. One-third of all countries have virtually no laws protecting their rights. Almost all permit at least some form of discrimination - against women and children who contract the disease, against gay men, against communities at risk."

Ban Ki-moon

7.1 INTRODUCTION

In order to attain a holistic narrative study of students' and staff's experiences of living with HIV and AIDS at Rhodes University, it is essential to have a contextual understanding of the interventions and responses to HIV at the university as these influence the individuals' illness experiences. As far as possible, and in line with Skhosana *et al.*, (2006: 18), the study emphasizes that experiences of participants are informed by the recognition that being HIV-positive is not just "a single crisis moment but a complex ongoing process" therefore, a holistic approach to illness experience has been followed. As per the discussion in Chapter Four, one of the goals of this study was to explore and understand Rhodes University's institutional practices and responses to HIV and AIDS and the impact these have on individuals' experiences.

Kelly (2003: 1) found that universities lack an institutional and consistent response to the epidemic. Moreover, the finding was that the disease is considered solely as a student or health issue and not an issue that must be integrated into a "university's core operations of reflecting on issues affecting society, teaching, research and community engagement" (Kelly, 2003: 1). This chapter sets out to discuss how Rhodes University's responses are perceived by those directly affected by HIV, with Kelly's assertion in mind. The discussion on interventions and responses to HIV at Rhodes University will be divided into two sections, namely: perceptions of university responses to HIV and HIV-related interventions at Rhodes University.

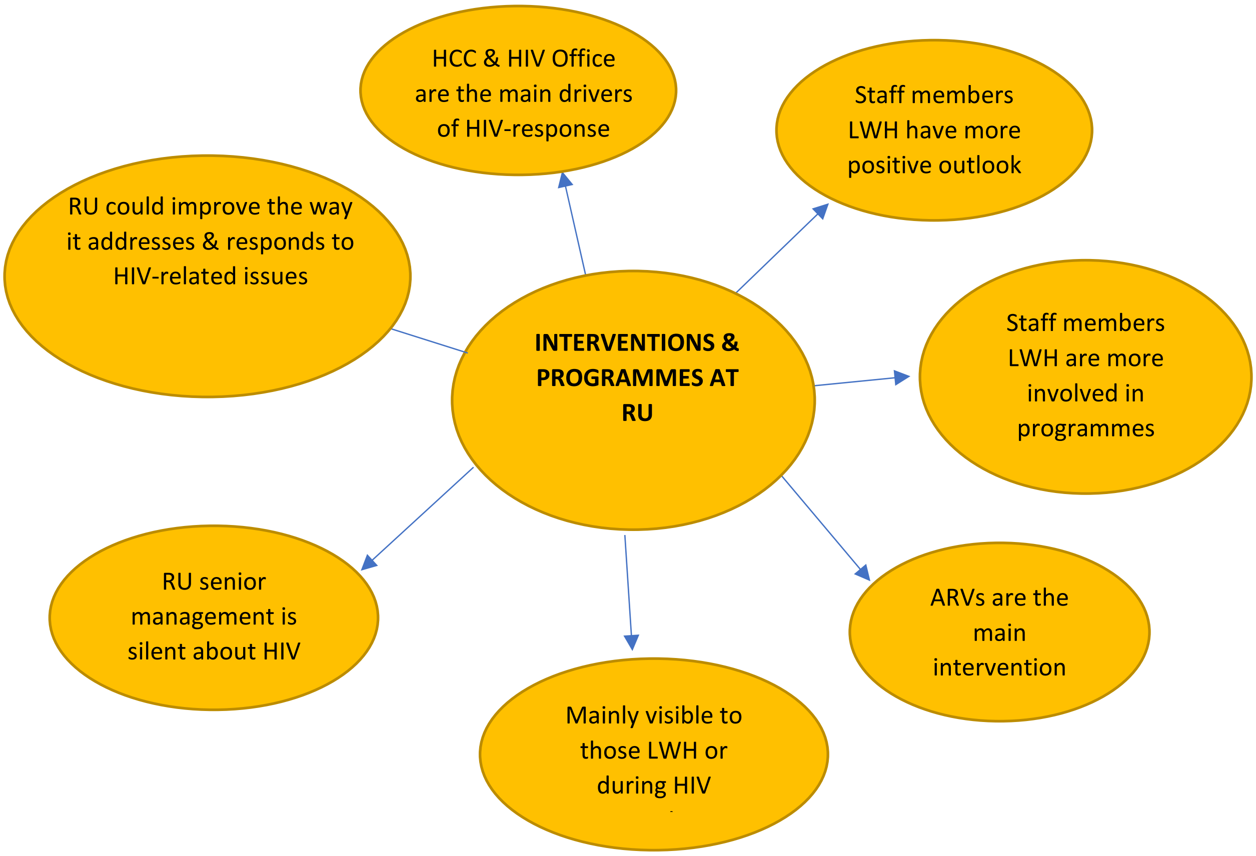

FIGURE 8: SUMMARY OF SUB-THEMES

7.2 PERCEPTIONS OF RHODES UNIVERSITY’S RESPONSES TO HIV AND AIDS

The Rhodes University website highlights that the university emphasizes a holistic approach to health and wellness. The assertion, according to the website, is that “wellness is not the mere absence of disease. It is a proactive, preventive approach designed to achieve optimum levels of health, social, and emotional functioning.” (Rhodes University, 2020). This view is in line with the World Health Organization’s definition of wellness (WHO, 2020). Within this category (health and wellness), Rhodes University lists the sections and areas of responsibility, namely: Health Care Centre, Counselling Centre, Career Centre, Harassment Office, HIV and AIDS Office, Campus Protection Unit, and Sports Administration – all of which are interrelated in ensuring the health and wellness of students and staff at the institution. In alignment with the *HIV Prevalence and Related Factors* (HEAIDS, 2010) report, which states that it is the responsibility of all South African Higher Education Institutions (HEI) to strive to be sensitive to and accommodative of the needs of people living with HIV (PLWH) (HEAIDS, 2010: xxii), Rhodes University has programmes in place for this purpose. In relation to HIV, specifically, the university offers Voluntary HIV testing, including pre-and post-test counselling for all students and staff, Pre-ART, and ART (Rhodes University, 2020). The participants of this study showed different levels of knowledge of the various programmes in place at the university for PWLH. The general feeling among participants was that the university could improve in the way it addresses HIV-related issues. Student 1 explained:

> "I think the work done by the HIV office is… *sigh*. It's huge because at some point, I remember being in a discussion or a meeting whereby Rhodes [University] students at some point couldn't access ARV drugs here on campus. They had to source their medication outside of the university. It took the HIV office actually to get that done and actually through the San Health Care Centre] have a collaborative idea to bring that [ARVs] here so I think they have made significant strides in terms of promoting student health, actually not only students but for staff members as well, especially those who are living positively so…yah. I think they are doing a pretty amazing job in that aspect. I do think the majority of the work and the core work is based at the San and the HIV office. If it wasn't for the remarkable people that work there, I don't think people at the top [University senior management] would necessarily think to necessarily include or think that perhaps there may be students or staff members living with certain ailments that you know, need some form of comfort within the space."

The student, later in the interview, added that in his view if the HIV office and the Health Care Centre were not as active and efficient, Rhodes University's response to HIV-related issues would be different. He added:

> "I think it [the response to HIV] would be slow. I think it would be slow, and to me, I attribute the work of the San and the HIV Office to being very steadfast in terms of like approaching HIV. Maybe it's because this form or line of work is their expertise for that office and the San, so I think it's entirely up to them. It's very convenient for the u university to have those type of spaces just for the nature and sake of it being an institution of higher education."

Based on the above account, and of many other participants, "the university" refers to Rhodes University's senior management. From the quote, it is evident that the student feels that HIV-related matters are only prioritized at the Health Care Centre and HIV office. This view is shared by other participants as well. For the next student, Student 3, to access information and interventions in place, the initiative has to come from those who need it rather than there being existing structures in place even for those who are not directly affected. When asked how she felt about the way the university addressed HIV-related issues, she shared:

> "Whooo. Address is a big word. They [the university] don't necessarily address it unless you have questions surrounding it. When you are willing to initiate the conversation and ask questions, they [Rhodes University] are willing to offer it, but it's not like out there if that makes sense. So, they don't address it like probably in reses in ways that it makes it an open space to actually ask questions or have discussions about it. So that's why when you say "address," it's a bit tricky. I mean, it's not like they are hiding the information, but they are not upfront and do not necessarily offer it to everyone. I don't know. I feel like, for me, the Health Care Centre was very central and essential to me because I was able to talk to the nurses, and they treated me the same. It wasn't anything out of the ordinary or anything like that. Which was nice because it's not like you are being excluded somehow or treated differently. But when you put it differently, for example, for me, after I found out I was positive, I wanted other people I could relate to and all those things. So, I went to the Health Care Centre and asked if there was a group session situation where people can talk about how it affects them and all those things, and I found that there wasn't anything like that, which was disappointing. So, I feel like there's a problem in the sense that a lot of people still find it challenging to open up to friends and even to people who infected them. Yah, I think that was the main thing because I was interested. I wanted to know if there was a space where I could be free to talk about this outside of my [individual] therapy sessions. I wanted to be in a space where people had all been directly affected by it [HIV]."

It is evident from the above account that there are perceived gaps in the way the university responds to HIV-related issues. One of these gaps is the absence of a space for PLWH to connect with one another in the form of a support group, for example – this will be discussed in-depth in the next section within the interventions at Rhodes University. Much like the two students above, another student shared views about the "unseen" ways in which the university responds to HIV-related issues. Student 2 shared:

> "In all honesty, HIV is not like your Rape of Gender-Based Violence (GBV) or any seen or visible issue that has designated attention in the university calendar like the

> Silent Protest[16] or such. HIV is an unseen disease, so how it is addressed is often unseen by the general public. HIV is unseen until you live with it and have to face it yourself. That has always been the case for me too. So how the university addresses it is purely relative to whom you're asking. For me, I think that if the university does address HIV-related issues, it is very low key. I don't know if providing ARVs constitutes as addressing the disease, but yeah, that's about all the university does. I can think of many other ways this could be improved. First of all, we are more than just "sick beings" who need medication. We are students and staff with emotional and social parts of our lives. Yes, I know that the university can't shelter us or treat us uniquely, but some consideration for our human side could go a long way. There's more to an HIV positive person than just the part that needs treatment. What about our feelings. What about our needs. We are whole humans with different feelings, and we're all at different places with our statuses, so a blanket approach to HIV doesn't really reach the depths of what it is like to live with HIV."

The idea that "there's more to an HIV positive person than just the part that needs treatment" as expressed by the student echoes Kalipa and Bereda-Thakhathi's (2014: 1321) claim that humans are complex and have multiple and diverse needs such as a sense of belonging, emotional, psychological, socio-economic, physical and health needs, among others. The student highlights the needs that go beyond accessing treatment, which, according to her narrative, are not emphasized enough at the university. The three theories underpinning this study are crucial here as they underscore the importance of understanding how individuals create or recreate a sense of self, both personally and in their social worlds. The symbolic interactionist perspective primarily provides a framework for understanding how individuals interpret actions, peoples and objects they encounter (Benzies & Allen, 2000: 544). Additionally, as discussed in Chapter Five, while ARVs are a virtual object that carries meaning, the person LWH is equally important as an object, thus highlighting the narrative that humans are complex with different needs, beyond treatment.

In line with the students above, Student 4, shared similar sentiments:

> "*sigh* honestly, I don't feel that the university addresses HIV or any HIV-related issues. From my observation, the university only deals with HIV testing and nothing else. The little that people know about HIV, they find out on their own through their

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[16] An annual movement and protest against rape and sexual violence of women and non-confirming bodies.

> curiosity. It's like HIV is this unspoken thing that affects us all, but lest we address it. The university could definitely, in my opinion, do more to address this."

It is worth noting that from the study's sample, only the students – all of whom had only accessed treatment from the university's Health Care Centre – identified gaps in the way the university addressed HIV-related issues. For the staff members, most of whom had accessed treatment at different facilities (mostly public), Rhodes University's response to the disease exceeded their expectations. This perception could be attributed to the negative experiences the staff members had had in their previous health care facilities, which will be discussed further in this chapter. While one student (who had contracted the virus through GBV) specifically mentioned that "HIV is not like your Rape or GBV or any seen or visible issue that has designated attention in the university calendar like the Silent Protest or such", it is worth mentioning that the university calendar does have "Wellness Week" and the *First Things First* campaign which runs three times annually – the former encompasses wellness awareness in its entirety and the latter is specifically for HIV testing and health screening.

As mentioned above, staff members' perceptions of Rhodes University's responses to HIV and AIDS differed from the students' perceptions. Staff member 1 highlighted that staff members are involved in some of the programmes that take place:

> "In my view, they address it well because sometimes they even call us [workers] to these halls, you know to educate us and show us how things work relating to HIV. [Researcher: Who calls you?] Uhm, what's his name? There's a man at the front [points towards admin building] Tata Mzizi, yes. He is the one who educates us and updates us how things are going with HIV; what's happening and how we can get help if we need it, you see…"

Another staff member, Staff member 3, shared similar views:

> "They are doing well. I have nothing to complain about. [Researcher: In what areas are they doing well?] For example, we have peer educators, where anyone who feels like joining can. It's a space for everyone, including people living with HIV, diabetes, etc. What we do is we meet and host workshops. We recently hosted a workshop at Gavin Reilly. In those workshops, it is a platform to speak openly about health issues. It is up to the person to speak from personal experience or in general. You're not forced to do anything. I really like that we are involved."

Only one of the staff members shared similar views to those of students. This staff member was, at the time of the interview, recently (less than a year) initiated on the ART programme at Rhodes University, having been previously accessing treatment from a public clinic. Staff member 2 expressed:

> "For me, there is nothing I know at the university about HIV and AIDS except that I can get medication. I've never heard maybe of [support] groups or things like that. So, I know nothing related to HIV and AIDS at this university."

Later in the interview, Staff member 2 shared that she would be interested in joining and being a part of spaces where HIV-related issues are discussed – this will be explored in-depth in the next section. From the accounts of the students and staff members LWH at Rhodes University, two things are clear. Firstly, students feel that more could be done to address HIV-related issues, going beyond providing ARVs and considering the holistic person as asserted to be the goal of the university's health and wellness programme. Secondly, the staff members of this study showed more involvement in HIV-related programmes taking place at the university – this raises the question of whether there are equal opportunities for students and staff to be involved.

In response to the question of whether or not there are equal opportunities to be involved in HIV-related programmes or events, both the Wellness Specialist and the Chairperson of Peer Educators asserted that the emphasis is similar for both students and staff members. The Chairperson of Peer Educators, Ms Mankantshu explained:

> "We reach out to all reses (residences) but…It depends on how we structure it [the programme/event] because we tried sort of forcing things where we just say this is happening come, and when you get there, and there are only three people. I remember when PrEP had just been launched at the university, we were meant to do a full-blown launch, but we figured it would take time to reach that level primarily because there were different stakeholders we wanted to be involved. So, we decided that since the PrEP medication had been available at the HCC we would rather have an information session type thing where we invite students and tell them about PrEP and then only, later on, have a full launch. When we arrived there, I think we had a total of five people, whereas we had invited the whole student body. It's let-downs like that mostly. But if we have lively events such as being outside, have music, have people etc. students get more attracted to that as opposed to something indoors and just giving out information.

> And also when we go to their respective spaces, they respond better as opposed to meeting at central venues with bigger crowds."

It is clear from the above that initiatives to engage the student body are there even though they are met with setbacks, including low participation and proper planning. These initiatives, however, do not address the needs identified by the participants in this study. The discussion on the kinds of initiatives missing at the university will be considered at a later stage in this chapter.

Continuous social support is an essential element of enhancing lives of PLWH (Smith *et al*., 2008: 1266; Auerbach & Mulhern-Pearson, 2008: 176) – for the participants of this study, this is evident in their narratives and demonstrated in the different empirical chapters of this study. At every stage of the disease, as has been discussed in Chapter Ten, social support has improved the quality of life of PLWH (Stinson & Myer, 2012: 67). Even though support looked different for each participant, the common theme amongst participants was that Rhodes University was supportive of PLWH in general and themselves personally. Much of this support, as has been mentioned above, has been attributed to Health Care Centre staff members who have a direct relationship with the participants as their primary healthcare providers. Mr Mzizi, the university's Wellness Specialist, has also been identified as a critical role player in being supportive of PLWH. The nature of the services and care given to participants will be discussed in detail in a different section of this chapter. For this section, a broad view of the support system will be addressed. Even though the first encounter with a healthcare worker, following a positive diagnosis, was not positive. Student 3's understanding of support was closely linked to the exceptional service of the nurses at Rhodes University, she expressed:

> "I have found the support system from the San to be the best I could ever dream of. The nurses are friendly and welcoming. I do not feel judged at all. Even though I don't have experience of the nursing system outside the university, I have heard and read about the horrendous treatment people living with HIV experience just to access treatment alone. For me, most of my support has been from the San and the one psychologist I disclosed to when I was diagnosed because I was diagnosed during these testing campaigns. On that note, I must say that the pre-counselling they claim to give at these tents is the bare minimum. The lady assumed that I already knew everything about HIV, and it didn't look like she expected a positive result. Well neither did I *chuckles* but she was as shocked as I was at the result, and she did not, I mean zero, did not offer any support.

> She asked if there's anyone I will call, and after I said no, she said, "it's not a death sentence" *laughs*. Of course, I knew that, but really? At that point, that's all she had to say to me as the professional I was hurt, shocked but I left… yah *sigh*"

Student 3's account highlights a lack of support during the *First Things First* Campaign where voluntary testing and counselling (VTC) is one of the primary services offered and plays a vital role in whether or not and if so, how long one seeks treatment following an HIV-positive diagnosis (Horter *et al*. 2017: 56; Stinson & Myer 2012: 67). Another participant, Staff member 5, shared how supportive the Health Care Centre staff were:

> "The staff members [of Health Care Centre] are supportive and caring because even when I walk into the San, they know who I am. I can go in even without having booked an appointment and randomly check-in with some of the nurses there, and they are very receptive to me. I don't want to regard them as merely as staff members, but like they are people who I can also relate with and you know have conversations with, which extend far beyond me living with HIV and AIDS, I mean living with HIV*chuckles*."

Participants, who had been diagnosed at Rhodes University, revealed a sentimental attachment to the staff at the Health Care Centre. Student 1 shared that the team is the "first point of call" following a positive diagnosis:

> "I personally feel that the Health Care Centre is doing an incredible job supporting us. They are the first point of call for us. I guess because of their efforts, one can say that the university is successfully supportive in that aspect. But with that said, the support is mostly medical. I know I am asking for too much, but as I said earlier, we're far more than just people needing treatment. We need assistance navigating the world with HIV. Maybe I feel strongly about this because I have recently been diagnosed, and it happened at the university, but I am also going through some developmental stages of life where I would appreciate assistance navigating things like dating, sex, drinking, etc. when you're HIV-positive. The only people who know my HIV status are the nurses at the Health Care Centre, mainly because I needed them to know my status in order to get the help I need medically. But I think I need social support as well. Sometimes living with this drains you so much that other parts of your life suffer. Even the academic side."

Staff member 1 also commended the support of the nurses and the Rhodes University Wellness Specialist:

> “I like that they [the nurses] encourage you to continue taking your treatment, take care of yourself, and all that. I mean, it’s up to you as the person if you listen, but you see, it’s all up to you how you take care of yourself and treat yourself. Take your pills, and they always encourage us. It's always the nurses when you go to them.” [Researcher: And how is Mr Mzizi involved?] He is also like that. He is like the nurses to us. He encourages us and makes sure that we know where to go if we need support.”

Lastly, Student 3 shared that she felt supported as a person LWH and highlighted that she took the initiative to maximize the support services offered at the university:

> “For me, the support is great because of the kind of person I am. I am that person who wants to know more because I can’t live with something and not understand how it affects my body and all those things. So, every time I have flu or get sick and go to the Health Care Centre it’s that thing of I am not just asking about this as a person who was sick; I am asking as someone positive. I am always asking how that flu, for example, is affecting my immune system and all those things. Even with going to therapy sessions, I wanted to understand better and to be at peace with how I got it and the fact that I am going to live with it forever. So, it’s that thing where I made sure that when I was talking [in therapy], I wanted to be as honest as possible and get to the root of anything that was making me seem like I wasn’t okay emotionally. Like essentially, they say you must be healthy or must try and like live a healthy life, but a healthy life is not just your body. Obviously, your mental state and you have to be sure of how you are and everything, so that’s why. For me, it is good in that sense, but I don’t know about other people or outside of that.”

Student 3’s account reveals how receiving support in the form of medical and psychological assistance have both been significant in her illness experience. It is clear from the participants’ accounts that support is available at the university for PLWH and that once students and staff get initiated into the ART programme at the university, they mainly have the direct support of the nursing staff. For staff members, the additional support comes from Mr Mzizi. Some students have identified the Rhodes University Counselling Centre to be an effective support service as well. The *Rhodes University Institutional HIV and AIDS Policy* as discussed in Chapter Two stipulates that, among other things, it commits itself to create “HIV and AIDS support structures directed at enhancing the health and welfare awareness of its whole community” as well as to “engaging actively with the prevention, treatment, care and support programmes in the fight against HIV and AIDS" (RU Policy, 2016). With this in mind, participants were asked which, if any, of the above (management of, support of, and prevention of HIV) were prioritized at the university. The responses reveal that while each of these dimensions is adequately addressed, the prevention of HIV is perceived to be prioritized. All the participants expressed how they each only became aware of the management and support structures in place only once they had been initiated into the ART programme at the university. Student 2 shared that the way the university prioritizes prevention is in alignment with the way HIV-related issues are addressed nationally in South Africa, which echoes this study's stance that universities are microcosms of society. The student expressed:

> "As I've just said, the HIV conversation nationally and to some extent is about prevention. The university also prioritises that somehow. There are condoms offered. Testing offered. These are things we know. But we don't know about the university giving ARVs, PEP or PrEP or even support groups. It's like those of us living with HIV have to make it work somehow. Yes, we can't expect the university to do all the work of healing us or making sure that our lives go on – but more support would make a difference. To know that we are seen, you know…"

Student 4 also expressed that only some services relating to the prevention, are emphasised:

> "Definitely prevention. Yah. They [the university] go all out to prevent, but even then, the only method is testing and offering condoms. I haven't seen or heard anything about PEP and PrEP or where one can get them, and I know Rhodes [University] offers these, and I only know now because I am with those infected. Otherwise, I doubt I would have known."

Staff member 3 added:

> "They are all important. Support and prevention mostly. But they are all important, I think. The university gives us support. Say, for example, I tell my manager that I have this and that problem, they will know my problem, you see. They support you when they know [the managers] what's going on. For me, prevention is the most emphasized actually you see… in the workshops, we go to, they teach us how not to get infected in the halls. They tell us to use condoms, behave, and all of that. How to protect ourselves."

Staff member 6, who works in the Housekeeping department in residence shared:

> "For me, since I know my status, it's my responsibility to ensure that I don't transmit the disease, to make sure I always use a condom. I can't sleep with everyone and anyone. The University also emphasizes that each res in the university has condoms. There's a big emphasis on prevention and making sure that the students don't get it. I must say, though, that the only place where there are posters educating people is at the San and nowhere else on campus."

For a Student 1 who, due to leadership positions, sits on meetings at different levels at the university, the emphasis on prevention was seen from a different perspective:

> "I think it's the prevention aspect of it because with the committees that I sit in now I find that they [the university] pride themselves more on the numbers of how many people that they actually have within the campus who are LWH they don't disclose names obviously, but they have like a huge sense of pride about the minimal numbers like we actually have on campus compared to promoting a strict sense of okay if I as an individual am living with this I have like an open door policy at the San. So, in terms of like the support aspect, yes, I do recognize that it does exist, but it is limited to me as an individual seeking it out for myself."

Once again, the notion of those LWH having to lead is perceived, where students and staff needing support are expected to take the initiative to access this. This is practical given that the university or Health Care Centre staff cannot know who needs assistance and when. Two participants, in contrast to the other eight, expressed that for them, support of PLWH and management HIV was prioritized. Staff 4 member shared:

> "I feel like support is emphasized. I haven't encountered much on the prevention side, so I'm not sure about that, but the support I have seen and experienced. Even now, this interview shows me that Rhodes [University] does care about us."

Even though in the following Student 4 expresses that management of HIV is prioritized at the university, she highlights themes that other participants mentioned, such as lack of visibility of interventions in place and the exceptional involvement of Health Care Centre staff. She expressed:

> "I think it mainly prioritizes the management of because if they looked at prevention, there'd be more talks surrounding it. It would be more visible. I'd understand what peer education means and all these campaigns. Sometimes they even put the stats about how

> many students are infected in a year and all those things and where Rhodes [University] is at and what but there's no understanding of what the university is doing to eliminate that out of the equation to ensure that not as many people are infected. But when you're in a position where you find out that you're infected, they help you manage it so well. They take you through how to take your ARVs, how to exercise, all those things. There's a lot there for you. They even refer you to therapy sessions. So, its many different things that you only get to see only when you're positive that when it comes to the management of it, they are very available."

It is clear from the above extracts that there are efforts in the university to support those LWH, manage the infection rate as well as prevent new infections. However, there is a perception from those LWH that prevention of HIV is prioritized, which in turn has the potential to give the impression that firstly HIV and AIDS is not prevalent at the university and secondly that there are no structures and services in place for those LWH. This view that prevention is prioritized was echoed by the Wellness Specialist, Mr Mzizi, who simply noted:

> "I think as HIV Officer I worked closely with the HCC together with peer educators to implement prevention programmes. The others were, unfortunately, not highlighted."

Contrary to the view that prevention was a priority, Sister Ferreira shared that it was the management of the disease that was prioritized:

> "Well… *sigh*. I think its management currently. Prevention means there should be many more campaigns, and prevention also means people need to start implementing what needs to be done, and that is not being done. The amount of PEP and PrEP we're giving out means that people are not preventing HIV. And because management has become so easy, people are going on with their lives and getting babies, and life just continues as usual. Management has just become easy – people are not dying of HIV, so the fear of HIV is gone. Stigma is still there, though. But if I am HIV-positive, it doesn't matter! Life continues. Management is easier, and there is more focus on that, but I think there should be more focus on prevention because obviously there's still no cure for HIV. There's still no vaccine for HIV, and we do not want to be HIV positive, and we do not want to be HIV-positive, and it's still a lifelong disease. But still, I'd say the focus is on management instead of prevention."

The participants' views suggest that the university has maintained the "successful tradition of HIV prevention" as was encouraged in 2010 by the Higher Education and Training HIV/AIDS

Programme (HEAIDS). This is emphasized by Sister Ferreira's point that PEP and PrEP are commonly accessed, which are key prevention drugs. The *HIV Prevalence and Related Factors* report (HEAIDS, 2010) encouraged Rhodes University not to become complacent to a point where student and staff's HIV-prevention motivation drops. From the above, it appears that prevention motivation is still prevalent, even though as Sister Ferreira notes, more initiatives should be implemented and rather than relying on PrEP and PEP.

7.3 HIV-RELATED INTERVENTIONS AT RHODES UNIVERSITY

As mentioned above, Rhodes University has various HIV-related interventions and programmes in place, including having an HIV policy, providing free HIV testing and counselling; providing PEP, PrEP, ART; HIV Peer Education and Educators; hosting HIV Campaigns and workshops or talks with students and staff as well availing free counselling services. The majority of the participants in this study were only familiar with the ART programme as they have direct access to the programme as PLWH. However, with the other interventions, little to no knowledge or exposure was expressed. The Institutional HIV policy was an unknown intervention among the interventions and programmes listed above, with only two of the ten participants knowing about the policy. Of the two students who knew about the policy, Student 1 expressed that he only knew of it because of the leadership positions he had occupied in the university, which required knowledge of university policies such as this. The other student, Student 4 expressed having a limited understanding of the policy. Student 1 shared:

> "I am very familiar with it because I sometimes sit in certain meetings that allow me to have certain disclosure of certain information regarding the university policies regarding student wellness, especially… so I am in my capacity very familiar with that aspect of university life yeah."

Student 4 shared:

> "I am aware that there is one, but I am not so familiar with the particulars of this policy. It only makes sense that there is one because we are an institution, and all institutions and departments have policies, but that's about it. Not even sure how it affects me as an individual in so far as my day-to-day life is concerned… I imagine it speaks to me or us accessing treatment and support from the university because that is what is happening. More than that, I would be lying."

The rest of the participants confessed that they had never heard of the Institutional HIV Policy at all, which, according to Sister Ferreira, is well known in the Rhodes University community:

> "With regards to the policy, I do not know if they [Rhodes University community] know about the actual policy, but as far as I know Mr. Mzizi, when he came working as the HIV Officer, he gave the policy, implemented the policy, and it was also given to the Student Services Council (SSC) at that time, the Student Representative Council (SRC) and all the important stakeholders at the university. So, it was given to a wide platform of people; so many stakeholders and I were also in that meeting with the SSC, and obviously, the policy was implemented so if people don't know, it's simply because they choose not to know or they are ignorant, or they just don't ask you know. But I must say it is a very good policy and we have implemented it immediately and put all systems in place, you know, and we worked with so many people trying to get it on the leg. We were all formulating the policy, and I think it should be well known by now, really."

According to both Mr Mzizi and Sister Ferreira, the responsibility is on individuals to acquaint themselves with the relevant policies as all policies are available for everyone to access. Both the key informants made no mention of introducing new students and staff to the policy, not even those LWH. The issue of visibility of HIV-related programmes and interventions was raised by research participants at different stages. The common theme among participants was that even though the university has interventions in place, the interventions are not known in the wider community, which speaks to a rift between intention and impact. The HIV Office, Health Care Centre, and the necessary stakeholders within the university have commendable intentions (through interventions and programmes), yet these don't always reach the target group in the way that they are intended. Both Mr Mzizi and Sister Ferreira identified that a lack of human resources and funding is a significant barrier to the implementation of programmes and interventions. Mr Mzizi explained:

> "Well, it's quite difficult to say, but in terms of programmes that are being implemented now at Rhodes [University], these only happen when I receive funding from Higher Health [previously known as HEAIDS]. Even then, I would argue that Rhodes University does not really try hard enough to implement programmes of HIV at Rhodes [University]. Why I am saying, that is because there's not much funding from Rhodes University to implement HIV and AIDS programmes, more especially workplace

> programmes. Rhodes University tends to…it's like it's only HEAIDS that they look to for funds for programmes, you see. And if one finds that they are HIV-positive, the staff members particularly use medical aid or access treatment from HCC, but the HCC itself gets the ARVs from the Department of Health. So, it's not the university's initiative, per se. These are all funded externally."

Mr Mzizi, later in the interview, explained the role of peer educators as follows:

> "To be honest, without peer educators, it would be difficult to disseminate information. Peer educators are the ones who help us spread awareness on campus. They are very important. I am saying even right now with COVID-19, peer educators will be the ones assisting us in educating the students and staff. There is only one of me, so it is difficult to reach the many different departments on campus, so I am only able to reach everyone through peer educators, both the staff and the students' ones. The staff group [of peer educators] is equally active. In fact, what I like about the staff peer educators is that there is more openness about LWH. So, they use themselves as examples."

Interestingly, and in contrast to Mr Mzizi's perceptions of peer educators, most of the student participants in this study were not clear about the role and activities of the peer educators. The participants acknowledged having seen peer educators only during the *First Things First* Campaign because they wear identifying red T-shirts marked peer educators. Student 4 shared:

> "I know they exist because I've seen them at these tents, but that's about it. I understand that resources are limited. But they could be more vocal about their purpose. It's like as the years go, we become more and more desensitized to HIV and PLWH. It's like we become part of the background. I don't want us [PLWH] to be in everyone's faces because that's crazy, but like there are so many developments in HIV that the peer educators could address, which would help us navigate being HIV-positive at Rhodes [University] and maybe outside better. Imagine if people were aware of PEP, PrEP, U=U, etc., how much easier it would be for us to disclose and even consider dating or being vocal about our illnesses."

Student 2 similarly admitted:

> "I really don't know what they do. Like I said earlier, I only see them during these campaigns and never again. I don't know which peers they educate or what the education entails because, as a Rhodes [University] student, I am a peer to them but

> have never been approached or invited. Well, I also haven't taken the initiative, but still. They only come up when they want us to test."

Likewise, Student 1 expressed:

> "I haven't met any of them actually. I'm not sure if they even exist because I haven't had like any form of interaction with a peer educator that speaks to HIV aside from the Director of the HIV and AIDS office. Or some of the San members themselves but to say that there are students or designated staff members that speak to the overall education of HIV, I'd say the experience has been very minimal or close to nothing in my own personal capacity."

Lastly, Student 3:

> "I hear about them, but I don't understand the whole thing because it is not clear whether it's a thing where I am talking to my peer as both infected people or me as an infected person talking to my peers about the fact that I am infected and how they can come to me and ask questions about the disease itself and about how I am living and how I am okay… So I don't understand whether it is either-or. That is where the issue is for me. I don't understand the role of peer educators."

The four students' accounts above offer a different view of peer education to what Mr Mzizi and Ms Mankantshu shared. Ms Mankantshu explained the role of peer educators:

> "So basically, peer educators work as foot soldiers to try and get information to wherever it needs to go. If something is going on, we are the ones that are supposed to get that out there. If there is an event, we're supposed to let people know. If there is a need for more people, we are the ones to go out and get more people. If there are residences that need talks on specific topics that are covered under the programmes in the HIV Office, we are the ones also to do that."

As mentioned in Chapter Two, peer education and support have been widely advocated as alternative or complementary to interventions presented by adults and are becoming an increasingly popular method for promoting behavioural change in prevention programmes (Visser, 2007: 680). In the Rhodes University context, the way in which peer education and support are implemented needs to be reconsidered. Moreover, it would be useful to get more students' views on the perceived impact and effectiveness of this theoretically necessary intervention strategy. Contrary to the opinions expressed by the student participants in this study, the staff members showed more knowledge of the peer educators and their programmes. Staff member 6 shared:

> "Peer Educators… they do well. They do their job. I know them. There's one I know personally who is a staff member, but I have never worked with her. They are also always at the workshops because they are the staff. They are the ones who bring awareness and educate us. Teach us about how one can live better with HIV."

Staff member 3, who is in the Housekeeping department, shared:

> "I like the work they do, but the issue is availability like I said. I have to juggle my work duties and events. They host workshops about many things related to health. I often don't have the time to participate. There are some that I don't get to hear about until they have passed, you see, but they have regular workshops."

Lastly, Staff member 4 shared:

> "I have seen them around, but I've never been involved. I've seen them, I think two or three months ago they had a workshop, and someone posted about it on Facebook that's how I saw. They usually send out a word on Facebook when they have events. I have never attended, but I see them all the time."

It is clear from both the student and staff participants of this research that there is knowledge of peer educators and the different interventions in place at the university. However, on the one hand students expressed a lack of understanding of the role and minimal exposure to their programmes. Staff members, on the other hand, demonstrated more knowledge of and involvement with peer educators and their programmes. The students' and staff's perceptions of the university's responses to HIV as well as the discussion on the interventions on campus are in line with the discussion in Chapter Two, that HIV and AIDS awareness at universities is still only concentrated on during the brief period of orientation; other responses to the epidemic, if any, are somewhat uncoordinated and disorganized (Kelly, 2003: 2). The HEAIDS report (2010: xvi) found similar results whereby students and staff perceived a lack of visibility and voice from campus management and student leadership.

Moreover, it was reported that HIV and AIDS was not seen as a strong priority on most campuses (2010: xvi). Both the students and staff gave suggestions on ways that the university could improve to make the experiences of PLWH better. The common themes among these suggestions were increased visibility of existing programmes, consistent activity throughout the year as well as additional programmes that could be implemented. Student 3 expressed appreciation of the *First Things First* Campaign and further shared a dilemma she often encounters as someone LWH:

> "I appreciate it somehow… it brings some visibility to HIV. It's like oh they remember that HIV is a thing… but even then, it's not really about us who are HIV-positive but more about ensuring that the numbers don't increase. Essentially that is what we all want. But what about us who are already living with this unfortunate reality, what campaign is there for us on this campus or the world. It's quite silencing how HIV is addressed from the view of prevention. There's a great population living with this thing, but nobody wants to speak to us or let us speak for ourselves. I mean, I wouldn't outright speak about being HIV-positive, and maybe that's because I haven't been made to feel safe enough. Not in this university, at least. Well, not anywhere. It's like being constantly caught between taking one for the team and being vocal and being aware of the stigmas that come with that. Going back to the question campaigns like FTF, these are great, but what more? The university could use its premises to educate people about what follows you test positive during these campaigns even go as far as showing what taking treatment does. It's like the university is still stuck in the 90s, having one side of the discussion. There's more to HIV than just putting up tents and calling people to test – you'd hope that a whole university would know that and show that but not."

Student 2, who stays in the university residences, the dietary options at the dining hall were a significant concern for her health. She shared:

> "For me nutrition is the big one because wow! The dining hall food is urgh, wow! It's not that great *laughs*. It's that thing where they say you have to eat your veggies or eat this and that, so it's the dietary plan part that doesn't correlate. Not everyone gets into it and decides yes, you know what? Now I am going to take care of myself. So at least if you know that, even though it is difficult for you to have that discipline of saying I'm going to the gym every day or that okay, I am now not gonna eat carbs and what what I am only gonna eat proteins and all those things. Just knowing that there are measures in place where, in the dining hall… they don't necessarily have to say "this is a diet for the HIV positive" no, but make the healthiest option available, you know… Sometimes even the "healthy" option is not exactly the most nutritious. Even the vegetarians can tell you that the vegetarian meals we have in the dining hall are not that

> great and health-wise also it doesn't help much. So, I think educating the kitchen staff about the benefits of what it means to include a healthy diet, not just for the HIV positive but for people who have diabetes, people with high blood, etc. It's because there are such a streamline of diseases that you need to be sure that when you eat, the diet you take in is a proper diet that actually can help you fight the illness within you. So it doesn't have to be only the pills trying to help fight the disease but you know that you've got the vegetable, the fruits, all those things."

Staff member 5 expressed reliance on the university for information:

> "Well, for one, I don't think that we need special treatment. We are just like everyone else. But the university needs to acknowledge that we are here. Them knowing that we are here is enough for me. All we want is recognition without the spotlight. I think more education more than anything. As I said, we don't need special treatment. We need everyone, positive or negative, to be educated. If there are any new developments in HIV treatment, for example, then maybe the university can host a workshop and educate us about it. Like there was something on Facebook about a cure, but we are not as educated, so we don't know how true it is. Suppose the university could maybe give us the correct information and direct us to where we can get said cures if they are out there. The university has the resources to provide accurate and valid information; we don't."

An additional form of support that was raised by some of the participants was the introduction of a support group. Student 3 explained:

> "Sometimes it feels like you are going through it alone coz you are essentially like alone… it seems like you're the only person going through this because it's not like you're exposed to other individuals living with the same virus or disease… I don't know… there is no I see you, you see me. Like… yeah… like a support group of like people living with this disease to come together and just be would make a difference."

Other participants noted the need for a support group, which, according to Marino, Simoni, and Silverstein (2007: 68), is a standard method of addressing the psychological and psychosocial stressors involved in LWH. Sister Ferreira agreed with the notion that support groups have the potential to alleviate the stressors involved in LWH. However, she shared that there were challenges in implementing such a programme at the university:

> "When it comes to the word support, there's always a little bit of a hiccup because well, I know they [PLWH] get support from the staff at the HCC that is something that there is no doubt about. But support also means that sometimes people need to go into a sort of group because they have maybe similar symptoms or similar diagnoses, and in that way they can maybe support each other as clients. But when it comes to support groups that, especially for HIV, we have tried over the years asking students and staff. We have said we want to form this specific group – specifically HIV support group so that you can sort of support each other, talk about challenges, issues, whatever, side effects of the drugs and worries about the future and getting babies and all the other things that entails being HIV positive. It hasn't happened, you know. Because I think at Rhodes University, I would say, the type of client that we have they want to keep it to themselves. They are not keen on another person to know. So, one student does not want another student to know that they are positive. Why is that? I do not know if Rhodes University thinks that HIV is still something to be ashamed of because of the way that maybe HIV is acquired. It is a sexually transmitted disease in most cases. Obviously, you can get it other ways like through pregnancy, sexual assault, and so on or maybe in the previous years through blood transfusions, you know. But solely the most common way would be sexually transmitted, so maybe it's still the stigma, and maybe at Rhodes [University] people are not HIV positive, so they are sort of in denial, or maybe they are just afraid that they will be discriminated against. They may not be as socially popular as before or… I actually do not know what it is. But the stigma is still in existence."

Once again, there is a rift in what the participants claim to want and what the health practitioners experience in attempts to implement said programmes. None of the participants in this study indicated having taken the initiative to form a support group or to seek one. Therefore, it can be argued that while the university can improve the programmes in place, those LWH have the potential to be or implement the change they so wish to see in the institution.

7.4 CONCLUSION

The students' and staff's perceptions of the strategies at Rhodes University resonate with Mavhandu-Mudzusi (2014: 214) proposal that there is a need for contextually relevant planning for managing staff and students living with HIV and AIDS in universities, which will improve the quality of life of the staff and students. In the Rhodes University context, this planning, according to the participants of this study, should focus on a holistic approach to managing and supporting those living with HIV. Additionally, the study posits that there is a need for more awareness and visibility of the existing strategies and programmes in place at the university. Lastly, the participants expressed a need for a sense of community for people living with HIV, in the form of a support group or similar intervention. The findings show that there is a need for a collaborative effort between people living with HIV and the different stakeholders or departments which offer services catering to the needs of PLWH. This collaborative effort has the potential to firstly ensure that PLWH have an active role in structures implemented for their needs and, secondly, alleviates the pressure on the university to present the university community with solutions.

CHAPTER EIGHT: ADHERENCE AND DISCLOSURE

"…because with normalizing HIV comes less stigma, with less stigma and discrimination comes more acceptance of one's HIV status and more adherence to ARVs, with acceptance comes sustained viral suppression and with this comes zero new infections."

Angela Motsusi, 32 years Nurse Clinician and HIV activist, South Africa

8.1 INTRODUCTION

It has been well over two decades since calls were made by HIV and AIDS activists, PLWHA as well as other groups and organisations such as the Treatment Action Campaign (TAC) to provide antiretrovirals to people who needed them (Uebel *et al*., 2010: 598). Due to this activism, the South African government officially approved a national programme that made ART available in the public sector as of 2004 (Van Dyk, 2011: 235). There has since been exceptional progress made in the fight against HIV in the South African context (NSP, 2017: 4), one of which is an increased life expectancy for PWLH. The national rollout of ART has offered an extraordinary opportunity for PLWHA to prolong their lives (Simbayi, Kalichman, Strebel, Cloete, & Henda, 2008: 1). While the aims of ART are clear, reaching these does not go without its challenges. Many factors contribute to the way in which patients respond to and experience their illness. The universal availability of treatment, however, does not guarantee a positive experience with antiretroviral therapy, and it does not equate to immediate access for patients.

Simoni *et al*. (2017: 564) assert that the main obstacle to achieving the best outcomes for patients receiving treatment is adherence. The researchers claim that while there are improvements in availability and affordability of antiretroviral therapy, the UNAIDS' goal of 90 per cent viral suppression is derailed by poor adherence by patients even when there has been funding allocated to interventions to promote adherence in both high-income and low-income resource settings (Simoni *et al*., 2017: 564). Adherence to ART, for many PLWH, is influenced by a myriad of factors such as facility and programme design: lack of training of service providers, lack of resources, long waiting times, and low quality of care; as well as psycho-social factors (Mokomane *et al*., 2017: 126).

HIV and AIDS has stimulated many types of reactions and responses, from "compassion for and solidarity with as well as anxiety about, and prejudice against, those living with HIV"

(Smith *et al*., 2008: 1266). The disease has also inspired many responses from PLWHA too. Disclosure of one's status and ARV consumption has both positive and negative consequences. Mostly, disclosure is associated with receiving social support, but it also allows for the possibility of stigma and shame. Gillet and Parr (2011: 337) explain that fear of blame, violence, and abandonment by a partner also contribute to why PLWHA do not disclose. Consequently, stigma and discrimination have developed into a barrier to HIV and AIDS prevention and care (Makoae *et al*., 2009: 1357).

This chapter follows that just as HIV and AIDS is a complex disease with many underlying nuances, so too are adherence and disclosure. Furthermore, the chapter seeks to highlight the link between adherence and disclosure. Lastly, the chapter explores participants' experiences of accessing ARVs at the university clinic and how this influences adherence.

8.2 DISCLOSURE OF HIV STATUS

Disclosure of an HIV-positive status has been identified as one of the challenges that PLWH have to continually navigate (GNP+, 2012; Van Dyk, 2011 and Gillett & Parr, 2011). On the one hand, when positively received, disclosure is closely linked with social support, which enhances the quality of life of PLWH. On the other hand, when negatively received, disclosure exposes PLWH to direct stigma and discrimination (Gillet and Parr 2011: 337; Kalu, 2015: 20). The *Positive Learning: Meeting the Needs of Young People Living with HIV (YPLHIV) in the Education Sector* report (GNP+, 2012) discusses the dilemma of disclosure. The report posits that this dilemma is recurring throughout the lives of PLWH as they respond to new and changing situations and relationships. Furthermore, the responsibility of disclosing one's status rests with the individual with consideration of the potential respective advantages and disadvantages. In Chapter Three, the discussion on disclosure explores the different ways in which disclosing benefits an individual. One of the essential aspects of disclosure, especially to health care workers, is that it links PLWH to treatment and care (Aulette-Root *et al*., 2014: 52). Horta *et al*. (2017: 56) and Stinson and Myer (2012) found that disclosure was helpful in the process of HIV status acceptance, which enabled for a better quality of life and linkage to treatment and care. All the participants in this study had disclosed to at least one group of people, and the common group (disclosed to) among them was health care workers. In this study, all but one participant (Student 3) had disclosed to people outside the healthcare system, for example, family, friends, or intimate partners. It is worth noting that the participant who had not disclosed to anyone outside the healthcare system is a student who had been LWH for less time than all other participants. She is the same student who shared that she was depressed and hopeless about the future, as a result of the diagnosis. Furthermore, the same student revealed more signs of self-stigma than other participants. The student said:

> "Nobody knows. Just the nurses and now you [the researcher]. The nurses have been really kind to me."

Student 3's idea of "nobody" knowing (as seen above) comes across in other participants' accounts of whom they had disclosed to. It is as though, to them, disclosure only carries weight if the recipient is not the health care practitioner or the researcher. Horta *et al*. (2017: 56) found that non-acceptance of an HIV-positive diagnosis was a barrier to the disclosure of HIV status "as the belief, perceived stigma, and fear of negative judgment may force HIV individuals to hide their positive result" (2017: 56). This idea of "nobody" knowing one's status is evident in another participants' encounter where the "nobody" refers to outsiders who are not in her immediate circle of loved ones. Staff member 2 explains:

> "For me, nobody knows about my status. It's only my first-born child because he is 21 years old and old enough to understand and the father of my children, my ex [whom she suggested had infected her]. Other than that nobody else knows."

For the rest of the participants who had disclosed their status, it was mainly to their immediate circle of family and friends and their accounts are in agreement with research asserting that disclosure has a positive effect on individuals' illness experiences (Aulette-Root, Boonzaler, & Alette, 2014; Horter *et al*., 2017;). Aulette-Root *et al*. (2014: 52) share that disclosure is essential as it allows PLWH to receive social, emotional, and adherence to treatment support. In this study, those who had disclosed to someone either than the health care practitioners expressed the following themes: support, acceptance, belonging – all of which are in agreement with Aulette-Root *et al*. (2014) and Horter *et al*.'s (2017) findings regarding the impact of disclosing. For all the participants who had disclosed to family, this was their first point of call, following testing and just before seeking ART. Staff member 1 recalled:

> "I remember I told my family as soon as I left the clinic. I don't want to lie, when I first heard the news, I cried. I didn't know what to do or how I ended up there. So, I told my brother, and he encouraged me and pleaded with me to go back for treatment. So, after that, I went for some counselling with that sister I was telling you about earlier who tested me, and then she referred me to the right department for my pills."

Similarly, staff member 6 shared:

> "I told my family from the very first day I found out, and they were welcoming. I don't have children, so I didn't have to tell children. They are very supportive at home. I don't trust friends, though, so I didn't tell any of them. I mean friends separate, and one day they will insult me in public about my status *laughs*. A person can insult you on the streets, so I didn't tell them. So, I only told my family, the nurses, and you are the third person to know. Oh, and my partners have also accepted, I tell them as we start dating. They don't have any issues luckily."

Staff member 2 also expressed:

> "I have only disclosed to the people I live and work with. I actually remember one day I decided that I was going to get tested at Eden Grove [during *First Things First* Campaign] I decided that even though I know my status, I would go. So, the nurse said to me, "you're positive" and I told her that I already knew. Then she said I shouldn't tell others of my status. I told her I would not keep my condition a secret. That's often what people say when I tell them my status – they ask me not to tell anyone. The people I am close to know. All of my friends know about my status. Even my family. I don't hide anything."

Staff member 2's experience with disclosure – where the recipients advise her not to tell more people – highlights the secrecy prevalent in an HIV diagnosis. Later in the interview, the staff member explained that she understood that her friends and family were protecting her from society, which links to the finding that there is greater safety in silence about LWH (GNP+, 2012). While the above mentioned is true, it is also an indirect (and in this case, unintentional) form of stigma because it involves shame, secrecy, and withdrawal triggered by applying negative stereotypes to PLWH (Kyakuwa 2009: 369). For Student 2, even though she had one negative encounter, disclosure was part of the healing process, she explains:

> "I feel like I publicized myself because I told a lot of my friends. I felt burdened because they didn't know, so it felt unfair to my being not telling the people who matter to me about what's going on within me, so that's why I felt the need to tell people what's happening and those who excluded themselves out of my life did. But you know how with friends you grow apart and not talk anymore – my status was never a contributing factor to us growing apart. For me, it was scary opening up and telling people that I'm positive. Still, the support I got from my friends and family was great except my aunt I

> told you about who was saying she doesn't understand how I could be positive and all these years I didn't get sick or anything like that. She thinks I didn't get sick because of the rape, rather that I was doing my promiscuity things at Rhodes [University] and whatever, so that's why I ended up positive. It hurt me because I was like as an aunt who knows me and someone who I grew up in front of, I didn't think it would come from someone like that. From someone else, it would have been better but not her, or a family member or someone who knows the type of person you are. We essentially got over it, and now it's not that deep anymore. But generally, my family and friends responded very nicely actually like they've been supportive."

For Student 1, even though supportive, those close to him also had difficulties coming to terms with his diagnosis:

> "When I first found out, which was in my first year of 2017 before June, my first point of call was my friend because she saw that I wasn't okay with the outcome, and there was three of us who all went to get tested together. After that, I went to my room, and I called my mom and told her my status. I think for my mother it was tough for her to comprehend that like okay this is her child. She knows she didn't pass it on to me and having had the numerous discussions with her in terms of like sexuality and living with this I felt like for her it was just like a very difficult to handle because yeah they are parents. Like no one wants to see their child actually go through something that is potentially, you know, life-altering. My sister, being a pharmacy graduate, I didn't actually tell her until she found my treatment and I feel like it negatively impacted her in a sense because she had to you know seek counselling for herself at work because she felt like I couldn't necessarily talk to her at that moment *tearing up* but you know, it's been like a journey in the sense that like as like a health professional in her own capacity like she has a level of understanding of what this actually means and how I can like better improve on my health, so she's been an asset per se to my own life. I haven't told my father yet maybe because I don't know how to, and I don't expect my mother to because it's not her place, so yeah…"

For Staff member 4, disclosure has been well received, but there are some limitations:

> "I've only told a few of the closest people to me, and they have been accepting. They don't fully understand, though. Most people think you get diagnosed, disclose, and then

> all is well. So, they try to be supportive, but they will never fully get it unless they experience it."

It is evident that for most of the participants, disclosing to loved ones improved their situations and increased support and quality of life, even though, for some, it exposed them to direct stigma. In the case of the one student, Student 3, who had not disclosed to anyone other than the researcher and health care professionals and who was in the early stages following diagnosis, the disruption of the diagnosis was still intense hence she demonstrated more negative feelings than others. Included in the discussion of disclosure, was a conversation of public disclosure. The critical themes among participants in this regard were unreadiness and uncertainty. The respondents expressed that disclosing to their immediate circles was a process and that they did not feel that they were at that stage of living with the disease where they could publicly disclose as yet and that they would not do it until they were ready to do so. However, participants expressed admiration for those who chose to. Student 4 explained:

> "I think it's a remarkable thing in terms of expressing yourself, and you know kind of breaking down the stigma especially for South Africa, having one of the largest populations in the world living with HIV and AIDS. I think it's a really commendable effort for people or bodies living with this disease because, in a sense, that's a form of raising awareness. I think for people on social media it encourages people to self-introspect and actually think about the broader impact or the message that should be done or like it encourages people to basically go out there and find out if they are 100% and not to say that I am not 100% *laughs* but you know in a perfect world I'd still be very much negative and you know carefree as I was back then in first year."

Student 2 also shared how those who have publicly disclosed became a source of information for her:

> "I feel like there are two sides to it [publicly disclosing]. There's the positive side where people are receptive and welcoming and look at the disclosure as something to learn from or some inspiration for those who are secretly living with HIV or scared to test. And then there's the negative side where you're crucified for telling the world something so private and shameful. There's a girl I follow on social media, Saidy Brown, who is positive, and she talks about how publicly disclosing was good for her mental health because it was therapeutic. Through her sharing widely, I have learned more about the virus".

When Staff member 1 was asked if she would ever publicly disclose, especially at the university, her response showed the prevalence of stigma on the campus. She exclaimed:

> "Never! There is a reason why not many people have never done it! In fact, I don't know anyone who has publicly shared their situation. *Bageza ukufa abantu apha asoze*[17]! You know what, some staff members won't even be focused on the disclosure itself or the disease you're living with *bazakwenza into yokuhlekisa ngayo, bayo hlekisa ngenxaki zam*[18]. I will become talk of the town and a laughing stock…"

Even though all but one of the participants in this study had disclosed to family and close friends, this section has echoed research which claims that disclosure is a continuous and multi-layered process which includes PLWH constantly gauging the type and extent of stigma, discrimination, rejection, and punishment that may follow after disclosure (Aulette-Root *et al*., 2014: 53). Whether or not a person LWH discloses, their positive status has an effect on how they go about reconstructing their narrative and, in turn, shapes one's illness experience. The discussion in Chapter Ten, lays out the relationship between disclosure and illness experiences. This current chapter, in conjunction with Chapter Nine, revealed a correlation between acceptance of HIV status, self-stigma, and non-disclosure. Those participants who had disclosed to people beyond health care practitioners showed more acceptance of their condition, which in turn made them present fewer signs of self-stigma. In contrast, the one student who had only disclosed to health care practitioners and the researcher showed more signs of self-stigma and non-acceptance of the diagnosis.

As previously mentioned, the number of years one has been living with HIV is among the critical factors related to acceptance, and in the case of Student 3, she had been living with HIV for just over a year. Hence the disruption of diagnosis was still rife. This conclusion is in line with Setlhare, Wright and Couper's (2014: 309) finding that stigma and discrimination not only undermine the biomedical developments of the disease but also influence individuals' illness experiences and constructions of self when LWH. Moreover, the stigma related to HIV and LWH often leads to psycho-emotional disturbances, which affect other areas of individuals' lives.

Disclosure of one's HIV-positive status demonstrates Blumer's notion of joint action/social action, whereby "participants fit their acts together, first by identifying the social act in which

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[17] Directly translated: "People are rude here, never!"

[18] Directly translated: "They will turn me into a mockery and make fun of my problems."

they are about to engage and, second, by interpreting and defining each other's acts as informing the joint act" (Blumer, 1969: 70). As discussed in Chapter Five, the actions of people are guided by the way they construct meanings and use symbols (Crooks, 2010: 11). For Charon (2001: 3), as the action unfolds, individuals get a sense of their environment and then define situations. In this case, the act of disclosure – as demonstrated by the participants' narratives, is guided by the way PLWH construct meanings of LWH. During the process, they undergo a process of navigating their environment and then deciding whether those spaces are safe enough for them to disclose. Therefore, the act of disclosure then is guided by the interactions and environments that PLWH find themselves in.

8.3 ADHERENCE TO ART

As per the discussion in Chapter Three, one of the practical and medical challenges for the ART programme and PLWH is adherence. Simoni, Aunon, Kemp, Kutner, Ramaiya, Velloza, and Yung (2017: 564) claim that poor adherence to ART derails the UNAIDS' goal of 90 per cent viral suppression. Research posits that even when there has been funding allocated to interventions to promote adherence in both high-income and low-income resource settings, adherence is a challenge (Simoni *et al*., 2017: 564). One of the goals of ARVs it to achieve viral suppression. ARVs, when adhered to optimally, stop or delay the adamant progression from HIV to AIDS.

Moreover, the medications stop the subsequent deaths of HIV-infected patients (Wood, 2010; Becker *et al*., 2020). According to Wood (2010: 529), poor adherence is the primary cause of failure to achieving this goal. The issue of adherence is multifaceted as there are various reasons for which individuals cannot religiously adhere to treatment. My findings in *A narrative study of patients' illness experiences on antiretroviral treatment* (Tsope 2018) show that adherence is an important aspect of consuming ARVs, but this is confronted with many challenges, some that can be controlled by individuals while others are entirely in the control of healthcare workers. Van Dyk (2011: 8) recognizes five factors that affect the ART programme: practical, environmental and service-related problems; lack of support by healthcare workers; personal and psycho-social factors; lack of ARV-adherence knowledge; as well as stigma and discrimination. For the participants in this study, these factors were not profoundly influential in their adherence journey, as they were considerably adherent to treatment. If at all, some of the abovementioned, such as fear of stigma and discrimination, support, and knowledge on

ARV-adherence, among other personal and psycho-social factors, propelled them to continue adhering to treatment.

In the current study, all the participants had reached an undetectable stage of the virus, which results in the virus being non-transmittable; thus, the person is not infectious, and then their "immune system gets the opportunity to replenish itself" (Van Dyk, 2011: 5). All the participants shared that they had missed a dose on one or two occasions but had a generally high adherence rate. Each of them had a variety of reasons for adherence, including seeing the positive impact of ART, wanting to live longer, and wanting to be there for their loved ones. Student 4 shared:

> "I've thought about it [stopping treatment] a few times but never really stop because I'm not trying to be another statistic. I am already a statistic for being a young woman living with HIV and now to be one of the people who die from it. Nah, I can't give it that much power. I have consciously missed my pill, though. I remember recently when I was just going through the most academically and stresses from home, and when the alarm went off, I looked at it and decided that I didn't need that added negativity. It gets tiring, you know, popping a pill every day at the same time. Yes, you get used to it, and the more you take it, the less daunting it becomes, but some random day you look at the pill and see it for what it is –control over your life. Without it, I'm dead, you know. So, it's sort of my lifeline. Unlike other people who can go on with their lives just fine, I have to rely on this pill to live. It's like I'm held captive. My life depends on a single pink pill. Wow. [rolls eyes]."

In Student 3's account, the symbolism attached to ARVs is highlighted – as an object with "power" and a "lifeline". This view of ARVs echoes Reynolds and Herman's (1994: 1) notion that symbols have motivational significance whereby "meanings and symbols allow individuals to carry out distinctively human action and interaction" (Reynolds & Herman, 1994: 1). For all the participants, the meanings they attach to the pill is what motivates their actions and interactions with the pill. Student 3 (who had not disclosed to anyone other than health care practitioners) expressed a similar sentiment:

> "[Laughs] believe it or not, I want to live. At the core of my being, I want to believe that it gets better. That I will one day be brave enough to disclose or live a positive life with HIV. I want to believe that I too will have a good story to tell one day, but right now, I don't. Right now I'm on autopilot. It's survival… do or die kind of thing – so I take my pill. I know I sound dark, and I can assure you that I'm okay, just that when

> something like this happens to you, you see life differently. [Researcher: how so?] Everything is different on this side of life. Everything you took for granted, you can't anymore. I think people like you take it for granted that you don't have to wait for the same time every day to take a pill to survive. Y'all take it for granted that you can date with no fear of rejection over something you can't take back or even explain. The trust issues that come with it. I can't trust anyone anymore because of this, and how am I to build relationships when I can't trust people… your life just changes in front of you, and the fact that your treatment is working means you live longer, which is great but also means you live with these feelings for longer. Like, what if we never get to a point where HIV is not stigmatized? So that means living with this seen but not seen disease all my life."

Student 3's account shows how the object – the pill – holds a different meaning for the consumer of the drug than it would for an outsider. Furthermore, the quote shows the many layers underlying what seems like a straightforward act of taking a pill. The theme of life and death is shared among the participants as motivation for adhering to treatment. When asked if she had ever stopped taking medication Student 2 exclaimed:

> "Oh, hell, no! No, no, no! *laughs* I've heard horror stories, I've seen things. Actually, people die, I have not seen that but in my family, people have died, and my mom told me that it was due to AIDS-related illnesses. One of my cousins, it was a far cousin, thought he was doing well on treatment and stopped and thought now he didn't need them [pills], and then he died. That's when I knew that you can't gamble with these pills. Even if it means I have to miss a class or work one day as many times as I need to, it's fine, but I'm not going to stop… no, no, no. It's not happening. Like me and that pill, we're best buddies till death *laughs* but there are a lot of other things like one day I'm going to want to have kids, and I don't want it to be that when I do want to have kids, HIV becomes a factor that stops me. I also want to get married one day, and I don't want to get married thinking that I am a risk to my partner or I am going to infect my partner or all that, as much as I will be honest with my partner. It's that thing where one must be honest with yourself and understand that outside of the pill, what else do you want to do and how can the pill itself help you do those things and become a healthier person."

Student 2's account demonstrates the narrative reconstruction that takes in the lives of PLWH, where one continually looks beyond their immediate situation. In Chapter Ten, this process is described as involving changing views of the future and seeking answers to questions regarding relations with the world; moreover, the individual embarks on a "biographical work" where their understandings of the disease and interpretation of its onset represent an important component (Pranka, 2018: 5). For Staff member 1 the motivation to continue taking the medication was mainly rooted in the scientific fact. As someone who strated treatment when she was ill, she has seen the positive effects of being on ART. She shared:

> "I have never stopped taking treatment, and I will never mainly because I can see the difference. From the beginning, I saw the improvement in my health. When I started taking it [ARVs], I saw that it is giving me life you see. I used to have sores all over my body and some lumps and bumps all over before taking treatment, but when I started, it got better and better until it was all gone, and it never came back. [Researcher: What about side effects?] It was just a minor rash on my face, which I reported, but it quickly passed and never returned. I got something from the clinic for the rash."

Among the staff members who were parents and had dependents, adhering to treatment and maintaining good health was essential for them to fulfil their roles as mother, breadwinner, caregiver, etc. Staff member 5, a mother of two, shared:

> "No, I have never stopped taking my medication. I am not even skipping one day. I don't want to get sick. I have my two children who look up to me and are dependent on me, so I can't take the risk."

Staff member 3 explained:

> "I have never stopped or skipped my treatment because I love myself. I have grandchildren who need me as well. My son was in a car accident and passed on. His children live with their mothers, so I always think about how they lost their father now they can't lose me too. I am the only family they have on my son's side."

All the participants claimed that they had never stopped taking treatment. However, some admitted to having skipped treatment for various reseasons. The reasons for skipping doses, fortunately, were not as potent as the barriers identified by Van Dyk (2011: 8). The reasons were minor and not consistent. Moreover, the respondents all showed awareness of the advantages and disadvantages of optimum adherence. Staff member 2 admitted to having missed her daily treatment. Her motivation to continue highlights elements of fear of stigma and discrimination associated with markers of living with the disease:

> "No, I have not stopped completely, but I have missed a day or two. I haven't stopped because I can't you know, it's not an option I have. I need the pills to work so I have to take them. Honestly, I just want to live man. Imagine dying of AIDS in this day and age where people are living long healthy lives with HIV. I also lowkey don't want to LOOK ill so then the only way to look and feel healthy is by taking my pills. You know how people who are positive are shamed already. Actually, even people who aren't, but if you lose a significant amount of weight, the talk is that you're HIV positive, so I don't want to look the part. Not that I am ashamed per se, but people don't need to see what I am battling internally, especially if they are going to treat me like an alien if they knew. The pills also work. Also, I've seen it. I don't know about my own body because I haven't changed at all, but I know of people who were really ill and have recovered very well on treatment."

Similarly, Student 1 admitted to skipping some doses:

> "No I have never [stopped taking treatment]. I have missed like certain nights, but like there's always this sense of overarching oppressing anxiety that okay, missing a day is fine, but two days in a row I can't. Like basically, there shouldn't be any point where I forget or even if when I do forget like I obviously have to take it within like a day or at the instance that I remember. So there's no point as to when I've actually stopped. Sure, like popping pills is not fun but I've never stopped or felt like I wanted to stop, no. I know that it [ARVs] suppresses my viral load, so in that sense and having that understanding like a sense of no, you're actually doing this [taking medication] for yourself. I've read other people's stories and how long they've lived, and I've followed their experiences with this so I remind myself that I'm not the only person going through this within the country and the entire world. So there hasn't been a moment where I just don't feel like taking my treatment for a week or a month because for me that has never been an option that I ever thought of."

Staff member 1 shared:

> "No, I was kidding about wanting to stop. I wasn't being serious. Sometimes you are forgetful though, you're busy in a family ceremony, and you're working, and you don't keep track of time, so that's how I have skipped. I think an injection ARV would be

> better coz it would probably be once a month or whatever, and then you go on with your life. Luckily when I get too busy or forgetful, someone at home reminds me."

It is clear from the participants' accounts that each one understands the importance of optimum adherence to treatment, and some have even attested to seeing the difference in their health since initiating ART. Additionally, though some have admitted to missing doses occasionally, it was not to an extent where it became detrimental to their health progress. Hence all still maintained an undetectable viral load and had not defaulted their treatment regimen or changed regimens, which is the most effective and used measure of adherence (Toupin *et al*., 2018: 207 Laxmeshwar *et al*., 2020: 1). Van Dyk (2011: 11) found that from the sample of those ARV users who defaulted on their treatment, 21%-24% said that they had often forgotten to take ARVs when they used alcohol or when they felt depressed respectively. Additionally, forgetfulness, lack of planning, communication problems, and treatment fatigue contribute to issues with adherence (Van Dyk, 2011: 11; Igumbor *et al*., 2014: 2). For the participants in the current study, reasons for skipping doses were more personal and related to psycho-social factors rather than structural and systemic issues such as stockouts, maltreatment by healthcare practitioners, etc.

Research has proven that high adherence to ART is a significant determinant of the success of ART and a challenge for both patients and healthcare providers (Toupin *et al*., 2018; Laxmeshwar *et al*., 2020). For both the patients and practitioners, viral load is commonly used as an indicator of adherence. Laxmeshwar *et al*. (2020: 2) explain that for health practitioners, routine viral load monitoring has been useful in detecting treatment failure, preventing unnecessary switches to second-line or third-line ART as well as encouraging adherence among patients. For patients, routine viral load monitoring, as mentioned above, promotes adherence, especially when the patient witnesses the drop in viral load and when they understand what that means for them as someone living with HIV. Treatment for HIV, when taken as prescribed, can improve immune functionalities and decrease morbidity, which in turn offers hope that the disease can be effectively managed (Becker *et al*., 2020). This improvement in immune functionalities and decreased morbidity has been shown to be a motivation to participants of this study to continue taking treatment.

According to Becker *et al*. (2020: 12-13), in the Sub-Saharan African region, ART non-adherence can be influenced by "risk factors" operating at multiple levels, namely: individual, household, and community/institutional levels. At an individual level, adherence is associated with age, gender, educational level, forgetfulness, ART duration, stress, lack of money, and lack of disclosure of status. At the household level, adherence is associated with household food security, socioeconomic status, lack of family support, and use of traditional medicine. Lastly, at a community/institutional level, adherence is associated with the area of residence, stigma, lack of privacy and confidentiality, proximity and transportation to a health facility, insufficient health care and maltreatment at health facilities (Becker *et al*., 2020: 12-13). Following this structure then, for the participants in this study, their non-adherence (as minimal and ineffective as it may be) was primarily influenced by factors at an individual level such as forgetfulness, ART duration, stress and lack of disclosure.

8.4 EXPERIENCES OF ACCESSING ARVS AT RHODES UNIVERSITY

It is clear from the participants' accounts in Section 8.3 (Adherence to ART) that every participant in this study understands the importance of optimum adherence to treatment. Additionally, though some have admitted to missing doses occasionally, it was not to an extent where it became detrimental to their health progress. Hence all still maintained an undetectable viral load. A significant contributing factor to the above mentioned is the smooth accessibility and availability of ART at Rhodes University, which in turn, as will be demonstrated in this section, results in positive experiences of accessing ARVs at Rhodes University. Factors such as "high cost of services, poor skills among service providers on how to deal with young people; stigma associated with using sexual and reproductive health services by young people as well as lack of privacy and confidentiality in service provision" have often been identified as barriers of accessibility of services which counteract government's work towards improving antiretroviral treatment programmes (Mokomane, Mokhele, Mathews, and Makoqe (2017: 125). For those participants who had accessed treatment from a different facility before the Rhodes University Health Care Centre, the university clinic offered a better alternative for various reasons, primarily relating to service delivery. Staff member 2 shared:

> "I asked to be transferred from the clinic[19] [to the HCC] to avoid missing work or being late or having to disclose to anyone. I like it here [at the HCC]. It's great. You see at the clinics in the location you get there and stand in long queues for a very long time whereas at the San [HCC] you make an appointment and go at a time you choose. I really applaud the San. It's much, much better. They know a person. They treat a person well. They take care of you, and they check everything. They ask you what's wrong

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[19] Local clinic.

> now. How do you feel? When you tell them the issue, they prioritise it, and you can see that they care you see."

Staff member 3 explained:

> "I started treatment at a private doctor, and then I moved to a pharmacy. Then I eventually changed from pharmacy to San because it is free here whereas at the pharmacy, I would have to pay, you see. It was more expensive, especially because I just need a pill daily. I can't remember exactly what happened that led me to change from the doctor to the pharmacy, but I remember I also changed my medical aids. Another thing that I didn't like at the pharmacy is that there are a lot of people there. There was a student cashier at the time who once asked me "are you here for your AIDS treatment?", now, I don't feel sorry or ashamed of my disease, but it's not AIDS. I didn't like it. There was also no need for her to say that so loudly and publicly. So, I called my medical aid and told them about the incident, and I believe they dealt with her because when I returned, she was nicer. The nurses here are lovely, they know you by name and the receptionist Ms Jadi. You know I have to go to the San before my date for example if I have to get pills on a Friday, I have to go earlier in the week to tell them then on the Friday I go to collect. I love that they give you enough pills to last three months. This means I don't have to go back and forth in the three months. They also respect privacy."

Similarly, Staff member 5 transferred to the Health Care Centre due to negative experiences at the local clinic:

> "I ended up at the San because I was looking to move from the clinic I was accessing treatment at. I wasn't too comfortable at that clinic, and then I went to the San to and told them my issues with the clinic. They [the San] said it was okay, and there was no problem. All I had to do then was to get a remove [removal/transferral letter] after that; I started at the San. I am happy. I am much happier than I was at my previous clinic. I think I'm more comfortable here. They [nurses] are secretive here. [nurses]. There are no labels as what treatment you are there for you see. So that's why I could trust the nurse to ask about treatment. For now, I am very happy. I left, Dlukulu [NG Dlunkulu] clinic because, you see there… first of all, there are different rooms where you go in to consult with the sisters. If you get into room 3 [for example], we [patients in the queue] know that okay you're there for this type of treatment. Then there are also different

> files. If you're carrying a blue file, we know what you have. We know that people carrying brown files are collecting ARVs. So for every sickness, diabetes, high blood pressure, they all have different files. The moment you leave the secretary's desk carrying that big file, everyone in the queue sees. You go from front desk to room three then it's obvious. There's not even one person in the queue who sees your file. Only the sister sees it. You arrive at the front desk, sign in that I'm so and so…you don't even have to say for what you are there. The person at the front desk doesn't even ask. When it's your turn, you go to the sister's room and only explain why you're there. The sister is the one who leaves the room to go look for your file. She is the only one who has the right to fetch your file, not the other ladies working there cleaning or whatever. They don't know anything. Even when you go get your treatment, it's the nurse who gets your pills and gives it to you privately in the consultation room. Even the packaging doesn't show what is in the packet. It's a clean brown bag that we all get. That way nobody sees what is inside."

Staff member 1 echoed:

> "I started here in 2011. The change made me very happy because I did not have to face the rude nurses who don't respect people's privacy anymore. I also stopped missing work or being late, and here only the nurses know my status."

The staff members' accounts highlight a change from local facilities to the Health Care Centre due to lack of privacy, fear of unconsented disclosure as well as disruptions in their work schedules. These challenges are not unique to the participants of this study. Mulqueeny and Taylor (2017: 1) found that while the public ART programme has been perceived by many to be successful, challenges such as PLWH receiving quality treatment, adherence, sustaining patients on ART, closing the gap between urban and rural health services and addressing operational problems have been prevalent. To curb these challenges, patients based in four ARV clinics in the eThekwini region made six recommendations as follows (Mulqueeny & Taylor, 2017: 1):

1. Waiting areas should be enclosed to protect patients from elements such as rain, cold, sun, wind, etc.
2. Patients should not have to return their own files to the main hospital or ARV clinic.
3. Stable patients should collect ARVs every three months.
4. Pharmacy operating hours should be revisited to accommodate patients' needs.

5. Each ARV clinic should elect patient reps to address patients' needs and ensure more patient-centred services.
6. ARV operating hours should be reconsidered to accommodate patients.

The above recommendations address some of the issues that led the participants of this study to change facilities. Furthermore, it will be shown below how the implementation of some of the above recommendations has positively influenced participants' experiences of accessing ARVs and optimum adherence in the Rhodes University context. Student 1 explained that accessing treatment on campus is more practical and convenient:

> "HCC is more accessible to me more, especially as a student here at Rhodes [University]. That's the first point of call that I used when I was diagnosed, so it became very quickly accessible to me and very comfortable for me to go there. As [compared to] say if I were to go to Settlers Hospital on my own and to have to navigate that space and having to deal with the uncertainty of who do I talk to next and how do I even say that I am this person and I am living with this, and this is what I need and, and… I think that for me at this current time would be a very daunting thing because I wouldn't necessarily know who to approach and how to basically go about expressing some of my immediate anxieties and you know how the facilitation should go if I were anywhere outside of Rhodes [University] because my comfort zone has been the San with the people that I see every day. At Settlers I feel like I'm just like at this point a number so I'm comfortable with being known as a number not just as a face to the broader hospital confines but the San is smaller and more intimate, very personal and I know that I have built some solid relationships with some of the nurses that work there. I guess I'm more comfortable personally."

Student 2, who was diagnosed at the university shared similar views:

> "Because I was diagnosed at Rhodes [University] it was not gonna work for me to try and find my medication somewhere else. I just thought, okay, this is my next step because if I don't do it, the next step is probably death *laughs* I was like, just go! It had to happen because I was like… even there going there it was difficult because you have to … well sometimes when you get there [HCC] they ask the questions of how did you get it [HIV]? And then you have to come to explaining you know… I had to sit with myself and say you know what, this thing is gonna be with me for the rest of my life and it's okay and even if I have to tell people, even if I have to get a bit of the pity

> look and all those things its fine as long as I get what I need to get you know…So that's why I chose to do it here. The HCC is amazing! It's honestly great! And it's that thing of the people get used to you. They know what you're there for. I don't know, maybe some people may feel otherwise, but for me, the treatment that I get from them is just amazing and how when you get there, and there is progress, they are excited with you and all those things. The nurses or whoever you're talking to in the room, if there are any issues they advise you as well and all those things and if they can see that emotionally you're not okay or you're struggling with something they make calls for you to get therapy and stuff like that. Having them is great, it's a great experience."

Likewise, Student 3 commended the Health Care Centre staff and shared some of her fears for the future:

> "I've only accessed my treatment at the HCC, luckily, and I am grateful. I can't imagine what it must be like in clinics and hospitals that are public. I'm sure every fear I feel is amplified and intensified in those settings… which makes me fear for the day I have to leave the university because I would have to start from scratch with familiarising myself with the public health system and the workers and the potential stigma that comes with it. It's scary. *giggles* living with HIV is constantly living in fear. Its fear of being stigmatised and ostracised. Or fear of the unknown. It's just fear all round *giggles*. You don't know if your body will one day reject treatment or the wrong person will come across your treatment… so yeah… to answer your question I am accessing at the HCC because it is the safest most convenient option for me. Confidentiality is respected. The people there are friendly and welcoming. The setting also makes it work – it's a small building far from the business of the campus life so when you go there you feel safe."

The participants in this study had very positive experiences of the Health Care Centre staff and accessing ARVs at the university clinic. It is worth noting, once again, that all the participants claimed to have maintained optimum adherence and had reached the undetectable stage of the virus. All of them had also been initiated on the 3-months pill collection system, which Sister Ferreira explains is linked with health stability and impressive adherence to treatment. Here then, a link between positive experiences with health care facilities can be linked to increased adherence. The participants share experiences of feeling safe, respected, encouraged by the Health Care Centre staff and the way the clinic is run. Sister Ferreira explained that non-adherence occurred at the Health Care Centre but at minimal levels:

> “Like any other lifelong programme, there will always be such [non-adherence]. Even with family planning, people default you know *chuckles* so defaulters will always be part of any programme. But what we do when we see that somebody didn’t come for a month or two to collect their treatment. Because basically they come monthly. The only time that we’ll give them a supply for two or three months is when we can see that wow you are an excellent client so we can see that you are thorough, you take your medication, you come on the prescribed dates and the pill count is right, and everything is good then we can give you a supply of three months because you are a reliable client. You are very good and doing everything that is right. But somebody doesn’t come for a month, and then we see okay the second month, and the person is not coming then we contact them because we’ve got all your information. We can either email you or phone you, and then we try to figure out what’s happening, why didn’t you pick up your pills. Then they will give their reasons – different reasons. From ranging to “oh no sister I got from my doctor”, or “I was in the hospital”, or “I was in prison”, “I forgot” or “I still have pills left”. There’s a whole lot of reasons why they say they didn’t collect the medication, but we try to get them, and then we restart the medication. So, we do contact the defaulters, but I would say there may be 2 to 3 per cent of our clients that are defaulters. So, it’s a low number, very low number because as I say we’ve got educated people, even our staff they are educated people, and they try by all means to adhere to the medication.”

The participants relate the nurse’s involvement in their patients’ medical wellbeing, and as mentioned above, the positive treatment at the Health Care Centre is a crucial factor in encouraging adherence to treatment. The booking system at the university clinic allows PLWH to book a time suitable and convenient for them and their work/school schedule. Furthermore, their privacy is guaranteed, which, as the staff members LWH have noted, was an issue at previous health facilities. The Rhodes University clinic then, in compliance with the HIV policy, ensures that it “create[s] a supportive and non-discriminatory environment for members of the university community infected with or affected by HIV and AIDS and to counteract prejudice and discrimination” and “protect[s] the individual’s right to confidentiality and freedom from discrimination” (RU HIV and AIDS Policy, 2016: 4).

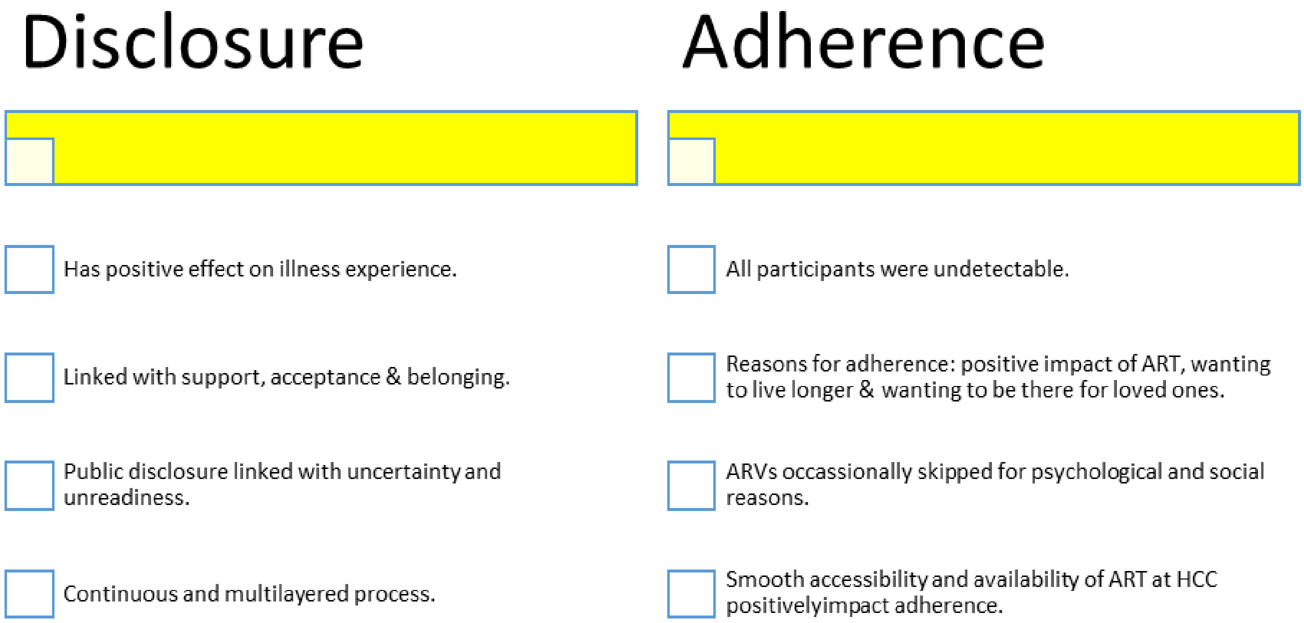

FIGURE 9: SUMMARY OF SUB-THEMES

8.5 CONCLUSION

This chapter has demonstrated that the process of decision making about disclosure, as discussed in Chapter Three, is a challenge as it happens amidst the context of various forms of stigma. Furthermore, some variables such as one's sex, age, race, number of years LWH and class contribute to this challenge. While none of the participants in this study had publicly disclosed their HIV-positive statuses, a majority had disclosed to their immediate circle of friends and family, which proved to increase support and enhance their quality of life. Furthermore, those who had disclosed to family and friends, showed fewer, if any, signs of self-stigma and generally better acceptance of their positive status. For the one student who had not disclosed to anyone other than health practitioners, the process of narrative+ reconstruction was still in its early stages hence she showed more signs or self-stigma, depression and lack of acceptance of status.

Adherence to ART among the participants was high, and this is proved by every participants' undetectable viral load. The reasons for adhering to treatment included fear of death and stigma, seeing the positive medical effects of treatment, maintaining an undetectable viral load and fulfilling their roles as mothers, breadwinners etc. It is clear from the participants' narratives that the symbolisms and meanings they attached to ARVs and LWH influenced their interactions with others in the process of disclosure. Moreover, these meanings influenced their adherence patterns. Lastly, accessing treatment at the university clinic has had a positive outlook on the overall wellbeing of participants.

CHAPTER NINE: STIGMA AND DISCRIMINATION

"There's still a long way to go. Medically, HIV is pretty much sorted. It isn't a cure but it's good as.
But society… it's got a long way to catch up."
Tom Hayes, 33 year old male living with HIV, London

9.1 INTRODUCTION

Research has proven that the face of HIV and AIDS was altered in the late 1990s with the development of ARVs transforming the disease from a fatal disease into a chronic illness (Makoae *et al*., 2009: 1357). While the transformation of the HIV and AIDS discourse has presented positive aspects, one of the prominent challenges faced by those LWH is stigma and discrimination, which is still heavily prevalent in South Africa (dos Santos *et al*., 2014: 11). HIV-related stigma and discrimination are not unique to South Africa. Stein (2003: 95) explains that PLWH have been stigmatised and discriminated against worldwide since the beginning of the epidemic, and instances of overt discrimination remain common. Stigmatising attitudes towards the disease and PLWH have a negative impact on people's willingness to have themselves tested for HIV (Peltzer *et al*., 2004: 96). Furthermore, these attitudes are an obstacle to achieving the best outcomes for patients receiving treatment (Simoni *et al*., 2017: 564). While there are improvements in availability and affordability of antiretroviral therapy, the UNAIDS' goal of 90 per cent viral suppression is derailed by poor adherence which is a causal effect of stigma and discrimination, among other factors (Simoni *et al*., 2017: 564). Overall, stigma and discrimination affect the pace of progress in reducing new HIV infections, increasing access to treatment and ending AIDS-related deaths (UNAIDS, 2020).

Smith *et al.* (2008: 1267) assert that stigma is a simplified and standardised image held by a community towards certain people; this image is frequently of disgrace. Tsope (2018: 15) asserts that stigma is primarily a social construct and view shared and perpetuated by a group. Thus, shame is an attribute applied to those who do not meet the definition of "normal" in a given social context. Additionally, Dos Santos *et al*. (2014: 1) maintain that this mark of disgrace is not only associated with people but also particular circumstance and qualities. Moreover, stigma is not new to public health or unique to HIV and AIDS. As per the discussion in Chapter Three, on stigma and discrimination as one of the challenges that come with HIV and AIDS and LWH, stigma is inescapable (Aulette-Root *et al*., 2014: 26). All PLWH experience stigma to some extent and these experiences are dependent on many variables, including class, gender, sexuality, race, location, age, and other marginalised attributes (Moyo

& Perumal, 2019: 2). It is important to note that while stigma is a social construct, it is not exclusively an external phenomenon; instead, it can also manifest internally.

This chapter follows the assertion that HIV-stigma is a multifaceted phenomenon (Peltzer *et al.*, 2004: 96) as such, the discussion will be split into three sections, namely: LWH and externalised stigma, LWH and internalised stigma, as well as stigma and discrimination in the Rhodes University context.

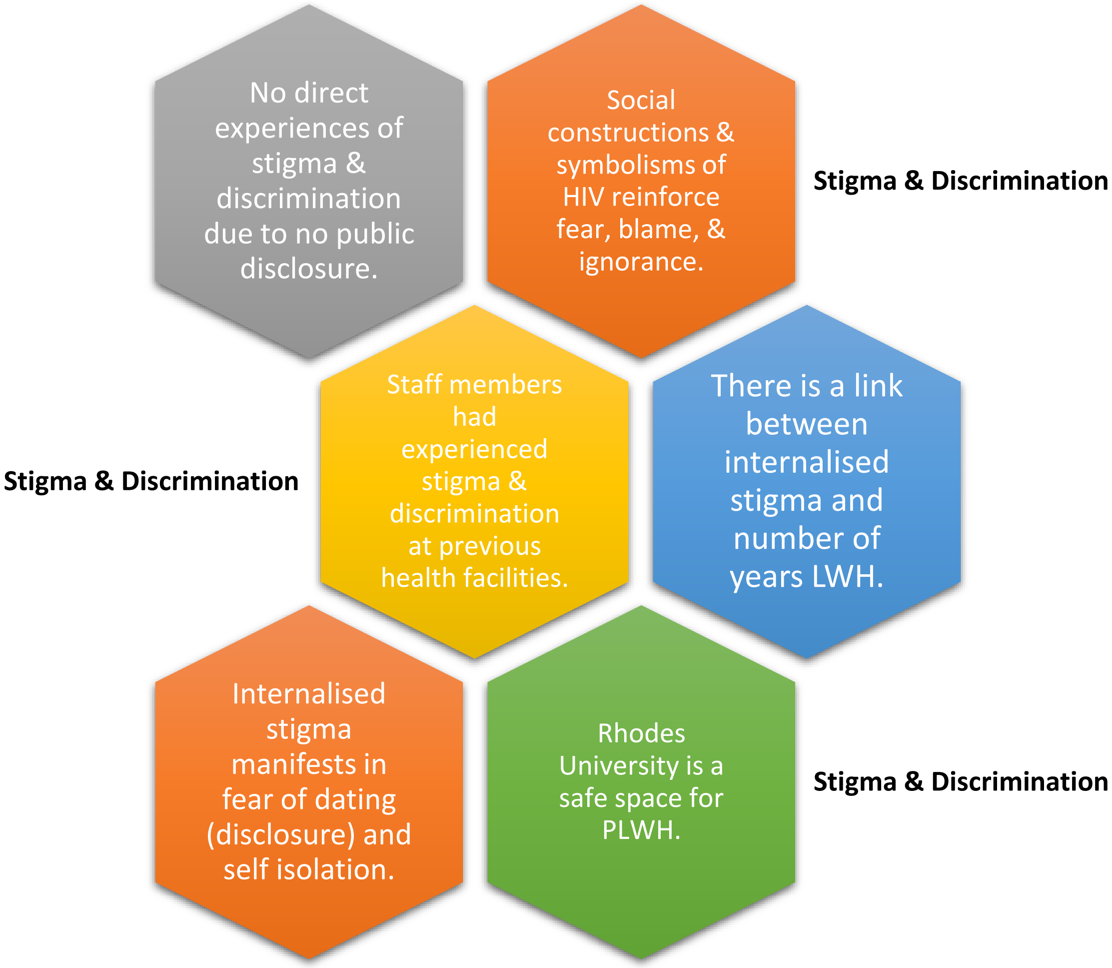

FIGURE 10: SUMMARY OF SUB-THEMES

9.2 LIVING WITH HIV and EXTERNALISED STIGMA

HIV stigma and discrimination have been identified universally as significant barriers to many aspects of the lives of PLWH (GNP+, 2012: 6; Cain *et al*., 2014: 263). Beyond affecting how individuals view themselves, the stigma surrounding HIV and AIDS often causes its victims to be troubled by anger, fear and uncertainty about the future, which in turn affects relationships with friends, colleagues and family (Moyo & Perumal, 2019: 5; Marino *et al*., 2007: 68). According to Reid and Walker (2003: 86), HIV-related stigma and discrimination are caused by social and cultural responses to the epidemic. Moreover, these stigmatising and discriminatory acts have the potential to be more explosive and as threatening as the disease itself. The claim, according to Reid and Walker (2003: 86), is that HIV-related stigma and discrimination perpetuate the reproduction of social difference. Therefore, it is closely linked with social inequality (Prinsloo *et al*., 2016: 263). In line with this, Stein rejects HIV-related stigma on the grounds that "all acts of social exclusion relating to HIV/AIDS are not only morally wrong but also counterproductive to effective HIV/AIDS prevention and treatment" (Stein, 2003: 95; Prinsloo *et al*., 2016: 261). Most of the participants in this study indicated that because they had not publicly disclosed their HIV status, they had not directly and personally experienced HIV-related stigma and discrimination. Instead, they had seen how others view HIV and AIDS and PLWH. Student 3, who tested positive on the Rhodes University campus and had only disclosed to Health Care Centre staff, shared:

> "It [stigma and discrimination] hasn't happened to me directly. But I've seen and heard how people who are thought to be or who "look" HIV-positive are treated or spoken about. Students still make HIV jokes or still wish HIV on others – it's like they know how shitty it is, but they wish it on others. The rest of us silently living with it laugh along out of fear, or ignore it while deep inside you're hurting. I feel safer here [Rhodes University] though… I can't imagine what being HIV positive in the location [Joza[20]] feels like."

Staff member 1 had similar views:

> "Many people shame it [HIV] you see, especially colleagues. You can hear from the way they speak that they shame it. They shame the virus. They say things like what kind of sickness is this that doesn't have the treatment and they also shame us for having it. But to me, HIV is better than Diabetes – even though they are not the same you see.

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[20] Joza is one of the townships in Makhanda (formerly known as Grahamstown).

> In the location, they look down on us for having HIV they think you are sleeping around and *ulihule*[21] who deserves what came for you."

Staff member 2 expressed the ignorance she had observed:

> "Well, some people… I won't lie; there are still many people who still need to be educated about HIV out there. Many people still don't understand how HIV is transmitted. For example, in my neighbour's house, there is a girl, I think she's ten years old, she was infected at birth. Both her parents passed away. Now she is left with the grandparents. The way in which they treat her *sigh + getting teary* they treat her in a painful way. *silent*. Even if she drinks maybe water, the other children are not allowed to use the same jug or her plates. It hurts me very, very much. She has an older sister who takes care of her who is about 19 years old, and the older one cannot manage on her own. She is even failing at school. She has all the pressure to be a parent and a child all at once. That's why I'm saying many people still have backwards understandings of HIV."

Similarly, Student 4 shared:

> "No, I've never experienced it. Not to me directly but PLWH, in general, are discriminated against in the most subtle and socially acceptable ways. People make HIV jokes. People diagnose others based on their weight. People talk about these horrible things they would do if they found out they were positives without considering those of us who already are. For most people, HIV is just another disease like Diabetes etc. until they or someone very close to them lives with it. Over the years, it has become a joke more than anything in the sense that people don't believe that it is chronic anymore, or there is no fear for it. They think people living with HIV are promiscuous, stupid for getting infected or even abnormal. It has become very normalised, and while that is not a bad thing, it is dangerous, especially for us because our voices and needs are silenced. So unlike AIDS days, we aren't given the support we need anymore."

The three quotes above highlight the fear, blame and ignorance that PLWH are subjected to due to the misconceptions society maintains about HIV and HIV transmission. This is in line with Reddy and Frantz's (2011: 166) finding that health care facilities need to be more proactive in disseminating HIV-related information. With that said, it is crucial for individuals

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[21] The isiXhosa term for a promiscuity.

to be more active in educating themselves about HIV and using the information that is already distributed. The participants' accounts demonstrate how HIV and AIDS is constructed as a disease for the promiscuous, irresponsible and results in weight loss. It is worth noting that in this study, only the female participants discussed promiscuity as one of the labels associated with them for LWH or HIV and AIDS in general. This finding echoes Aulette-Root *et al*'s claim that women and men are stigmatised differently and that the blaming perpetuated in HIV-stigma is "linked to gender and reproductive roles that define 'good' and 'bad' behaviour and 'wrongdoings', especially sexual and 'misbehaviours'which are different for men and women" (Aulette-Root *et al*., 2014: 66).

For those participants who had directly and personally experienced stigma and discrimination, their encounters were within the context of healthcare settings such as clinics and hospitals. Williams *et al.* (2017: 1) maintain that stigma and discrimination are not only limited to social spaces; health settings also perpetuate stigma such that it is healthcare providers and professionals who fail to maintain confidentiality and in turn treat patients inappropriately and unprofessionally. The experience of direct stigma and discrimination was unique to staff members, because, unlike the student participants who had only accessed treatment at the Rhodes University Health Care Centre, the staff members all first accessed treatment from different facilities before accessing it at the Health Care Centre. Staff member 3 experienced stigma and discrimination, both directly and indirectly:

> "Yoh… I almost fought with someone. They were talking about a young lady who was dating a guy… so they were like how can she date so and so who has AIDS? I quickly intervened and told her that 'that is not how we speak about people, because you don't know what tomorrow looks like. And you don't even know your status'. For people like me, I was never sick. All I did was go to the clinic for a check-up and I found out. Even the nurse from Joza who was checking me out tried to spread rumours about my status. She told a man who was pursuing me that I am sick and will die. I went straight to her to tell her that she has disappointed me because I trusted her, and she humiliated me. So she apologised. The worst thing is that I know that her daughter is HIV-positive, but I never even brought that up."

For Staff member 5, the maltreatment at the clinic led to actively seeking a different facility to access treatment:

> "The reason I left the clinic in the location was because of this [discrimination and stigmatisation]. I was not comfortable. It was as if we're [PLWHV] excluded. We were treated as less than other people you see *tearing up*. So, I figured I should move. It's like if you're HIV-positive, you were galivanting, so you deserve it, like what did you expect. Some even think you're stupid. People don't understand that it [HIV] can find you sitting in your comfort zone, trusting someone who turns out to be careless."

In Staff member 4's case, the treatment by nurses in the public clinic inspired her activism:

> "Usually, I fought a lot with the nurses, and in most cases, it had to do with how they treated us. Sometimes it's like they wanted the whole facility to know that someone is positive, and they would say mean things and make us feel small and insignificant based on our status. At the clinic, I was usually that person who was going to be like no, you're a nurse you're supposed to know better. So, we usually fought over things like that, but generally, it's okay to use clinics. Once I started speaking up for myself, they treated me better."

These accounts of stigma and discrimination in healthcare facilities reinforce the notion that stigma creates inequality, undermines trust and reduces opportunities for interpersonal interactions between community members (Prinsloo *et al*., 2016: 263), especially in spaces that are supposed to be safe and welcoming. Kyakuwa (2009: 367) discusses the pivotal role played by nurses in the care and treatment of individuals with HIV-related illnesses, therefore, as frontline members of the healthcare system, they have a responsibility to eradicate stigma and discrimination in their workplace and their communities. In line with this, Rispel (2016: 21) asserts that, in South Africa, there is a crisis of "unprofessional behaviour, poor staff motivation, suboptimal performance and unacceptable attitudes of health workers towards patients" – all of which contribute to the illness experiences of patients.

The findings of this study reiterate Stein's (2003: 95) claim that HIV and AIDS stigma has diminished substantially over time. However, the participants of this study revealed that, on the one hand, there is less perceived stigma and discrimination directed towards PLWH individually for various reasons, especially non-disclosure. On the other hand, collective stigma and discrimination are more evident where PLWH as a group are labelled and treated in specific ways. According to the labelling theory, (Ritzer, 2004: 427), which is also referred to as societal reaction theory, the primary goal is to investigate how social groups create and apply definitions and labels for behaviour. Aligned with symbolic interactionism and social constructionism, the labelling theory holds that labelling is not an intrinsic behavioural trait, rather, that it is acquired through the process of socialisation. Herewith, labels attached to PLWHA are not labels with which individuals were born, instead, the labels are formed and perpetuated through and within the interaction of social groups. Moncrieffe and Eyben (2012: 19) assert that labels are made through symbolic processes of communication. Therefore, they are influenced by rules, stereotypes, and beliefs; hence being labelled may be more about the demographics of individuals than their behaviour. Being labelled has consequences; the label can either be positive or negative. At times, the label cannot be undone, it can increase the probability of future behaviour, and it can also impel society to treat the labelled individual differently – mostly in a negative light (Larsen & Lubkin, 2009: 44). Shepard (2009: 184) explains that negative labels give more room for stigmatisation and discrimination.

This study's participants demonstrate that HIV-related stigma and discrimination can be experienced directly and indirectly as well as covertly and overtly. Furthermore, according to the participants' narratives, HIV-related stigma and discrimination have less to do with the illness itself, instead, it is more concentrated on specific behaviours and markers that have been socially identified to be symbolic of HIV and AIDS. This is evident in the participants' referral to labels such as promiscuity, stupidity and physical markers such as loss of weight. Furthermore, this conclusion is supported by the way in which every single participant who had not disclosed their HIV-positive status or accessed public healthcare facilities either than the Rhodes University Health Care Centre, therefore maintaining their "normal" pubic identity, had not been assigned any labels and their behaviours had not been linked with HIV in any way.

Stein (2003: 98) distinguishes between instrumental stigma and symbolic stigma. The former refers to stigma rooted in fear of infectivity and the potential terminal nature of the disease. This type of stigma also arises from "utilitarian self-interest". The latter kind of stigma, according to Stein (2003: 98), stems from value-based ideologies. Student 1's account incorporates different kinds and extents of stigma and demonstrates the dilemma of living with HIV. He shared:

> "*sigh* I think it's a very daunting thing to have to deal with for people who don't necessarily have this lived experience because of the routine of it and you know, and you'll always get this impending thought of for me in my instance, of like how and when and why yeah…it's those type of like questions that come naturally to almost

> everybody, so I feel that for outsiders or for people who don't live with this experience its very daunting to have to think about you know going through this journey and taking steps to make sure you [him] are living in a healthy way and living your life to the optimum and best you know self or the highest expression of what that possibly could be at that point because I feel like some people would instead choose to stop and cease to exist or they wash away almost and like in what they basically carry within their body. Still, for me, it's like okay I carry this, but this does not necessarily define me."

The argument is that instrumental stigma diminishes as the potential terminal nature of the disease is controlled. In other words, due to the development of ART, which in turn transforms the condition from a fatal disease into a chronic one (Makoae *et al*., 2009: 1357), instrumental stigma has declined. However, because HIV and AIDS is strongly linked with a moral or value-based component "due to its relation to sexual activity, especially promiscuity and homosexuality, not to mention injecting drug-use" (Stein, 2003: 98), symbolic stigma – which is evident in the study's participants' experiences – remains prevalent. Within this model by Stein (2003: 98), symbolic stigma is based on judgemental attitudes towards those perceived to have put themselves at risk of infection through immoral and irresponsible behaviours.

Just as the HIV and AIDS discourse has evolved over the years, so too has HIV-related stigma and discrimination. According to Prinsloo *et al*. (2016: 261), the view of HIV-related stigma has "shifted from, a specific emphasis on the devaluation of an individual's identity, to a broader view of stigma as a dynamic social process characterised by exclusion, rejection, blame, or devaluation of people with an identifiable difference" (Prinsloo *et al*., 2016: 261). This dimension of stigma results in PLWH experiencing, perceiving or anticipating harmful or unfavourable social judgement about themselves. These experiences are discussed in detail in Chapter Ten.

9.3 LIVING WITH HIV AND INTERNALISED STIGMA

Often when HIV-stigma and discrimination are addressed, it is the externalised stigma that is highlighted (Hasan *et al*., 2012: 22). This section sets out to bring to the fore the internalised stigma that PLWH experience. The Global Network of People Living with HIV asserts that there is a "pervasive and inextricable link of HIV and blame" as such, in addition to the biomedical, social and physical burden of infection, individuals have to carry the burden of self-stigma (GNP+, 2012: 21). Self-stigma, which is also known as internalised stigma, takes place when an individual internalises and shares the negative perception of others about themselves, LWH or the disease itself (GNP+, 2012: 23). All the participants in this study acknowledged in one way or another the role of non-disclosure in pursuit of protecting their wellbeing and public image. This is in line with the GNP+ findings that there is greater safety in silence about LWH. As mentioned in Section 9.2 above, those participants who had not disclosed their HIV-status and had only used the Rhodes University Health Care Centre were spared direct externalised stigma. However, all participants in the study experienced internalised stigma, knowingly and unknowingly and at different levels. Moreover, for the participants in this study, internalised stigma was more prevalent in the early stages following diagnosis. The assertion that HIV-stigma is a multifaceted and complex phenomenon (Peltzer *et al*., 2004: 96) is evident in the following accounts, where participants share their experiences of navigating stigma and discrimination directed at the group but affecting them directly as people secretly LWH. Student 3 expressed:

> "People think its easy man. And you see that in these dumb comparisons between HIV and Diabetes or whatever other diseases. People are quick to say "HIV is not a death sentence", but they are the ones killing you with the stigma and discrimination and shaming tactics. Like there is no winning. If you're vocal about it, you're attacked, and if you're silent, you die in silence. But from the looks of it, it's better to be quiet. Well, for me, as a private person, it is. People claim that they will never look at you differently, but they will. For me, it doesn't even have to be me experiencing these things – the fact that someone else can be dragged to filth on social media for posting about their positive status means I can be too… I just feel that people on the outside will never understand until it is them face with this. Not even if it were someone close to them. You have to live with it to feel it."

Student 4 also expressed how difficult it is to separate herself from the disease and all its associations:

> "How I view myself can never be separated from this disease or other people living with it. Whenever I go on Twitter and see someone trolled for being HIV positive, it makes you actually see how people see other people living with what you are living with are treated, and sometimes I get it. I get why people say all these mean things because some of it is true."

In describing the reconstruction which took place in her life following the disruption caused by an HIV-positive diagnosis (discussion in Chapter Ten), Staff member 2 explained how her life had changed and would not ever be the same again. This extract demonstrates the nuances of internalised stigma:

> "…I am not the same person I was before diagnosis as I said. You know, what if maybe I meet someone who is negative who won't be comfortable with my status so then I'd have to lie and be sneaky so that he doesn't discriminate me or look at me differently. Then when it's time for my pills, I might even forget to take them because I am hiding them from this person. So that is why I have decided to wait. I don't even think I will go back to dating. I don't want someone who will feel sorry for me. In terms of friendships I have changed, most of the time I'd rather be home watching tv with my kids to avoid them looking at me funny."

The participants' reasons for non-disclosure, which are discussed in detail in Chapter Eight, also demonstrate covert internalised stigma. Even though participants did not explicitly express having internalised stigma, and in turn self-stigmatising, there is a connection between participants' fears of being stigmatised and discriminated against with internalised stigma. According to Kyakuwa (2009: 369), internalised stigma involves shame, secrecy, and withdrawal triggered by applying negative stereotypes to oneself or the fear of being discriminated against. For the participants in this study, the common forms of internalised stigma were secrecy, withdrawal and fear of being discriminated against. All these elements result in further reduction of the quality of life and physical wellbeing of PLWH (Poku *et al*., 2005: 345), which is evident in the participants' experiences of depression and anxiety. In *Psychological Disorders Among Human Immunodeficiency Virus-infected Adults in Southern Nigeria* (2013), Ofovwe and Ofovwe discuss the effects of HIV-related stigma and discrimination on PLWH. The study reports that PLWH, in comparison to other chronic diseases, experience more internalised shame and lower self-esteem (Ofovwe & Ofovwe, 2013: 180). As mentioned earlier, for this study's respondents, internalised stigma was more prevalent in the earlier stages following diagnosis. Thus, the student participants and one staff member, who have all been LWH for less than five years, were still in the early stages of reconstructing their narratives to accommodate the new diagnosis. In all their accounts, these participants –who had all but one contracted the disease through intimate relationships – expressed fears around dating again, and they used self-isolation as a coping mechanism. Student 1, who, earlier in the interview, shared having experienced rejection from an intimate partner following diagnosis shared:

> “At this point like I don’t know how the next person will react even though people are understanding I don’t want to have to expose myself to a situation where I am possibly stigmatised and have to relive that experience yeah.”

Similarly, Student 5 expressed:

> “Well, it means I have to carry this burden for the rest of my life. It means that before I can consider going into a relationship, I have to first think or figure out how to disclose and then run the risk of being judged, crucified or accepted.”

Student 3, who chose to not disclose and instead used self-isolation as a coping mechanism shared:

> “… you just start thinking about whether you’ll ever meet anyone who will accept you, what your friends and family will say if you disclose, how you will deal with the reality out there of clinics and stigma and, and, and you know. It’s just easier to deal with it on your own… I also have my own space here [Rhodes University], so I can take my pills in peace without having to hide them from anyone. At home, on the other hand, I act like I am on contraceptive pills just so they can get off my back.”

Staff member 4 also shared:

> “I haven’t been able to date since my baby was born [at the same time she was diagnosed], and I have told myself to wait for her to grow up. I am not sure, but I am not ready to date.”

The above accounts of fears around being discriminated against and stigmatised in romantic and close social relationships highlight the social constructionist view that illness is not just a physical state, but that it is also a social phenomenon. Collins (2006: 110) argues that HIV and AIDS is not just a sexually transmitted disease but a socially transmitted disease as well, because it does not only affect the physical body but also affects the social body – the relationships between people. Hence, HIV and AIDS was categorised as a ‘social disease’. Social constructionists are led by the idea that humans create their own reality through social interactions, relationships as well as experiences (Leavy, 2014: 85), therefore through this lens, the quality of life of PLWH and their connection to the social world is negatively impacted by HIV-stigma and discrimination. In *A narrative study of patients’ illness experiences on antiretroviral treatment*, Tsope (2018: 82) found that the participants in the study had not directly encountered stigma due to consuming ARVs but their HIV-positive status elicited stigma from people, especially in intimate relationships. Furthermore, it was found that the participants' experiences of stigma lessened with time, mainly because the participants had publicly disclosed their statuses. From their accounts, participants expressed that publicly embracing their statuses had taken power away from outsiders and given them (the PLWH) the control over the HIV-narrative. Furthermore, by publicly disclosing, they showed how "normal" they are. Thus, took away ammunition from people who might wish to reduce them to their statuses.

According to Kyakuwa (2009: 346), self-stigma arises out of "symbolic expressions and symbols that aid in the derivation of meanings that one attaches to ideals of the self and others". Therefore, the idea of the "looking-glass self" in this case implies that what moves individuals to pride or shame is not "mechanical reflection of ourselves, but an imputed sentiment, the imagined effect of this reflection upon another's mind" (Kyakuwa, 2009: 346). Symbolic meanings, according to the symbolic interactionist perspective, are a product of social interactions (Benzies & Allen, 2000: 544). As per the discussion in Chapter Four, individuals actively participate in the construction of their social worlds, and this process includes the development of individual selfhood through social interaction (Goffman, 1963). Symbolic interactionists then, in looking at illness, virtually explore, in detail, the experience of disease within the context of individuals' daily social interactions which consequently shape the performance of self (Conrad & Barker, 2010: 568). In this way, symbolic interactionists, as mentioned above, focus on the micro-level to supplement the macro-level view of life (Schwartz & Rutter, 2000: 17). Therefore, within this view, the externalised stigma, which commonly takes place through social interaction, directly affects individuals' performance of self and leads to individuals often internalising this stigma which then impacts their social interactions. Stigma then can be said to have a ripple effect on the holistic illness experiences of PWLH.

Herek *et al*., (2013: 41) and Fielden *et al*., (2011: 276) discuss how individuals living with a concealable stigma experience different social challenges compared to their counterparts living with the stigma that is readily apparent. The former type of stigma is attributed to individuals who can live with their condition in secret and still maintain their public identity. These individuals can "pass" as members of the non-stigmatised majority in many social settings, and as a result, these people are discreditable rather than discredited, particularly if they fail to "pass" as members of the non-stigmatised group. In contrast, the latter form of stigma is attributed to individuals with conditions that cannot be concealed and in turn, elicit direct stigma; an example is living with physical impairments. Individuals with visible "markers" or stigma symbols are then, easily discredited (Herek *et al*., 2013: 41). According to this model, initially conceptualised by Goffman (1963), to minimise being stigmatised and discriminated against, people living with stigmatised conditions engage in behaviours of the non-stigmatised majority, to pass as part of the non-stigmatised majority. Thus the potentially discredited engage in impression management, whereas the discreditable engage in information management (Fielden *et al*., 2011: 276). HIV and AIDS continues to be a heavily stigmatised disease and if treated, is concealable. Therefore, for those LWH, it may be possible to monitor their public behaviour to avoid being stigmatised – examples are changing treatment facilities, labelling ARVs as contraceptive pills and comparing HIV to less stigmatised conditions such as diabetes.

Fielden *et al*. (2011: 276) contend that there is a relationship between silence and erasure, where health practitioners create non-identifying spaces for clinical and social programmes to occur. This relationship can be seen in individuals as well, where individuals – as is evident in this study's sample – create non-identifying identities and concepts to remove what Goffman (1963) refers to as the "stigma symbols", visual reminders, or space participation in managing the HIV-stigma (Fielden *et al*., 2011: 276). Poku *et al*., (2005: 346) justify the erasure of stigma symbols or markers by asserting that these contribute to "identity debasing resulting in the subsequent devaluing of individuals, thus affecting social interactions". In line with this erasure and normalisation of the disease, Staff member 1 shared:

> "I know I am living with this [HIV], but I am still me, and I don't want this to define me. I am still normal. I take my sweets and life goes on. Being undetectable is a mental thing as well… my mind has shifted. I'm freer now… I'm not scared maybe that I could infect my children by accident or any other person. I'm not a danger to anyone anymore… I can't infect anyone else…I can say that I am healthy too like other people."

The above staff member's account highlights a few things: the erasure of the disease labelling through choosing not to name it, the way she had internalised being "a danger" to society and the importance of passing as one of the non-stigmatised majority who is healthy. The above is but just one example of how stigma motivates individuals to modify their behaviour to avoid enacted stigma by, for example, concealing their group membership working towards passing as members of the non-stigmatised group (Herek *et al*., 2013: 48).

It is evident that internal and external stigma are interlinked. Hasan *et al*., (2012: 22) explain the relationship between the two kinds of stigma as such: “people experience discrimination because of stigma, discrimination leads to internal stigma and internal stigma again reinforces and legitimises stigma” (Hasan *et al*., 2012: 22). Fielden *et al*., (2011: 269) explain that internalised stigma represents a possible reaction to the experience of external stigma which has the ability to turn stigmatised people against themselves through using self-isolation as a coping mechanism. The assertion is that worse than the social and cultural alienation stigmatised people face, is the process of self-enforcement that turns individuals into their “own ‘jailors’, their own ‘chorus of denunciation’ and what takes ‘inhumanity to an ultimate pitch’” (Fielden *et al*., 2011: 269). For the participants of this study, this process of self-isolation is evident soon after diagnosis and discussed in Chapter Ten, on the disruption following an HIV-positive diagnosis. It is at that stage that most participants have to navigate firstly the new diagnosis and secondly the burdens that come with it socially, culturally, medically and personally. The following section will discuss stigma within the Rhodes University confines.

9.4 STIGMA AND DISCRIMINATION IN THE RHODES UNIVERSITY CONTEXT

It is evident from the participants’ narratives that the Rhodes University context is a safe space for PLWH in comparison with other contexts like the students’ and staffs’ home communities. This, as the participants have shared, is due to a myriad of factors, including but not limited to, the educational environment, the low prevalence of HIV, little to no information about those LWH in the university as well as no persons having had publicly disclosed. With all that said, the reality of stigma and discrimination must be acknowledged and addressed accordingly. Furthermore, as *The Positive Learning: Meeting the Needs of Young People Living with HIV in the Educational Sector* (GNP+, 2012) reports, the responsibility for challenging prejudice and advocating for the rights of PLWH should not only be on those LWH. Instead, “educational institutions and their managers have the responsibility for ensuring that school environments are supportive and protective of privacy and dignity of all including those LWH” itself (GNP+, 2012: 23). As highlighted in Sections 9.2 and 9.3 above, stigma can take the form of actual discrimination which is a consequence of the “stigmatised person existing in the margins of society, or a person’s ‘felt’ stigma, where they live in fear or anticipation of discrimination and rejection often resulting in an internal sense of shame and reluctance to disclose the stigmatising condition” (Hutton *et al*., 2013: 66; Hasan *et al*., 2012: 23). However, stigma can be internalised, whereby the label is embedded in an individual's self-concept, and the individual assumes behaviour in line with the label (Crooks, 2010: 15).

The findings of this study are in line with *The Report of the Study on HIV Prevalence and Related Factors at Rhodes University (2010),* which showed low levels of overt stigma. However, the report found that profound levels of perceived stigma exist on campus often in subtle forms such as avoidance of shared toilets, distanced friendships, and great gossip and suspicion about people's HIV status. It is worth noting that only one of the participants – a staff member – experienced what she perceived as direct discrimination due to her HIV-positive status. Staff member 3 shared:

> "I remember a few years ago, in a house [university residence] that I was working in. I would arrive in the staff room and on my desk where I sat and kept my things I found that someone had put an AIDS pamphlet. A few days later, they left condoms. It was just at my desk and no one else's. I never said anything. I didn't speak. I know that whoever did that was trying to prove *la way yokuba siyakwazi*[22]. But I didn't even react. I didn't give them the satisfaction. It was just after I had disclosed to someone on campus and you know news travel. Someone can tell one person, and they tell someone else. But I didn't care. I'm not living my life for anyone but myself."

Unlike the above account, the rest of the participants did not experience direct stigma or discrimination. Instead, they witnessed how the HIV and AIDS discourse unfolds in the university context and in those discourses perceptions of stigma and discrimination were predominant. Student 1 shared an account about how he felt following an anonymous confession by an HIV-positive student on the university social media page, Rhodes Confessions[23]:

> "Being from a small campus like ours it is easy to know what everyone is talking about. I remember the time last year [2018] where somebody had found out their diagnosis, and they were willingly spreading the virus here on campus as revenge. People had a wide range of reactions to that particular post on like RU Confessions. Most people were you know, fearful because of the unknown and fearful too because for them it brought a sense of reality like 'oh no actually I might have been in contact with

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[22] Loosely translates to: "we know about you".

[23] Rhodes Confessions is an online (Facebook) platform for individuals to anonymously make confessions which are often responded to by the university community in the comments section.

> somebody you know earlier on this week so what are the chances for me'. There was somewhat a meltdown here on campus. I didn't feel stigmatised at the time, but I felt heavily I don't know… I don't feel like that was my safest point being here [Rhodes University] because of some of the projections coming out from the people but like I understood where those like those fears and statements came from so yeah…"

Student 3 referenced the same anonymous confession as such:

> "It was kind of triggering for me. It brought back the memory of actually going to test and like what that meant for me. It was, I don't want to say ruining the experience but like denting what it actually means to live with this at that moment. I kind of like attached some kind of like blame policy for how they handled their situation, but I had to understand that at that moment that was their coping mechanism. I felt vulnerable and a bit exposed. It was a very dark time because everybody is worried about a certain thing here on campus and I live with it, so it doesn't necessarily sit with well with me that okay to some people I'm seen as a danger so yeah… The comments were made. People went off to talk about how the government shouldn't waste resources on promiscuous people. Some said we deserve to die. All those things. It just makes you scared to be living among people who think like that."

The two students' accounts counter Nettleton's (2013: 86-87) explanation that the use of social media also helps create more positive images of illness and creates a space where people living with chronic conditions can be proud, develop positive self-identities and have power over their narratives. Perhaps it is the nature of the original anonymous confession of disclosure and further declaring revenge that elicited a negative response from the online community because Tsope (2018: 86) found that online platforms created a community for PLWHA and broader society to constructively engage with issues pertaining to HIV and AIDS. The other participants' accounts revealed that even within the Rhodes University context, there are perceptions of stigma mostly due to lack of information among laypersons whereby PLWHA are perceived to all be infectious and contagious. This stigma and discrimination is a result of faulty sociocultural beliefs and moralistic views toward sex as well as poor education and awareness (Jain *et al.*, 2017: 6). Student 2 said:

> "As I said, it's crazy how even students, who are educated think we're promiscuous, irresponsible, were drunk or with multiple partners but that's not always the case. I was with the same person I loved and trusted for a very long time, and they betrayed my

> trust. Even though we used to test together and so forth here, I am. People also think "how could she be so stupid to catch HIV" as if you see it coming. If I did see it coming, I can assure you I would have run fast."

Staff member 6 shared similar views:

> "They talk. People talk. I mean, for example, they talk about how it is transmitted and sometimes what they are saying is nonsense. Like, you can't be infected through saliva. When I listen to some of these things here at work, I'm like ah ah *shakes head*. A person will say people get infected by sharing a toilet seat. No, there's no such thing. I know how it's transmitted you see. And some people clearly don't."

In all their narratives, all the participants expressed the importance of acceptance of their HIV-positive status, and this had a direct relationship with how they dealt with the challenges that come with LWH, including stigma and discrimination. Acceptance, according to Stinson and Myer (2012: 67) enabled a better quality of life and linkage to treatment and care for PLWH. Staff member 5 summed it up as follows:

> "I long accepted the fact that I am HIV-positive. From the very first day, I accepted it. The most important thing is acceptance, taking your treatment and taking good care of yourself. Life goes one. My life continued."

In agreement, Staff member 4 expressed:

> "What I can say is that I have accepted. I won't question why me or hope to pass the buck or the disease to someone else. I grew up in a Christian family, and we were taught that whatever we are faced with, we must accept. I'm not the kind to want to pass the buck. For me, the most important thing is that this [HIV] can be managed. I only get worried when someone doesn't take their treatment and speeds up their own death, knowing very well that the treatment works and it's not the end of the world."

All the participants' experiences of stigma and discrimination within the university were among their peers (students and colleagues). The narratives reveal that, even though minimal, negative ideas about HIV and PLWH are not foreign to the university community. None of the participants alluded to structural or systemic forms of stigma and discrimination at Rhodes University, which indicates that the participants perceive of the university as a safe space.

9.5 CONCLUSION

This chapter has demonstrated that stigma is an inescapable aspect of LWH whether the stigma experienced externally and internally. Furthermore, it is clear that experiences of stigma fluctuate across many variables, and in the case of the participants, including age and class. This chapter has also demonstrated that stigma is a "complex phenomenon and interaction, which is both covert and overt and is subjectively experienced in various ways" (Poku *et al*., 2005: 345). This chapter, in line with Herek *et al*. (2013: 49), has highlighted that internal and external stigma should be considered as related but distinct constructs. As has been shown by the participants' accounts, both staff and students felt stigma and self-stigma are significantly correlated with psychological wellbeing, anxiety and depression being the most prevalent.

According to Herek *et al*., (2013: 48), the awareness that one's group is stigmatised may be a purely cognitive process with minimal impact on the self. However, stigma can be perceived, by the individual, as a stressor insofar as it "creates expectations that stigma enactments will occur and motivates minority individuals to maintain continual vigilance to avoid them". Thus, as a stressor, stigma may be a source of distress and have indirect effects on psychological wellbeing. Herek *et al*. (2013: 50) further assert that the perception of belonging to a stigmatised group may exact a psychological toll on PLWH, regardless of whether the individual regards the stigma as legitimate.

This chapter highlights that although the prevalence of HIV, thus HIV stigma and discrimination, among students and staff at higher education institutions is not as common as it is in the general population, institutions cannot be complacent as the sexual and social behaviours of sections of university communities puts both PLWH and the greater community at risk of infection and stigma and discrimination (Buldeo & Gilbert, 2015: 209).

CHAPTER TEN: DISRUPTION AND RECONSTRUCTION OF NARRATIVES

"Nothing breaks my heart like seeing people living with HIV feeling like their lives are over because of their HIV statuses. No one should have to feel that way, and no one should be made to feel that way. Life doesn't have to end after an HIV diagnosis. I'm sorry that we still have to go through the stigma from other people, sometimes even internally, but we should not write ourselves off because of HIV. We are also deserving of life beyond HIV, and as life changing as living with HIV could be, it's not impossible. Your life does not have to end, and you are definitely not alone."

Saidy Brown, 25. HIV Advocate and Activist, South Africa

10.1 INTRODUCTION

This chapter follows that the process of coping with an illness introduces an individual to new ways of being. For the individual faced with an illness, especially chronic, in some cases, dealing with the physical body comes before one must cope with relationships, disruptions, and any form of reconstruction (Kelly & Field, 2004: 259). According to Burton-Jeangros, Cullati, Sacker, and Blane (2015: 1), people's health is influenced by complex social and biological processes. Furthermore, there is a combination of physiological and social resources that people can rely on and can impact their ability to adapt, with responses ranging between vulnerability and resilience.

As per the discussion in Chapter Five, Bury (1982: 169) contends that chronic illness is a significant kind of disruptive experience or a critical situation. As such, a good deal can be learned about "day-to-day situations in routine settings from analysing circumstances in which these settings are radically disturbed" (Bury, 1982: 169). In line with Bury's findings, this chapter draws attention to the notion that chronic illness is the kind of experience that disrupts structures of everyday life and the "forms of knowledge which underpin them" (Bury, 1982: 169). When faced with a chronic illness, individuals are forced to acknowledge and deal with worlds of pain and suffering and possibly death, which they otherwise would not have to. Charmaz (1983: 171) adds that chronic illness presents individuals with a unique opportunity to "study the self because self-concepts typically become so visible". This visibility of self-concepts compels ill individuals to confront aspects of self which were previously taken for granted because, due to illness, they are altered or gone. The disruption caused by a disease further affects how an individual perceives one's self-identity and has led to the introduction of concepts such as "biographical disruption" (Bury, 1982) and "loss of self" (Charmaz, 1983).

The idea of biographical disruption (Bury, 1982) speaks to the ontological uncertainty and questioning that accompanies the suffering experienced when one is living with a serious or chronic illness. This ontological uncertainty is addressed "in terms of their [the individual's] biography and their stock of common knowledge about health and illness" (Chisaka & Coetzee, 2009: 109).

According to Alexias, Savvakis, and Stratopoulou (2016: 49), illness narratives are a useful means of studying not only the biomedical reality but also the illness experience and its social and cultural underpinnings. The assertion is that people's narratives "give voice to suffering in ways that lie outside the domain of the biomedical voice" (Alexias *et al*., 2016: 49). This stance is in line with the study because it advances the qualitative nature of this research, in recognition of the contention that a great many of the issues faced by the HIV infected individual are better examined through qualitative paradigms (Parker & Carballo, 1990). This chapter will discuss the disruption and reconstruction of illness narratives in three parts, namely: the disruption following an HIV-positive diagnosis, reconstruction of narratives following diagnosis, and illness experiences in the context of Rhodes University.

10.2 THE DISRUPTION FOLLOWING AN HIV-POSITIVE DIAGNOSIS

As mentioned above and will be further demonstrated in this chapter, critical or chronic illness intrudes and at times, stops the progression of someone's life. This disruption caused by an illness can happen in various ways. Tembo (2017: 254) explains that for some people the disruption can shatter one's dreams and aspirations for the future, present a physical attack on one's body, sense of self and identity, and sometimes introduce uncertainty and confusion about self and life. The participants of this study all agreed that in the early stages of diagnosis, the disruption manifested in different ways. For the Student 1– who shared that he had not shown symptoms, had not ever been sexually active and never been potentially exposed to the virus – the HIV-positive diagnosis was overwhelming and confusing. He shared:

> "*sigh* I feel like it hit me. That at that point, I was actually, you know… I wasn't as healthy like I expected to be. So, I feel like there was like a wave of like okay… questioning within me *tearing up*. I'm sorry *clears throat*… I had to question where I got this from because my immediate call was my parents because I was a virgin! I had never had sex with anybody up until that point, so how come me? Where did I get this from? I don't remember being in a significant life-threatening incident where I was perhaps in a car crash or, you know, sexually abused or being in an instance where

> basically there could have been a moment where my blood was transfused with another person's, and it was visible to me. So, I still live with that every single day… but I try not to think of it because you know… I didn't per se ask for this, but I am living with this. I had to then think at that moment and time as to how do I go about like best handling this and being so far away from home and my friends only providing a sense of understanding but like a limited amount of support as best as they could."

The above quote demonstrates a student's thought process immediately after testing positive for HIV on the university premises during a *First Things First* Campaign. It is clear from the quote that the diagnosis brought the student face to face with a new world and reality, one which was not, up to that point, considered. The student's experience reveals one of the three ways in which chronic illness disrupts an individual's life in line with Bury's theory of disruption – the "disruption of taken-for-granted assumptions and behaviours and breaching of common-sense boundaries" (1982: 169). Consistent with this, Chisaka and Coetzee explain that at this level, the most basic underlying existential assumptions that people hold about themselves and the world – such as good health – "are thrown into disarray during a serious or chronic illness" (2009: 112).

Alexias *et al*. (2016: 586) illustrate that chronic illnesses, like HIV, result in a rupture in the continuity of an individual's biography due to the changes that are a consequence thereof. One of the most critical issues that PLWH have to deal with following an HIV-positive diagnosis is control over their lives due to the event of a biographical disruption (Alexias *et al*., 2016: 586). Moreover, a reconsideration of dreams for a family, children, and career advancement takes place as these, for some, are perceived as unfeasible.

As Student 2 put it:

> "In the very beginning, I was depressed for about two weeks and didn't attend any classes. I was genuinely upset and lost all hope for my future. I couldn't even get an LOA[24] coz how do you say to your lecturer that you are HIV positive and can't attend classes and tutorials. I mean, people are battling demons and still show up to school. I couldn't even get myself to go to the San or the Counselling Centre – I was just in a dark place. But after going to the San the first time, I started getting more and more comfortable. I have had other days where I just feel drained by this thing and just don't

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[24] LOA: Leave of absence certificate issued to a student to be excused from a lecture/tutorial/test etc.

> want to face the world. It's like even though you come to terms with it, it still lingers at the back of your head and sometimes it just consumes you, and you just start thinking about whether you'll ever meet anyone who will accept you, what your friends and family will say if you disclose, how you will deal with the reality out there of clinics and stigma and, and, and you know.

As outlined in Chapter Three, mental illness, especially depression and anxiety, are additional burdens faced by PLWH and show up at different stages and in different ways, following an HIV-positive diagnosis. The student (directly) above demonstrates the complex way in which biographical disruption takes place. More than the interruption of taken-for-granted assumptions and behaviours, this student's perception of the future was altered, hence, leading to feelings of uncertainty. Moreover, it is evident that the healing process following diagnosis is not linear – rather, circular involving bearable and sometimes debilitating moments throughout one's experience. Staff member 4 shared:

> "This disease came with a bigger emotional burden than medical for me. I think I may be depressed and angry even…My life is not the same anymore. I am not the same anymore, and I am doing the best I can to go back to who I was, but I can't. How I view, myself can never be separated from this disease or other people living with it. Whenever I go on Facebook and see someone broken to pieces for being HIV-positive it breaks me too. It's hard living with HIV and not showing. Like, when you look at me, you can't tell, and yes, that's good because it means my treatment is working, but somehow, somehow that makes it easier for my emotional needs to be overlooked."

As discussed in Chapter Three, the emotional burden of living with HIV is a critical element of the experience of LWH. Staff member 4 above echoes Turner and Kelly's (2001: 124) assertion that individuals living with chronic conditions must cope with the disease itself and the emotional dimensions of the disease which are commonly overlooked when medical care is considered. The staff member's account also demonstrates a struggle that a few participants noted – the battle of the invisibility of HIV – as discussed in Chapter Nine. However, for the purpose of this chapter, it is worth noting how the development and success of ART neglects the emotional and psychological element and disruption due to LWH. ARVs work such that they delay or prevent the progression from HIV to AIDS and the death of HIV-infected patients (Wood, 2010: 529; Bartlett & Finkbeiner, 2006: 67). The upside of this is that it results in the repression of the virus, whereby optimum adherence to ARVs then leads to the viral load being undetectable, thus resulting in the person becoming non-infectious, and then their "immune system gets the opportunity to replenish itself" (Van Dyk, 2011: 5). Consequently, the individual reclaims "healthy" status with no physical markers of LWH. What has been continuously emphasized by participants is that, while ART results in positive medical outcomes, those positive outcomes create an illusion of "being healed"; therefore, needing little to no psychological support.

The three quotes above further illustrate how, due to the disruption of testing positive for HIV, individuals also went through a process of meaning-making about the self, the future, and the new reality.

Student 1:

> "I didn't per se ask for this, but I am living with this, and I had to then think at that moment and time as to how do I go about like best handling this…",

Student 3:

> "…sometimes it just consumes you, and you just start thinking about whether you'll ever meet anyone who will accept you, what friends and family will say if you disclose, how you will deal with the reality out there of clinics and stigma and, and, and you know…"

Staff member 2:

> "…I am not the same anymore, and I am doing the best I can to go back to who I was, but I can't."

Through this process of meaning-making, individuals start the journey of producing various realities that constitute the sensory world (Lune & Berg, 2017: 17). Moreover, they start shaping and re-shaping their realities to accommodate the illness. Staggs (2017: 4) adds that once a disruptive event like testing positive for HIV happens, an individual's life, sense of being and the world around them is recast in a different light where they have a "before" and "after" in the way they view themselves (Staggs, 2007: 4). According to Tsope (2018: 40) this "before" and "after" consists of new meanings, objects, actors, and acts which propel the individual to begin interacting with the world and reality of HIV and AIDS and LWH. Additionally, the transition into this new reality results in further social actions that were possibly not considered up to the point of disruption. Staff member 5 explained the change:

> "It's changed a lot [her life] because I am not the same person I was before diagnosis. Now I am more careful about what I eat, drink, do, etc. because they [health practitioners] tell us that you can have kidney failures and all that. So, it's my duty to do everything on point. Less mistakes. I haven't been able to date since my baby was born [at the same time she was diagnosed], and I have told myself to wait for her to grow up. I am not sure, but I am not ready to date."

In talking about their experiences of diagnoses, all the participants shared how testing positive for HIV caused a disruption in their lives in different ways and extents. Furthermore, they shared how a fundamental rethinking of their biography and self-concept took place. Pranka (2018: 1) describes how the experience of a chronic illness breaks the individual's social and cultural knowledge by threatening their self-identity. Hence confessions such as "I am not the same person I was before diagnosis". This is in line with Kelleher and Leavey's (2004: 190) claim that chronic pain or severe illness causes a revision of life goals.

In *Critical Illness as Biographical Disruption,* Tembo (2017: 254) defines biographical disruption by breaking down the two concepts: biography and disruption. The former is commonly defined as "the history of a person's life written by someone else," and the latter is defined as "a disturbance or problem that interrupts, causes confusion or impedes the progress of something or an event" (Tembo, 2017: 254). The combination of these words then, in the context of illness, means that illness, chronic illness in this case, "interrupts, impedes and at times, stops the progression of a person's life" (Tembo, 2017: 254). This interruption, as previously mentioned, presents itself in a myriad of ways, including shattering one's dreams and aspirations for the future, as has been the case for some of the participants. Pranka (2018: 1) adds that the significant changes that follow biographical disruption are experienced at an objective level and explained and interpreted subjectively in a person's biography.

Tembo (2017: 254) claims that a disruptive event such as illness "heralds attack" on a person's physical self and sense of identity, introducing uncertainty and confusion about self-worth in that individual. The discussion on uncertainty in Chapter Three, highlights that beyond the uncertainty of biomedical factors, personal and social forms of uncertainty are equally critical in illness experiences (Kuang, 2018: 16). Uncertainty of this form (personal and social), as expressed by participants, refers to the doubts and questions about their valued identities, personal and professional roles, financial stability, and life plans (Kuang, 2018: 16). Additionally, uncertainty refers to the particular questions that people have about their intimate and professional interactions and relationships following the biographical disruption (Kuang, 2018: 16).

Another recurring theme in the participants' experiences of the disruption brought about by testing positive for HIV, is the notion of a "turning point" or "fateful moment". Pranka (2018: 2) describes this as the different processes or moments in which the individual becomes an entirely different person, for better or for worse, put in motion by a single point – the turning point. This turning point is "initially identified as the critical event that provokes the person to admit that 'I am not the same as I was before' and is accompanied by surprise, shock, bitterness, confusion, tension and/or a feeling of defeat in his or her experience of self" (Pranka, 2018: 3). Pranka (2018: 3) furthers that this turning point propels an individual to seek a new self to fill the unique experience and overcome the biographical disruption. This links to the earlier mentioned notion of "before" and "after".

10.3 RECONSTRUCTION OF NARRATIVES FOLLOWING DIAGNOSIS

Intimately linked with biographical disruption is the process of narrative reconstruction, which is commonly the next step following a critical situation. Pranka (2018: 5) describes that once someone experiences a biographical disruption, they enter a process of attempting to connect their previous identity with the new identity. This process involves changing views of the future and seeking answers to questions regarding relations with the world; moreover, the individual "conducts a biographical work, where the understanding of the disease and interpretation of its onset represents an important component" (Pranka, 2018: 5). At this stage, the individual makes adjustments in their lives, and often before the changes have been made, individuals grieve the new condition they are faced with (Turner & Kelly, 2000: 124). According to Williams (1984: 254), narrative reconstruction is an "attempt to reconstitute and repair ruptures between body, self, and the world by linking-up and interpreting different aspects of biography in order to realign present and past self with society".

In this process of reconstructing one's narrative and overcoming biographical disruption, individuals additionally look to various forms of social support to facilitate a "return" to life before the biographical disruption or an orienting to the new situation. According to Pranka (2018: 5), social support serves to "amortise and decrease the negative influence on individuals of shocking, traumatic events by helping the individual to adapt socially". Additionally, the availability of social support systems and the option to use these positively influence the health and overall wellbeing of the individual. In agreement, Toombs, Barnard, and Carson (2995: x) claim that personal narratives about illness are embedded in more than just one's disease but also one's social context – the social world in which one lives in.

The process of narrative reconstruction highlights two aspects of disruption in the unfolding of chronic illness as identified by Bury (1982: 169) and discussed in Chapter Five:

1. The disruption of critical systems usually used by people. This stage requires an individual to rethink and reconceptualise their biography and self-concept.
2. The response to disruption. In this stage, the individual needs to readjust their lives to accommodate the interruption and mobilise resources for the change.

The aim of narrative reconstruction for PLWH is to adapt their lives to accommodate their illnesses in pursuit of continuity (Bury, 1982: 168). Staff member 6 shares how disclosure and social support both from family and healthcare professionals assisted:

> "It was painful at first, but I told myself that it's not a thing I can change. I can't remove the pain. The only way for me to deal with it was to disclose to my family. Them knowing made a difference. I also went to counselling when I was diagnosed at the hospital. They [healthcare professionals] basically sort of taught me how to take care of myself. How to take treatment, eat healthy foods and all that... They helped me deal with this. Now, if I need to talk, I talk with my sisters. They understand my struggle. I once told my mother that this pill irritates me, and she warned that I should not even think of stopping treatment. *chuckles*"

Staff member 3 shared a similar experience:

> "I don't want to lie, when I first heard the news I cried. I didn't know what to do or how I ended up there. So, my brother said, 'don't do that to yourself'. So, I went for some counselling with that sister [nurse] I was telling you about earlier. Eventually, I was fine. I didn't lose weight or get sick. I don't remember anything like that. That's why some people even think I am lying about my status because I didn't get sick. My son also didn't worry about me because I'm sure he could see I was still the same and looked healthy. The people in my circle are supportive. They don't even worry when I share cups or cutlery with them. They don't act strange."

The above participants' experiences speak to the social constructionist and symbolic interactionist view that people create their reality through social interactions, relationships, and experiences (Leavy, 2014: 85; Charmaz, 1983: 70). Through tapping into their social networks, the participants were able to not only deal with the biographical disruption but also lean on their networks for meaning-making purposes and orientation into their new reality. The second participant's experience further demonstrates Leavey's (2004: 191) claim that those who are ill feel the need to assert and legitimise themselves through emphasizing their autonomy and adaptation. In the quote, the staff member distances herself from the common visible markers or "stigma symbols" such as weight loss, skin rashes, etc. which for some people are side effects of illness and treatment (Aulette-Root *et al.*, 2014: 26), as a way of showing how healthy she is. This was a common narrative among participants. Bury states that distancing oneself from the disease assists the claim that one is a victim of external forces rather than fully accepting entirely the burden of responsibility (Bury, 1982: 172).

Another more practical approach or response to biographical disruption is the mobilisation of resources (Williams, 2000: 43). For Student 1, mobilisation of resources meant early access to treatment more than seeking social support:

> "I didn't feel like I needed to go to the psychology centre [Counselling Centre] … I knew my life changed; you know. So, I went to my room, and I called my mom. I told her about my status. I then gave myself a week or two then went to the San, and I was like 'I better get my life' because if I'm living with something and it can be controlled, then I might as well manage it from the early onset. So that's the kind of mindset and feel I adopted and approached to myself. Not relying on the psychology centre. I didn't feel like I needed to go there in order to validate my own experience."

The quote above displays that, for the student, accessing treatment symbolised health and reclaiming control over their lives after the diagnosis had shifted their equilibrium. This is the same student whose diagnosis revealed to them that they were, in their own words, "not healthy like I expected to be". The student's experience highlights two concepts that Blumer (1969) discusses: the object and joint action/social action. The object, in this case, is the treatment that is given meaning. The student shared in the interview that they had always known about ARVs, but their importance and relevance only became of importance to them once they were confronted with the HIV-positive diagnosis. Only after that biographical disruption did ARVs mean something – good health/ control/ managing disease – and in turn, prompted the action of seeking treatment. According to Charon (2001: 3), as the action unfolds, individuals get a sense of their environment and then define situations. The student then, in reconstructing their narrative, acted in accordance with their meanings of the circumstances.

According to Williams (2000: 43), there are two types of meaning that can be seen to coalesce around chronic illness. Firstly, the purpose of chronic illness can be viewed in terms of its practical consequences for individuals and their immediate social network (family, close friends, intimate partners etc.) as individuals live in independence or situated networks of relationships (Burton-Jeangros *et al*., 2015: 4). At this level, the effects of the beginning of the disruptive symptoms, time spent on symptom management or treatment as well as the socio-economic costs involved with especially long-term chronic illness may be predominant. The second way in which the meaning of disease may be seen is in its symbolic significance: "different conditions carry with them different symbolic connotations and imagery, which vary markedly within different segments of the cultural order…" (Williams, 2000: 43). These meanings consequently have a far-reaching effect on how individuals view themselves, how they think others perceive them, and in turn, experience their illnesses.

10.4 ILLNESS EXPERIENCES IN THE RHODES UNIVERSITY CONTEXT

Sections 10.2 and 10.3 have demonstrated the disruption and reconstruction that follows an HIV-positive diagnosis. It is worth noting, once again, that biographical disruption, reconstruction, and illness narratives are interlinked entities that manifest in different ways for different individuals. Tsope (2018: 15) simply defines illness experience as "the way in which the illness is reflected in an individual's life". In order to understand these reflections, narratives were sought from the individuals directly. In describing their experiences of living with HIV at Rhodes University, all participants shared that the campus environment has had a positive contribution to their illness experiences, even though, as is discussed in Chapter Eight, degrees of stigma were perceived. Participants also shared ways in which the biographical disruption shifted their lives positively. This idea of a positive shift is in accordance with Kelleher and Leavey (2004: 191), who assert that those who are ill "have a particular need to legitimate themselves, for example, stressing their autonomy, adaptation, personal control, and goodness". Narratives of illness then, according to Kelleher and Leavey (2004: 191), are used to sustain a positive definition of the self even though biographical disruption may have taken place. Kelly and Field (2004: 259) stress that even though self and identity change in chronic illness, these also have an enduring quality such that even as an individual's illness develops, there is still “an important sense in which they are the same person they were before their body began to alter, albeit in a different situation”. To echoe this view, Staff member 1 shared:

> “For me nothing big has changed [since diagnosis]. My life is still the same. There’s nothing much. The only thing is that I started with three pills *neh*, now I take one pill combined. It’s a relief that I am now on one pill instead of three, even though it’s the same pill. The pill has become a sweet to me. It’s like a sweet. I don’t even stress about it anymore. But to me, there’s no difference. I don’t see myself any differently. I am still the same Loraine[25] I was then. I am still the same. *laughs*”

In *Understanding HIV/AIDS through Sociological Theory: An Application of Symbolic Interactionism and Labelling Theory*, Staggs (2017: 10) asserts that how individuals give meaning to their lives following an HIV-positive diagnosis is affected by the way their narratives are perceived. The assertion is that some stories of PLWH are oriented toward the future, and others are present-oriented (Staggs, 2007: 10). Thus, how an individual views the possibility or impossibility of hope transforms their narratives, their identities, and social action. Some participants’ responses showed that there is a third way of perceiving narratives – past-oriented. In this way, individuals still hold on to their narratives (and who they were) prior to diagnosis. This is demonstrated by Student 3, who expressed that the diagnosis put a halt to their biography:

> “My life stopped since I was diagnosed. Like I said I am on pilot mode. Just doing what I need to do, to get by. All the extra flowery things of life stopped mattering to me. I don’t have a social life anymore. I have about two friends. I feel alone in this world. It’s just me and my pills.”

Student 3 expresses feelings of helplessness and despair as well as negative expectations about interpersonal interaction, which, according to Ofovwe and Ofovwe (2013: 178) are consistent with depression following an HIV-positive diagnosis. The same student shared the following earlier in the interview:

> “I’m not too involved in the community [Rhodes University]. I’m just a student. And being a student on its own is difficult; now add being HIV-positive on top of that *laughs*. There are no advantages [to living with HIV while at the university] … well, maybe the fact that I don’t have to access a public clinic and deal with nurses who hate

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[25] This is a pseudonym.

> their jobs. That's the only advantage. Well… I also have my own space here so I can take my pills in peace without having to hide them from anyone. At home, on the other hand, I act like I am on contraceptive pills just so they can get off my back. The disadvantage is that at the end of the day, this is a place of learning; it is not some hospital or NGO set up to cater to me and my personal needs."

Student 3's narrative highlights a proposition made by Tsope (2018: 13) that disclosure, among other factors such as health policies, adherence, stigma, and general healthcare, plays a crucial role in understanding how individuals form narratives about their illness experiences. Furthermore, there is a relationship between an individual's illness experiences and their capacity to engage in the social world, so, "the social world (societal attitudes, social practices, public policy), influences the subjective experience of illness and its meanings" (Toombs *et al*., 1995: x). In line with this, Hardon *et al*. (2013: S3) assert that disclosure increases both practical and emotional support and enables self-acceptance for those disclosing and those who are privately dealing with their diagnoses. This student's, and other participants', reasons for non-disclosure are discussed in Chapter Eight, however, for the purpose of this chapter, it is worth noting that for those participants who had not disclosed to anyone other than healthcare workers, their illness experiences presented more negatives than positives for their overall wellbeing. Contrary to the Student 3's narrative above, which is past-oriented, Student 1 shared a present-oriented narrative:

> "I honestly don't remember life before this… I do know that everything was easier and all. Since diagnosis, I am more guarded. At first, I was afraid of infecting anyone else, so I distanced myself from any possibility. Now I know I can't infect anyone, but I still don't want to be put in a situation where I have to be judged or vilified for something I have taken so long to deal with and accept. It's isolating this disease. It's not easy to carry it, especially in a time where everyone makes it seem like it's not that intense or that everyone and anyone can live happily with it – that narrative silences those of us who aren't there yet or who are not publicly disclosed. It's just a rollercoaster like I said. But I'm healthier, and I make better decisions for my body and my health as a whole. I've come to terms with it, and I do have to live with it forever at the end of the day."

Student 1's experience mainly highlights the social aspect of LWH and the different things that an individual possibly must navigate, i.e., romantic relationships, the complexity of public disclosure, and the more personal minute adjustments. Both these students' experiences reveal a lack of social support to some degree. Lack of social support, according to Pranka (2018: 5) can lead to social exclusion and, in some cases, marginalisation. Pranka (2018: 5) explains that various forms of social support can be useful in facilitating a "return to one's previous life or a coming to terms with one's new situation," thus overcoming biographical disruption. It is clear from the above extracts that lack of social support has resulted in strained illness experiences.

Student 2, who had enough social support in the form of friends and family, addressed the long-term challenge of LWH and illness experience as follows:

> "I've only told a few of the closest people to me, and they have been accepting. They don't fully understand, though. Most people think you get diagnosed, disclose, and then all is well. People don't realise that it is a continuous process. We, well I, constantly have to deal with this or that relating to my status. I can say that I have healed, but I don't think one fully heals. One day it just hits you that you're different from others and that you depend on pills and then the emotions come. It's like an up and down. There are highs and lows, and the people in my life think it's a once-off event that happens when you first get diagnosed. So, they try, but they will never fully get it unless they experience it."

This student raises a key point of living with a chronic illness, especially one without a cure – the long-term challenges and effects of LWH. Nettleton (2013: 74) calls this the long-term course of suffering. Burton-Jeangros *et al*. (2015: 2) claim that a combination of physiological and social resources that individuals can rely upon influences their ability to adapt to illness and that responses to illness range between vulnerability and resilience – highlighting and advocating for the circular nature of illness experiences and healing rather than the linear form. The authors further explain that individuals' illness trajectories unfold differently in different pathways of life thus can "fluctuate in an unclear trend among individuals who experience successive episodes of good and poor health" (Burton-Jeangros *et al*., 2015: 2).

The participants' narratives demonstrate that once one's life has been disrupted by the illness that they are experiencing, such as HIV and AIDS, one goes through a process where "the individual's narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose" (Williams, 1984: 179). This process helps the individual deal with the disruption and create a “new identity” in relation to their illness as some illnesses do change almost everything in one’s life. Williams (1984: 181) further explains that one’s narrative about their disease has to revolve around the medical world within which the illness is defined. In this research, this is illustrated by references to ARVs, symptoms, and side effects as well as interactions and relationships with healthcare professionals. Pierret (2003: 8) explains that the inquiry into meaning does not prohibit references to the discourse of medical professionals. Instead, personal narratives may broadly include medical professionals as key figures illness experiences.

Kelly and Field (2004: 251) describe how chronic illness also involves changes in self-conceptions, which are “reciprocal to bodily experiences, feelings, and actions”. In other words, the individual goes through a process of transformation in their body, feelings, and actions due to chronic illness. Furthermore, an illness may also result in a shift in the way the individual is perceived and defined by others. All of which contributes to the way an individual experiences their illness. Another factor that significantly affects the illness experiences of PWLH, as mentioned in Section 6.2, is the battle of the invisibility of HIV. Kelly and Field (2004: 260) explain that a well-controlled illness like HIV, through optimum adherence of ARVs, shows that the disease is virtually invisible to all but the individual and intimate others who know about it. Hence the identity of the individual may remain unchanged; however, this may result in the individual’s sense of self being intricately tied to the routines attached to managing the illness with physical activities like taking the pill daily, monthly check-ups, blood results, etc. The assertion made by Kelly and Field (2004: 260) is that “as long as the self-management practices remain private or concealed in ordinary interactions, the identity of a well person can be maintained”. The invisibility of HIV in this instance then allows the individual to maintain their public image.

An observation made during the analysis of interviews is that the older participants, i.e., staff members who have also been LWH for much longer than the students, expressed more comfort with their HIV-positive status. This could be attributed to a myriad of reasons such as “wisdom that comes with age”, as a staff member put it, as well as having lived with the diseases longer, therefore having had more time to reconstruct narratives positively. Thus, the significance of age and years LWH cannot be ignored in understanding illness experiences.

The participants also shared experiences of one or more of the four key areas that individuals suffer from: leading restricted lives, experiencing social isolation, being discredited, and burdening others as identified by Charmaz (1983: 168).

1. **Leading restricted lives**

Charmaz (1983: 168) explains that following the disruption of illness, individuals become aware of the limitations that come with their new reality. For some, the things they valued and enjoyed in the past cannot be enjoyed in the same way, or at all. Charmaz (1983: 168) asserts that these tangible restrictions become daily reminders of the disease, the lessened freedom, and for some, the diminished self that individuals experience. Student 4 describes the limitation as follows:

> "If I'm a hundred percent with you, the diagnosis comes with like other things attached to it like taking treatment every day so I can't like other people go out and be in the streets till 4 am in the morning and not have to worry… that aspect of carefreeness I feel like has been stolen from me, especially thinking about my youth. I'm in what is said to be my prime so I've kind of had to conscientize myself. I've had to you know to apply a certain growth mindset as to how I have to live on a daily basis that other individuals don't necessarily have to…that's the kind of freedom that like they have opposed to me, and that's my reality every day. I'm not saying that's it is negative, but it's what I have to go through because of my diagnosis."

The above student's feelings resonate with all the other participants who have recently been diagnosed, i.e., less than five years LWH. All the participants (including those who have been LWH for more than five years) shared how in the early stages of the diagnosis, they experienced restricted living to some degree. However, for those who have been LWH for much longer, the restrictions decrease as the years go. This was attributed to the development of positive coping strategies or mechanisms. According to Martz and Livneh (2007: xvii), persons living with a chronic disease develop coping mechanisms from as early as the diagnosis stage. Coping can take many forms – for some, and it is growth-oriented, where the focus is on problem-solving and thinking positively about the possibilities available in the future. For others, the coping mechanisms are negatively weighted whereby individuals avoid certain situations and catastrophize (Martz & Livneh, 2007: xvii).

Some participants' narratives unveiled that their lives are sometimes more restricted than they need to be due to negative perceptions of self and internalized stigmas.

2. Experiencing social isolation

Experiencing social isolation is often a consequence of living a restricted life. The more restricted one's life is, the more isolated they will feel. Another factor contributing to social isolation, according to Charmaz (1983: 177), is the amount of time individuals spend on medical regimens. The claim is that this is isolating for three reasons: being on medication sets an individual apart from others, treatment takes place in the privacy of a home away from people, and it is a personal experience that focuses the individual's attention on self. In the participants' narratives, this aspect of suffering is commonly linked with depression and anxiety, which, Ofovwe and Ofovwe (2013: 180) found, are significant co-morbidities in HIV and AIDS. Both have far-reaching implications as they have been found to correlate with lower adherence to ART, which in turn results in poorer health, social isolation, and faster progression from HIV to AIDS (Ofovwe & Ofovwe, 2013: 180). Additionally, depression has been reported to be a severe manifestation of the HIV disease progression (Sahay *et al*., 2007: 12).

3. Discrediting definitions of self

Discrediting definitions of self from interactions with others or developing from unmet expectations of the ill individual often lead to a loss of self among people living with chronic diseases. Charmaz (1983: 181) points out that discreditation is not only displayed in diseases that have physical impairments which readily result in stigmatised identities. Rather, discreditation is also found in individuals who experience a decreased and marginal participation in the normal world. In this study, the participants who had been LWH for less than 5 years expressed experiencing the latter as all of them had no visible markers of LWH.

4. Becoming a burden

In Charmaz's work, becoming a burden "essentially involves becoming more independent and immobilised" (1983: 188). The participants in this study, however, stressed the psychological burdens of LWH both for the individuals themselves and for those close to them. Student 3 shared:

> "Maybe I am depressed, I don't know… I wonder if other people LWH go through this. And I can't even tell if it's the HIV or the depression speaking right now all I know is that this came with the diagnosis. My life was simple before. Yes, I had challenges and stresses but nothing of this kind. So, that's what it means to me [living with HIV]. It means being burdened even though the viral load is decreasing. Like, scientifically,

> there's less and less HIV in my body, but emotionally and psychologically, it's like the HIV is increasing. Every decision you make has to include thinking about your status. It's exhausting."

Student 1's experience highlights all four areas of suffering that Charmaz (1983: 190) discusses:

> "I don't want to have to explain to someone that like this is what I am going through and this is what I'm living with. I feel like that's still a very huge thing to be entrusting somebody with. Not to say, like okay I've never had a partner sure I did, that was in my first year but like yah they also revealed some things about themselves which are very similar so it worked in that sense because…but for other individuals I've had to like kind of just gage… I'm in a zone or moment of being kind of like selfish and being about myself at this current point and time because I don't know he [potential partner] will react to me, two they are a student and having student things to deal with, imagine now like adding an individual living with this. That's a stress that I don't want to have another individual carry or like anxiety or stress that comes with being with me and thirdly it's just like a comfortability aspect of it. I don't know how the next person will react even though people are understanding I don't have to have to expose myself to a situation where I am possibly stigmatised and have to relive that experience yeah and by me saying I don't have like a regular life for me it often means sometimes I have to say no perhaps going out you know… I don't want to possibly endanger my health. I feel like that's where it basically ends. It extends more to like a very social aspect than the individualistic because of some of the limitations that you have to always self-guard yourself with and almost practice every day and have to become habit for yourself. I feel like this is why I keep myself so busy so that I don't have to feel like I am not a part of like a greater holistic form of living as an individual."

This section has demonstrated the different ways in which illness experience manifests in individuals' lives. Additionally, the section made links between participants' experiences and Charmaz's key areas of suffering, to demonstrate how these play out for some individuals LWH.

FIGURE 11: SUMMARY OF SUB-THEMES

10.5 CONCLUSION

This chapter has demonstrated how an HIV-positive diagnosis disrupts an individual's life and consequently leads to the reconstruction of self, narratives, and embodying illness experience. It is worth emphasizing that illness experience does not only speak to a moment or event; instead, it speaks to an individual’s life holistically where their disease is concerned. Therefore, even though this chapter specifically discusses illness experience, the discussion forms a part in a whole just as this research in its entirety speaks to a part of the participants’ illness experience. This chapter has also echoed Kelly and Field’s (2004: 256) argument that illness is a multi-phenomenal experience and, therefore, a multi-layered object of analysis. Therefore, those who have the illness and experience the physical, psychological, and pathology thereof will experience and narrate their illnesses in a variety of ways.

Having explored how individuals reconstruct their narratives after a biographical disruption, the importance of Chisaka and Coetzee’s (2009: 110) claim is stressed, that “biographical disruption does not necessarily result from chronic or serious illness” there are in fact other factors that lead to it and these are influenced by one’s demographics too. When looking at illness experiences, it is easy to generalise and use blanket statements however, exploring each case individually reveals more than the presented literature provides. As shown, age and the number of years an individual has been LWH are significant contributing factors to illness experience. This is one category, but there are many more than can be and will be explored in other chapters. This proves that personal narratives about illness are embedded in more than just one’s illness but also in one’s social context – the local world in which one lives (Toombs, Barnad, & Carson, 1995: 18). In the same breath it is evident that being at Rhodes University plays a crucial role in the way individuals experience and live with the disease. The environment allows for more freedom and openness than other contexts.

The recurring themes in the participants’ narratives were perceived depression, uncertainty and psychological neglect. These were apparent in all the participants’ narratives however, the extent to which this is the case is dependent on various factors such age, sex, years LWH, and whether or not individuals had disclosed their status to close ones.

CHAPTER 11: CONCLUSION AND RECOMMENDATIONS

"The future of the HIV response will also require looking beyond HIV care provision and ensuring that the disease response is embedded in universal health coverage. Ending AIDS is unlikely to ever happen without an integrated health system that provides HIV prevention, diagnosis, and treatment as well as care with other essential health services. As well as support to other co-morbidities such as TB, NCDs, and mental health at the community level. A people-centred, human rights-based and holistic approach is crucial."

Dr Naoko Yamamoto, Assistant Director-General for Universal Health Coverage and Health Systems, WHO.

11.1 INTRODUCTION

This chapter concludes the thesis and offers recommendations for future studies. The study primarily aimed to explore HIV-positive staff and students' experiences and perceptions of living with HIV at Rhodes University. The study also sought to explore strategies (and responses thereof) to address HIV and AIDS at Rhodes University, stigma and discrimination, and last, to uncover whether and how people living with HIV at Rhodes University reconstruct their narratives when they are at the institution. The lived experiences of participants were analysed from the social constructionist perspective, symbolical interactionist perspective as well as using the biographical disruption theory. The qualitative research paradigm and the use of face-to-face interviews specifically, we appropriate and suitable in line with the theoretical underpinnings and the nature of the research questions of this study.

This final chapter begins with methodological considerations and critical reflections thereof. The chapter also offers recommendations on how the lives of PLWH at Rhodes University can be improved. Additionally, a discussion on the strengths, limitations, and suggestions for future studies in this area is offered.

11.2 METHODOLOGICAL CONSIDERATIONS AND CRITICAL REFLECTIONS

Lived experiences and narratives are sensitive and personal (Given, 2008: 471), more especially HIV-narratives and experiences. Thus it was crucial to employ a methodology that is cognizant of the sensitivity. For this reason, the in-depth face-to-face interview was the most appropriate and suitable tool as it firstly allowed the researcher and the participant to form direct rapport and get to know each other better. Because I was unknown to all but one of the participants, introducing myself and establishing that even though I am a researcher conducting a study, I am also a member of the Rhodes University community aware of the culture and environment was important. For the student participants, it proved to be a commonality between us, which allowed me to understand some social and colloquial nuances such as the references to the Rhodes University Confessions page, the local dance clubs and restaurants etc. For both the student and staff member participants, my introducing myself was received well and created a safe space for both of us – which is a critical element of qualitative interviewing (Given, 2008: 471).

I specifically made it clear to all participants that while they were in an interview, there was an allowance for conversation and for most participants this created a space for them to not only be more open but to also ask questions. An example is my interview with Staff member 3, who at the end of her interview, with her friends, enquired about me at a personal level and questions regarding my family, study interests, and experiences in the Makhanda broader community (outside the university) were asked. This kind of engagement would not have been possible or as effective using a different method of data collection, such as surveying and ethnography for example.

The nature of the interview itself was structured such that the first set of questions were general and about the individual beyond their HIV-status. In these questions, the aim was to get to know the individual outside the Rhodes University context and to accomplish rapport. Thus, questions about their children, families, communities were asked. In instances where there we commonalities between myself and the participants, I would share these without taking the attention away from the participant. This style of interviewing largely closed the gap between myself and the participants, and I could see the participants become more and more comfortable with me. Prior (2017: 6) explains that affiliation and empathic displays can be a critical means by which the research participant can she personal information more comfortably.

All participants were asked how they felt about taking part in the study and sharing such an intimate part of their lives at the beginning of the interview, following the introductory set of questions. At the end of the interview, each participant was asked, again, how they felt about having shared their stories with me. These two questions were important not only for the research but for me as the researcher because they were a tool for getting feedback on how to improve the next interview or study conducted. Stuckey (2014: 1) shares that analysis begins after the first interview when the researcher examines whether participants are responding to the research questions or whether the interview guide needs to be refined. Asking participants how they felt following the interview highlighted one of the recommendations for this research – the need for safe spaces for PLWH in the university. Additionally, I realised how empowering it was for participants to be asked such questions and questions about what they would like to see more of on campus – a student shared that it was not common to be included in decisions and discussions about how to improve programmes and initiatives for PLWH on campus. A staff member also shared that it was the first time she had spoken about her illness experience and that she did not realise how much emotion she was harbouring until the interview. As a researcher, this is a success and strength of this research (to be discussed in Section 11.5).

Another significant strength of the research was the depth of information gathered (to be discussed in Section 11.5). A contributing factor to this success was the sample size. Due to the sample size of 10 used in this study, I was able to form an intimate relationship with each of the participants. As mentioned in Chapter Four, this study followed a purposive sampling strategy where participants voluntarily joined the study based on their capacity to share their narratives and experiences of LWH. Through this, richly textured data was gathered. In line with this, Vasileiou *et al*. (2018: 2) assert that qualitative sample sizes "should be large enough to allow the unfolding of a new and richly textured understanding of a phenomenon under study, but small enough so that the deep case-oriented analysis of qualitative data is not precluded". The sample size of this study was such that it was small enough to procure rich and usable data from each participant.

As mentioned in Chapter Four, each participant chose their interview setting. Giving participants the option to select a location they were most comfortable with was a form of power-sharing between myself and the participant to provide the participant with the autonomy to decide where and how they shared their stories, which positively affected the quality of the interview.

To ensure transparency, trustworthiness, and credibility of the study, the research was reviewed by two institutional ethical committees, namely: The Sociology Department Ethics Sub-committee and the Rhodes University Ethics Standards Committee (RUESC). Furthermore, to guarantee the safety of participants, gatekeepers were approached to act as the liaison between myself and participants. Throughout the research process, the participants' interests were a priority to me. To ensure confidentiality, I was the sole researcher conducting the interviews, transcribing, and translating the data as well as analysing it. Stuckey (2014: 1) explains that as each interview is completed, the researcher "examines its content to determine what has been learned and what still needs to be discovered or needs elaboration". Consequently, interviews with the key informants took place after I had interviewed all the participants and transcribed their interviews; therefore, the interviews with key informants were informed by empirical findings from the data. It is worth mentioning that I kept a journal where I would record notes during interviews and reflections at the end of each interview. This journal was particularly useful to keep record of each interview and also alleviated the distress that I experienced as a researcher during some of the emotionally charged interviews. During analysis, the journal entries helped recreate the moment with each participant.

Overall, the chosen methodology produced the desired outcomes and ensured that each of the research goals was adequately responded to. In the following section, I offer recommendations from the empirical data, which might work towards improving the lives of PLWH at Rhodes University.

11.3 RECOMMENDATIONS

The recommendations made in this study are in line with the assertion by the GNP+ (2012: 16) proposal that while understanding the nuances and changes in HIV epidemiology is essential, understanding the dynamics of the HIV epidemic in different and even smaller contexts is a critical step to knowing the kinds of scenarios PLWH are experiencing and how to provide adequate and appropriate support. The following sections offer recommendations (thematically categorised) that could improve the lives of PLWH at Rhodes University.

11.3.1 Recommendation 1: Safe space for PWLH

The findings in this study show some of the complexities and difficulties of LWH, and specifically LWH within the Rhodes University context, in the process of coming to terms with their HIV-positive diagnosis and reconstructing their narratives. The participants shared experiences of emotional disruption following diagnosis and the emotional burden of LWH. While the university has interventions in place such as the Counselling Centre, Peer Educators and HIV campaigns, the participants expressed the need for a holistic approach to managing and supporting those LWH. In addition to the existing initiatives and structures, HIV-specific psychological interventions for PLWH such as support groups or buddy systems, were identified as a need. The participants demonstrated a need for continuous emotional support, or a community made up of other PWLH, as they navigate LWH and the progression of the disease. Perhaps an introduction of such structures will help PLWH overcome self-stigma, which, as demonstrated in Chapter Nine, is common among participants, especially those who had been living with HIV for less than five years. Such spaces also have the potential to assist PLWH to navigate disclosure, which is characterised by complexities, as discussed in Chapter Three.

11.3.2 Recommendation 2: Visibility of HIV-programmes and interventions

This research has also demonstrated that Rhodes University has structures in place to address HIV-related issues, including an HIV policy, the Health Care Centre, Counselling Centre, and Peer Educators. The participants in this study, however, expressed having limited knowledge of these structures and the work done by them. It was also described that these structures become more visible once one tests positive, thus suggesting that the wider Rhodes University community may have limited knowledge and understanding of the structures and their offerings. This recommendation, in line with Buldeo and Gilbert (2015: 209) who follow that institutions cannot be complacent in addressing HIV (prevention, management, care, etc.) as the sexual and social behaviours of sections of university communities puts both PLWH and the greater community at risk of infection and stigma and discrimination. The visibility of HIV-programmes and interventions will also educate the wider Rhodes University community about HIV and AIDS and the developments thereof, which will, in turn, contribute to the fight towards ending HIV and AIDS.

11.3.3 Recommendation 3: Collaboration between PLWH and the university

Being at Rhodes University plays a crucial role in the way individuals experience and live with the disease. The environment allows for more freedom and openness than other contexts. Furthrmore, accessing treatment from the Health Care Centre has had a positive impact on the quality of life of participants. That being said, participants expressed a need for collaboration between PLWH and the different stakeholders or departments within the university which offer services catering to the needs of PLWH. By partnering with PLWH, the university would be creating an oppportunity to firstly ensure that PLWH have an active role in structures implemented for their needs and, secondly, alleviates the pressure on the university to present the university community with solutions. This will also bring awareness to the wider community that there are PLWH in the University campus while also empowering those LWH to educate others, disclose and fight stigma and discrimination.

11.4 SUGGESTIONS FOR FUTURE RESEARCH

In conducting future research in this area, it would be useful to address some of the gaps in knowledge identified in this study. As mentioned in Chapter One, much of the existing literature about HIV and AIDS, especially in the university context, presents PLWH as passive individuals who are studied, yet not given much room to speak of their experiences of living with HIV and AIDS and responding to the different strategies and policies put in place to address a condition that they are living with. Therefore, while the current study contributes to the school of knowledge by giving participants the autonomy to speak, more studies of this nature are needed.

There is a need for research to develop and measure the effectiveness of HIV programmes and interventions at the university; therefore, both qualitative and quantitative studies with PLWH at the university could be conducted. Moreover, to gauge whether the existing interventions and programmes at the university are efficiently reaching a wider audience (apart from those LWH), a study including the general student and staff population would be effective.

Replication of this study with a bigger sample, and a wider variety in the characteristics of the selected participants to reflect the Rhodes University community diversity, would be useful in understanding wider experiences and perceptions of LWH at Rhodes University. The suggestion is that future studies explore how variables such as class, age, race, nationality, disability and even years LWH affect illness experiences and responses to interventions for PLWH. Such studies would explore a sample of both those accessing ARVs from the Rhodes University Health Care Centre as well as those students and staff of the university assessing treatment from local facilities such as private GPs and public clinics.

Finally, this study was focused on Rhodes University alone. The experiences of PLWH at Rhodes University may well be different from the experiences of PLWH in other Higher Education Institutions. Therefore, further qualitative research to understand the experiences of LWH at other universities may also make a significant contribution to the school of knowledge.

11.5 STUDY STRENGTHS

This is the first study that explored the lived experiences of PLWH at Rhodes University using the social constructionist approach, symbolic interactionist approach as well as the theory of biographical disruption. The study has successfully fulfilled its goal to offer PLWH the opportunity to contribute to the HIV discourse and narrative at the university. Furthermore, the feedback from participants and key informants revealed that the study exceeded expectations by additionally creating a safe space for discussion and reflection both for the PWLH and for the key informants.

11.6 STUDY LIMITATIONS

While the sample size produced the desired results, the study initially sought to interview at least 12 participants, however, only 15 agreed to take part in the study and of those, only 10 were interviewed. Three student participants withdrew their agreement to participate in the study and the reasons included not being ready to talk about their HIV status, not being in a good place emotionally and being preoccupied with academics. The other two participants were not reachable on the cellphone numbers provided in the agreement form.

The World Health Organization (WHO) on March 11 declared COVID-19 a pandemic. As a result, Rhodes University brought forward its first term recess to 18 March 2020. When the President of South Africa announced a National State of Disaster in response to the COVID-19 Pandemic on 26 March it became apparent that we would not be able to resume face-to-face teaching. The university had to migrate teaching and learning to remote and digital delivery platforms. This affected the recruitment of more participants and the initial plan to do follow up interviews with the participants who had already been interview. Furthermore, the pandemic added more pressure to the small university clinic thus limiting the researcher to only interview the Head Professional nurse, instead of all nurses as had been the plan.

Lastly, while the findings of this study may be relevant in other contexts, these are solely experiencing and perceptions of the interviewed PLHW at Rhodes University.

11.7 CONCLUSION

The participants' narratives revealed a positive and inspirational side of living with HIV and AIDS – especially emphasizing that PLWHA do not have to surrender to the deadly narrative of the disease. The narratives also revealed that stigma, both internal and external, largely influences illness narratives. Furthermore, the study revealed the social reconstruction of life narratives both in order to understand the illness in terms of past social experiences and to reaffirm the impression that life has a course and the self has a purpose. All the participants in this study found that accessing treatment from the Rhodes University Health Care Centre positively influenced their experiences of adherence and reconstruction of narratives.

The study indicates that HIV-related interventions in place at the university need to pay more attention to the psychosocial needs of PLWH, involvement of PWLH, as well as keeping up with the continuously changing global HIV narrative. The study argues for more attention to in-depth experiences and personal narratives in HIV and AIDS and PLWHA education at Rhodes University.

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APPENDICES

Appendix 1: Recruitment letter to participants

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Dear Participant,

Working Title: Understanding the lived experiences of HIV-positive students and staff at Rhodes University.

My name is Lindiwe Tsope (student no. g13t0193). I am a PhD Candidate in Sociology at Rhodes University under the supervision of Professor Michael Drewett (**m.drewett@ru.ac.za**) and writing to request your assistance in conducting this study. Furthermore, this letter serves to inform you about the purpose of the research and what you might expect from me regarding ethical practice, should you agree to participate in the study. I have asked Sister Ferreira and/or Mr Mzizi to communicate the intentions of the study and your role in the study however, this letter serves to ensure that you also have a copy of the information in writing. Please be aware that should you decline participation in the study, I will not know who you are. I will only know who you are once you have signed the agreement form attached which states that you are happy for me to contact you.

The intention of the study is to focus on the personal and social symbolisms and meanings attached to living with HIV by members of the Rhodes University community. I am particularly interested in Rhodes University's institutional responses to HIV and its HIV prevention, support and management initiatives on campus. Moreover, I am looking to understand how you have experienced the above factors.

The research is predominantly reliant on the participants' perceptions and voices and therefore will use in-depth interviews and advocates for the inclusion and prioritisation of people living with HIV in conducting research on issues that directly affect them.

In utilising this methodological approach, it is envisioned that the final report, based on the collected data, will provide evidence-based beneficial information that can assist relevant stakeholders in making Rhodes University a better institution for current and future students and staff members living with HIV. Considering this, I am hereby writing this letter to kindly request you to consider being a participant in this study.

I assure you that I will strictly preserve the anonymity of my participants by employing pseudonyms and by removing any personal information from transcripts that might in some way identify you as participant as I will transcribe these interviews personally. I will ensure that you are not identified or identifiable in the final research paper. I undertake to treat your stories with respect and confidentiality during the process of transcription, analysis and storage of my data. Participation in this research is of course entirely voluntary and if at any stage you wish to withdraw your consent for some reason you are fully entitled to do so.

The following **ethical standards** will be put into place:

I assure you that I will strictly preserve your anonymity by employing pseudonyms and removing any personal information from transcripts that might in some way identify you as a participant.

I undertake to treat your story with respect and confidentiality during the process of transcription, analysis and storage of my data.

Participation in this research is of course entirely voluntary and if at any stage participants wish to withdraw consent for some reason they are fully entitled to do so.

Only the researcher (myself) and Professor Michael Drewett will have access to the raw data. However, Professor Drewett will not have access to the identity of the participants.

Motivations for risk and risk precaution

As a researcher I have conducted similar research with participants living with HIV in the previous years and I have ensured that participants were aware of their role, risks and benefits as well as the researcher's role. Furthermore, I also emphasised the points raised in the consent form. Both in my Master's research and the proposed research I am not interested in how you contracted the virus, rather your experiences following the diagnosis. I previously ensured, and will do so again, that the interviews do not coincide with any significant event in the participant's life that may trigger negative emotions such as the date in which they were diagnosed, exam period, the silent protest (in the case of gender-based violence), or any other dates that participants would not be happy to share their stories. Therefore, in our setting up of interviews I would appreciate it if you could pick a time that suits you.

As the researcher I am mindful that the interview process may trigger feelings regarding living with the illness and I have consulted with the Counselling Centre to provide counselling should you need it. Furthermore, I understand that disclosing your HIV-positive status to me may be concerning in terms of trust and confidentiality hence I give you my word that only I will know and have access to the raw data (the agreement forms, notes, transcripts). My supervisor and readers of the research will not have access to this information and will not be able to identify you as I will omit any information that may make you identifiable such as your name, residence, faculty, department etc. I will ensure that in the study you are referred to in pseudonyms which are made up names. Should your participation in the study cause any harm you are welcome to withdraw from the study or pause the interview until you are ready to proceed. You are also allowed to choose not to answer questions that you are not comfortable discussing.

While there is no remuneration in your participation I hope that the you will see value in your contribution to academic work and potentially influence in the University setting. Furthermore, I hope that you will be happy to be involved in how the HIV-narrative is constructed, particularly because I embrace the notion of “Nothing about us without us”, meaning that I believe that HIV related research cannot be done without those directly affected.

I look forward to receiving your consent for carrying out this study, with your assistance. Your approval will be very much appreciated. If you have additional questions, I can be reached at 083 331 0389 or by email at lindiwe.tsope@gmail.com. Alternatively, you can contact my supervisor, Associate Professor: Sociology Department, Rhodes University Prof. Michael Drewett, at 046 603 7549 or by email at m.drewett@ru.ac.za.

Thank for your time and consideration.

Sincerely
Lindiwe Tsope
Lindiwe.tsope@gmail.com
0833310389

Appendix 2: Staff agreement form

RHODES UNIVERSITY
Where leaders learn

Department of Sociology
Prince Alfred Street, Grahamstown, 6139, South Africa
PO Box 94, Grahamstown, 6140, South Africa
t: +27 (0) 46 603 8361
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www.ru.ac.za

Interview Release Form for staff member participants

As a Rhodes University staff member living with HIV who is 18 years and older and has opted to disclose my status and share my experiences, I hereby give permission to:

Name ____
Principal Researcher____
Address ____
Phone _________________________ E-Mail _________________________________

1) to interview me and record my voice,
2) and to use my direct quotes from the interview for writing a research report for the PhD thesis,
3) and not to use my full name, but pseudonyms in connection therewith,
4) I will make no monetary or other claim for the use of the interview and recording of my voice,
5) I reserve the right to decline to answer certain questions and to stop the interview if I become uncomfortable.

Name of Person to be Interviewed:

Print Name: ____
Signature:
____

Witness:
Print Name: ____
Signature: ____
Date: ____

Appendix 3: Student agreement form

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<u>Interview Release Form for student participants</u>

As a Rhodes University student living with HIV who is
18 years and older and has opted to disclose my status and share my experiences, I hereby give permission to:

Name ____
Principal Researcher____
Address ____
Phone _______________________ E-Mail ___________________________________

1) to interview me and record my voice,
2) and to use my direct quotes from the interview for writing a research report for the PhD thesis,
3) and not to use my full name, but pseudonyms in connection therewith,
4) I will make no monetary or other claim for the use of the interview and recording of my voice,
5) I reserve the right to decline to answer certain questions and to stop the interview if I become uncomfortable.

Name of Person to be Interviewed:

Print Name: ____
Signature:
____

Witness:
Print Name: ____
Signature: ____
Date: ____

Appendix 4: Letter to HCC

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Heather
Ferreira
Head Professional Nurse
Rhodes University
P.O Box 94
Grahamstown
6140

15 August 2018

Ref: Request to circulate on my behalf the call for participation by students and staff living with HIV and accessing ARV treatment at the Health Care Center.

Dear Ms Ferreira,

Working Research Title: Debunking the lived experiences of HIV-positive students and staff at Rhodes University.

I would like to thank you for meeting with me to discuss my research topic and goals. Your insight and time are greatly appreciated.

My name is Lindiwe Tsope (student no. g13t0193). I am a PhD Candidate in Sociology at Rhodes University under the supervision of Professor Michael Drewett (**m.drewett@ru.ac.za**) and writing to request permission to work with the Health Care Centre staff, as gatekeepers, in conducting my research.

The intention of the study is to focus on the personal and social symbolisms and meanings attached to living with HIV by members of the Rhodes University community. I am particularly interested in Rhodes University's institutional responses to HIV and its HIV prevention, support and management initiatives on campus. Moreover, I am looking to understand how the above factors have been experienced by individuals.

The research is predominantly reliant on the participants' perceptions and voices and therefore will use in-depth interviews and advocates for the inclusion and prioritisation of people living with HIV in conducting research on issues that directly affect them.

In utilising this methodological approach, it is envisioned that the final report, based on the collected data, will provide evidence-based beneficial information that can assist you and other relevant stakeholders in making Rhodes University a better institution for current and future students and staff members living with HIV. Considering this, as Head Professional Nurse, I am hereby writing this letter to kindly request you to allow me to work with the Health Care Centre staff as gatekeepers for recruiting the identified participants. The role will be such that you, or a nurse of your choosing, will share the attached cover letter and agreement form to students and staff who meet this sample criteria and also notify them that I do not have prior knowledge about them and will only access this information directly from them should they agree to participate in this study, as participation in voluntary.

I would be grateful if you could circulate the cover letter and agreement form to as many potential participants as possible because owing to the sensitivity of this research, I do not have direct access to potential participants. I have also chosen to this form recruiting strategy as it ethically respects the confidentiality of participants.

The following ethical standards will be put into place:

I assure you that I will strictly preserve the anonymity of the participants by employing pseudonyms and removing any personal information from transcripts that might in some way identify a participant.

I undertake to treat their stories with respect and confidentiality during the process of transcription, analysis and storage of my data.

Participation in this research is of course entirely voluntary and if at any stage participants wish to withdraw consent for some reason they are fully entitled to do so.

Only the researcher (myself) and Professor Michael Drewett will have access to the raw data. However, Professor Drewett will not have access to the identity of the participants.

I look forward to receiving your consent for carrying out this study, with your assistance. Your approval will be very much appreciated. If you have additional questions, I can be reached at 083 331 0389 or by email at lindiwe.tsope@gmail.com. Alternatively, you can contact my supervisor, Associate Professor: Sociology Department, Rhodes University Prof. Michael Drewett, at 046 603 7549 or by email at m.drewett@ru.ac.za.

Thank for your time and consideration.

Sincerely
Lindiwe Tsope
Lindiwe.tsope@gmail.com
0833310389

Appendix 5: Letter to HIV Office

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Thandi Mzizi
Institutional
Wellness Specialist
HIV and AIDS & Staff Wellness Office Rhodes University
P.O Box 94
Grahamstown
6140

16 August 2018

<u>Ref: Request to circulate on my behalf the call for participation by students and staff living with HIV and accessing ARV treatment at the HIV Office.</u>

Dear Mr. Mzizi,

Working Research Title: Debunking the lived experiences of HIV-positive students and staff at Rhodes University.

I would like to thank you for meeting with me to discuss my research topic and goals. Your insight and time are greatly appreciated.

My name is Lindiwe Tsope (student no. g13t0193). I am a PhD Candidate in Sociology at Rhodes University under the supervision of Professor Michael Drewett (**m.drewett@ru.ac.za**) and writing to request permission to work with the HIV Office, as gatekeepers, in conducting my research.

The intention of the study is to focus on the personal and social symbolisms and meanings attached to living with HIV by members of the Rhodes University community. I am particularly interested in Rhodes University's institutional responses to HIV and its HIV prevention, support and management initiatives on campus. Moreover, I am looking to understand how the above factors have been experienced by individuals.

The research is predominantly reliant on the participants' perceptions and voices and therefore will use in-depth interviews and advocates for the inclusion and prioritisation of people living with HIV in conducting research on issues that directly affect them.

In utilising this methodological approach, it is envisioned that the final report, based on the collected data, will provide evidence-based beneficial information that can assist you and other relevant stakeholders in making Rhodes University a better institution for current and future students and staff members living with HIV. Considering this, as Institutional Wellness Specialist, I am hereby writing this letter to kindly request you to allow me to work with the HIV Office as gatekeepers for recruiting the identified participants. The role will be such that you will share the attached cover letter and agreement form to students and staff who meet this sample criteria and also notify them that I do not have prior knowledge about them and will only access this information directly from them should they agree to participate in this study, as participation in voluntary.

I would be grateful if you could circulate the cover letter and agreement form to as many potential participants as possible because owing to the sensitivity of this research, I do not have direct access to potential participants. I have also chosen to this form recruiting strategy as it ethically respects the confidentiality of participants.

The following ethical standards will be put into place:

I assure you that I will strictly preserve the anonymity of the participants by employing pseudonyms and removing any personal information from transcripts that might in some way identify a participant.

I undertake to treat their stories with respect and confidentiality during the process of transcription, analysis and storage of my data.

Participation in this research is of course entirely voluntary and if at any stage participants wish to withdraw consent for some reason they are fully entitled to do so.

Only the researcher (myself) and Professor Michael Drewett will have access to the raw data. However, Professor Drewett will not have access to the identity of the participants.

I look forward to receiving your consent for carrying out this study, with your assistance. Your approval will be very much appreciated. If you have additional questions, I can be reached at 083 331 0389 or by email at lindiwe.tsope@gmail.com. Alternatively, you can contact my supervisor, Associate Professor: Sociology Department, Rhodes University Prof. Michael Drewett, at 046 603 7549 or by email at m.drewett@ru.ac.za.

Thank for your time and consideration.

Sincerely
Lindiwe Tsope
Lindiwe.tsope@gmail.com
0833310389

Appendix 6: Letter to Counselling Centre

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Sarah Green
Head of
Counselling Department
Rhodes University
P.O Box 94
Grahamstown
6140

23 August 2018

Dear Ms. Green,

Working Research Title: Debunking the lived experiences of HIV-positive students and staff at Rhodes University.

I would like to thank you for meeting with me to discuss my research topic and goals. Your insight and time are greatly appreciated.

My name is Lindiwe Tsope (student no. g13t0193). I am a PhD Candidate in Sociology at Rhodes University under the supervision of Professor Michael Drewett (**m.drewett@ru.ac.za**) and writing to request permission to work with the Health Care Centre staff, as gatekeepers, in conducting my research.

The intention of the study is to focus on the personal and social symbolisms and meanings attached to living with HIV by members of the Rhodes University community. I am particularly interested in Rhodes University's institutional responses to HIV and its HIV prevention, support and management initiatives on campus. Moreover, I am looking to understand how the above factors have been experienced by individuals.

The research is predominantly reliant on the participants' perceptions and voices and therefore will use in-depth interviews and advocates for the inclusion and prioritisation of people living with HIV in conducting research on issues that directly affect them.

In utilising this methodological approach, it is envisioned that the final report, based on the collected data, will provide evidence-based beneficial information that can assist relevant stakeholders in making Rhodes University a better institution for current and future students and staff members living with HIV. Considering this, as Head of the Counselling Department, I am hereby writing this letter to kindly request to work with you and the Counselling Centre in ensuring that support, in the form of counselling, is offered and provided to the participants to be interviewed should they need to access it. I, as the interviewer, will therefore direct interviewees to the Centre should they indicate to me that they need such support.

I look forward to receiving your consent to include the Counselling Centre and the services offered, in my communication with potential research participants. Your approval will be very much appreciated. If you have additional questions, I can be reached at 083 331 0389 or by email at lindiwe.tsope@gmail.com. Alternatively, you can contact my supervisor, Associate Professor: Sociology Department, Rhodes University Prof. Michael Drewett, at 046 603 7549 or by email at m.drewett@ru.ac.za.

Thank for your time and consideration.

Sincerely
Lindiwe Tsope
Lindiwe.tsope@gmail.com
0833310389

Appendix 7: Participant consent form

Consent Form

Working Title: Understanding the lived experiences of HIV-positive students and staff at Rhodes University.

As a Rhodes University staff member/student living with HIV, by agreeing to participate in this research I understand that:

1. My participation will involve being a part of a face to face in-depth interview with the researcher. If necessary, there will be a follow-up interview, depending on whether or not the researcher has obtained sufficient information.
2. I am giving permission for this interview to be audio-recorded, transcribed by the researcher who will then use the transcribed data (e.g. my direct quotes) to write a Doctoral Thesis.
3. I may be asked to answer questions of a personal nature, but I can choose not to answer any questions about aspects of my life which I am not willing to disclose.
4. I am invited to voice to the researcher any concerns I have about my participation in the study, or consequences I may experience because of my participation, and to have these addressed to my satisfaction.
5. I am free to withdraw from the study at any time should I have concerns about my participation which I did not originally anticipate.
6. Should I feel any emotional discomfort during the interview or study, I can be referred to the RU HIV and AIDS Office. The researcher must however seek my permission if I need that support first prior to this referral. I can also personally consult the RU HIV and AIDS Office.
7. The results will be reported in the form of a submission for the awarding of a PhD.
8. The report on the project may contain information about my personal experiences, attitudes and behaviors, but that the report will be designed in such a way that it will not be possible for me to be identified by the general reader.
9. There is no remuneration for my participation in this research.
10. The information will be recorded and may be used for future references such as a publication.
11. Should I wish to, the researcher agrees to send me reports on the findings of the research which I am contributing to and I am invited to comment.
12. The researcher has fully explained the research aims and given a breakdown of my role in it.

13. I hereby agree to participate in the study.

Signed on (Date):

Participant: ___________________________ Researcher: ______________________________

Appendix 8: Participants interview sheet

Interview Sheet

General:

1. Please tell me about yourself.
2. How are you feeling about taking this interview?

Strategies at Rhodes

3. How familiar are you with the University's HIV and AIDS policy?
4. How do you feel about the way the University addresses HIV-related issues?
5. How is the support system at Rhodes University for people living with HIV or you specifically?
6. Tell me about how you feel when the University hosts HIV campaigns such as the First Things First campaign all around campus?
7. What are your thoughts and feelings about HIV peer educators at the University?
8. Between management, support and prevention of HIV, what does Rhodes University prioritise, in your experience?
9. What can the University change or do better to make your experiences as a person living with HIV better?

Affordability. Regularity. Availability

10. Are you accessing treatment from a private facility, public facility or the Health Care Centre? Why?
11. How does it feel to use this facility?
12. Have you ever experienced a stock-out? What did you do in this case?
13. Have you had to change your treatment since the first time you started? How did you respond to this change?
14. Have you ever had to miss class or work due to HIV-related issues?

Adherence

15. Have you ever stopped taking treatment, why?
16. What motivates you to continue taking treatment?

Stigma

17. What do you think living with HIV means to outsiders (community members, colleagues, etc.)?
18. What does it mean to you that you are living with HIV?
19. From the time you joined the Rhodes community to now, have you ever felt othered or discriminated against because you are living with HIV?
20. How have those close to you responded to you living with HIV over time?
21. What are the stigmas attached to HIV and people living with HIV on this campus?

22. How different is treatment to people living with HIV outside the Rhodes University community?

Reconstruction

23. How has your life changed from the time you were diagnosed to now?
24. How has your involvement in the Rhodes community contributed to your experiences?
25. What are the advantages and disadvantages of living with HIV at Rhodes?
26. What is the biggest adjustment you have had to make to since you joined the Rhodes community

General:

27. How are you feeling after sharing all this with me?

Appendix 9: Key informant interview sheet

RU Key Informants Interview Sheet

Strategies at Rhodes

1. How do you feel about the way the University addresses HIV-related issues?
2. How is the support system at Rhodes University for people living with HIV?

3. What are your thoughts and feelings about HIV peer educators at the University?
4. Between management, support and prevention of HIV, what does Rhodes University prioritise, in your experience?
5. What can the University change or do better to make experiences of people living with HIV better?

Affordability. Regularity. Availability

6. Has the university ever experienced a stock-out? What happens in this case?
7. Tell me about the ART programme at the University?
8. What does the University do to ensure that students and staff know of the HIV-related services offered?
9. How does the University deal with HIV-related infections/illness e.g. opportunistic infections?

Adherence

10. What role does the University (Health Care Centre/HIV Office/DSA) play in encouraging adherence of treatment?

Stigma

11. What do you think living with HIV means to the Rhodes University community?
12. Are there any cases of discrimination against people living with HIV on campus, that you are aware of and how are these addressed?
13. What are the stigmas attached to HIV and people living with HIV on this campus?
14. How different is treatment of people living with HIV outside the Rhodes University community?
15. Many participants have indicated that Rhodes is a safe space for them, what would you say the university is doing differently compared to other contexts?