A PHENOMENOLOGICAL STUDY ON EXPERIENCES OF PEOPLE LIVING WITH HIV AND AIDS: TOWARDS THE DEVELOPMENT OF A USER - LED INTERVENTION MODEL IN THE VHEMBE DISTRICT, LIMPOPO PROVINCE

By

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THESIS

Submitted in fulfilment of the requirements for the degree of

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in

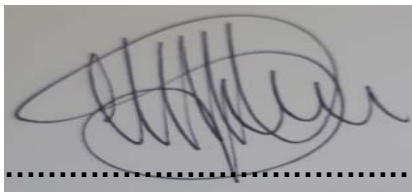## SOCIAL WORK

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DECLARATION

I, Mabogo Mokgadi Germina declare that A **PHENOMENOLOGICAL STUDY ON THE EXPERIENCES OF PEOPLE LIVING WITH HIV AND AIDS: TOWARDS THE DEVELOPMENT OF A USER –LED INTERVENTION MODEL IN VHEMBE DISTRICT, LIMPOPO PROVINCE** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution

……………………………………………   .….07/10/2019…

MOKGADI GERMINA MABOGO   **DATE**

DEDICATION

I dedicate this work to:

- My mother Motlatjo Maria Monyemangene Sikhweni for her unconditional love and support;

- My grandmother Muhanganei Phophi Nesamvuni Sikhweni for teaching me the value of hard work; and

- My father Mutshinyalo Samuel Sikhweni for his unwavering faith in me.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Background information: Persistent poor health outcomes among People Living with HIV and AIDS (PLWH) is a concern for service users and the HIV care system. Since its discovery, different AIDS response strategies were implemented but the level of poor health outcomes among PLWH prompts the need for other dimensions in the AIDS response.

Purpose: The purpose of this study was to explore and describe 'lived experiences' of PLWH in order to utilise their personal experiences to develop a user- led intervention model.

Methods: From a phenomenological orientation, an in-depth interview was used to gather data from seventeen PLWH who are living in communities. Purposive sampling was used to locate the participants. The compiled data collected was then analysed using the Collaizzi's seven-step data analysis strategy. This was followed by a focus group discussion session which was held with nine of the seventeen participants.

Findings: The study found that communities' meaning of HIV and AIDS is outdated as it is still loaded with stigma and discrimination. Consequently, it alienates PLWH living in communities, and thus compounds poor health outcomes among PLWH. Many PLWH view themselves through their communities' meaning of HIV and AIDS. the shared meaning of HIV and AIDS by communities created a complex task for PLWH to reconcile their prior meaning of living with HIV and the 'new' meaning they acquired post-diagnosis. Due to this, many PLWH experience high levels of intrapersonal and interpersonal challenges. Intrapersonal challenges manifest as self and anticipated stigma while the interpersonal ones result in poor relationships in different setting. It was also found that the availability of antiretroviral treatment significantly changed the meaning of living with HIV and AIDS for many PLWH as it provided tangible medical support to mitigate the impact of HIV and AIDS. In addition, the availability of different types of social support from family and non-family sources reassured and gave them

hope for a better life. However, the availability of medical treatment and social support could not completely buffer the intrapersonal and interpersonal challenges experienced by PLWH in their daily lives. They had to continually fight for their social space post-diagnosis through activation of two major coping strategies, namely emotion and problem-solving focussed strategies. Significant features of these strategies are that they changed their thinking patterns and engaged in actual activities to improve the quality of their lives. Through these strategies, many PLWH attained relative post-traumatic growth. This study found that through their lived experiences, they command personal competence to guide user-led HIV care interventions as they clearly articulated the design, content and approach for user-driven HIV care.

Conclusions and recommendations: The psychosocial dimension of living with HIV and AIDS in HIV care is not adequate as many PLWH who are in care experience poor health outcomes long after they have been diagnosed until they received psychosocial support from other PLWH. On this basis, a psychosocial seven-step user-led intervention model was designed to provide psychosocial education, care and support to PLWH, families, support groups and community mobilisation for HIV care. The implementation of a true psychosocial user-led intervention model in the continuum of care which recognises the interaction between the three dimensions of the health condition should be located at the point of entry into HIV care to ensure timeous access by PLWH and their families.

Keywords: phenomenology, HIV and AIDS, lived experience, user –led interventions

CHAPTER ONE

GENERAL ORIENTATION OF THE STUDY

1.1 INTRODUCTION

This study is a response to the persistent poor health outcomes among People Living with Human Immunodeficiency Virus (HIV) (PLWH) and Acquired Immunodeficiency Syndrome (AIDS) in communities, Vhembe District, Limpopo, South Africa. The Joint United Nations Programme on HIV/AIDS (UNAIDS) 2018 report found that since its discovery, HIV and AIDS had caused devastating health outcomes for individuals, families and communities. The same report confirmed that there were approximately 36.9 million people worldwide living with HIV and AIDS in 2017.

The World Health Organization (WHO) 2010 and the Kaiser Family Foundation (2014) confirmed that the HIV and AIDS epidemic was first discovered three decades among gay men, injecting drug users and sex workers. Consequently, the world viewed the epidemic as a disease of the marginalised subpopulations. HIV and AIDS was from the onset accompanied by negative responses, which were conveyed through misinformed languages, symbols and metaphors. Implications for such response is that the general population internalised that HIV infection is a disease of certain groups of people whose sexual behaviour is compromised, as was later established by the Joint United Nations Programme on HIV/AIDS [UNAIDS] (2003), Yebei, Fortenberry and Ayuku (2008), Mbonu, van Der Borne and De Vries (2009) and the Human Sciences Research Council [HSRC] (2015). These inaccurate phrases fuelled stigma and discrimination, and consequently, shaped the meaning of living with HIV and AIDS till to date. Since then De Bruyn (2003), Gallo (2006) and Kaiser Family Foundation (2014) showed that HIV was understood as 'their' disease and not 'ours'. Due to this attitude, UNAIDS (1999), Bourne, Knight, Guy, Wand, Lu and McNulty (2011) and HSRC (2015) found that many people did not want to acknowledge that they can acquire the virus as they understand it as a disease of people of 'immoral' sexual behaviour, people who lack self-control and

of questionable decisions. This complacent attitude as found by UNAIDS (1999), Lyons, Lindsell, Hawkins, Raab, Trott and Fichtenbaum (2008) and the Kaiser Family Foundation (2014) became an escalator for HIV transmission as it swiftly evolved from a concentrated epidemic into a generalised one.

UNAIDS (1999), Chitereka (2009) and Kaiser Family Foundation (2014) confirmed that the ravaging effects of the epidemic later became evident when people in the general population began to get sick and many died. Then the world got into an emergency AIDS response mode which primarily focused on behaviour change and biomedical interventions. As confirmed by UNAIDS (2012) and Statistics South Africa [STATSSA] (2013), the response mitigated a lot of human suffering and averted many deaths, but stigma and discrimination did not subside as negative connotations which accompanied its discovery appear to have received minimal attention. UNAIDS (1994) noted that the need for an additional prevention strategy was acknowledged. This was evident when the UNAIDS (1999, 2004), Coates, Richter and Caceres (2008), Morolake, Stephens and Welbourn (2009) and WHO (2010) advocated that an effective AIDS response should go beyond the two components, and should create a space for PLWH to contribute their personal experiences to shape the AIDS response. The 1994 Paris Summit on AIDS adopted Greater involvement of PLWH (GIPA) in shaping the AIDS response. It was confirmed by WHO (2010) that forty two countries, including South Africa (SA) committed to implement the GIPA principle in the continuum of care. But Morolake et al. (2009) and Berg, Gamst, Said, Aas, Songe, Fangen and Rysstad (2015) later found that the implementation of the true user-involvement was only a handful as many countries, especially developing countries involved them in PLWH programmes as a token. According to Cornu and Attawell (2003), tokenism is a form of non-involvement of PLWH which manifests in two ways. First, tokenistic involvement is where PLWH are assigned management positions because they are living with HIV and AIDS, but do not have access to the decision-making process. They do not have influence on policy, programming or financial issues. Second, tokenism also includes visibility; for example, PLWH attend meetings, give testimony and attend conferences, but are not allowed to speak on behalf of the organisation with which they are involved.

Consequently, as shown by UNAIDS (1999, 2004) and Gohain and Halliday (2014), poor health outcomes, especially those of a psychosocial nature continued to escalate. As asserted by Merriam, Bradley, Courtney and Reeves (1997), Dorrel, Earl, Katz and Shirley (2008), Habib and Rahman (2010) and Moonaghi, Areshtanab and Jouybari (2014), the escalation of poor health outcomes among PLWH arises from the simplistic assumptions by healthcare providers about what works for PLWH, especially the psychosocial care and support component in HIV care. Consequently, the HIV diagnosis as shown by the WHO (2004, 2010) still means what it meant when it was first discovered three decades ago. The WHO (2004, 2010) and UNAIDS (1999) asserted that the true implementation of the GIPA principle is not supposed to be an afterthought in the continuum of care as it is intended to improve the psychosocial functioning of PLWH, but is a fundamental component of the AIDS response. The Lived experiences of PLWH thus provide a blueprint of true user-involvement in the continuum of care which actively recognises the interaction of all dimensions of HIV and AIDS, in particular the bio-psychosocial component.

Primary Health Care Systems (PRIMASYS) (2017) found that Post-1994, the South African (SA) democratic government adopted the 1978 Alma Ata declaration which emphasises access to health services. The SA government provides health services to its citizens through the Primary Health Care (PHC) system with infrastructure which is nurse-based and doctor-supported. Nongovernmental organisations (NGO) and Community based organisations (CBO) are the main PHC stakeholders. Common models of GIPA which are practised in many developing countries identified by Cornu and Attawell (2003) include access, inclusion, participation and involvement models. In SA HIV care services is provided within the PHC in collaboration with NGOs through the four models. The PHC is the major custodian of the Access model, while the Inclusion, Participation and Involvement models are practised mainly by the NGO located in different areas. Despite this setup, PLWH continues to experience poor health outcomes. This justifies a different approach to HIV care interventions.

1.2 BACKGROUND AND MOTIVATION

It has been observed that in general, many people living with Human Immunodeficiency Virus (HIV) delay to seek medical and psychosocial intervention due to various reasons. When they ultimately do, many do not stay in care. A few of those who stay in care struggle to cope with the meaning of the HIV diagnosis, stigma and discrimination, disclosure decisions and adherence to medication, among others. Consequently, they continue to present with poor health outcomes even when they are in care. Due to the persistent poor health outcomes, many of them get lost from the HIV care system. They later resurface again into HIV care when the disease has progressed into the terminal stage. Based on this observation, it is concluded that the continuum of HIV care shows a gap with regard to its ability to recruit and keep people living with HIV (PLWH) in care. These observations were made by the researcher while working in the generalist Social Work settings and specialised employee health and wellness public services.

These observations were also acknowledged by numerous authors such as Corn and Attawell (2003), Tan and Wu (2005), World Health Organization [WHO] (2010) and Sanchez (2010) when they cautioned that HIV care is not only about using condoms and adherence to medication, but also about dealing with other factors which impede HIV care. In particular, they identified the need to have adequate access to a combination of bio–psychosocial intervention services which help PLWH to disentangle from the post-HIV diagnosis reactions and related coping challenges. Subsequently, they recommended active involvement of PLWH in the continuum of HIV care to augment the disease based model HIV care. This recommendation was further supported by the British Psychological Society, the British HIV Association and Medical Foundation for AIDS and Sexual Health (2011), UNAIDS (2012) and Khanna and Madoori (2013), who asserted that the involvement of PLWH in HIV care is cost-effective, efficient and in some instances surpasses the standard intervention models provided exclusively by healthcare professionals. Despite such recommendation, Kaufman, Cornish, Zimmerman and Johnson (2014) later found that popular HIV care intervention models are still mainly disease-based wherein healthcare professionals

provide crisis interventions and support for a brief period to reach treatment goals. Gohain and Halliday (2014) found that such did not adequately meet the complex needs of PLWH. Several authors such as Merriam et al. (1997), UNAIDS (1994,1999), Morolake et al. (2009), Habib and Rahman (2010) and Berg et al. (2015) concurred that the HIV diagnosis is accompanied by new needs which require unique interventions. In support, Greene, Derlega, Yep and Petronio (2003), Stephenson (2009), Feyissa, Abebe, Girma and Woldie, Feisal (2012) and Yi, Chhoun, Suong, Thin, Brody and Tout (2015) acknowledged that if such needs remain unmet, they may deteriorate into poor health outcomes among PLWH such as experiences of stigma and discrimination, difficulties with HIV diagnosis disclosure, poor treatment adherence, alcohol and drug abuse and mental health problems, among others.

1.3 OPERATIONAL DEFINITION OF CONCEPTS

1.3.1 Phenomenology

As discovered Gallagher and Zahavi(2008), Sloan and Bowe(2014) as well as Tembo (2016), Phenomenology is a philosophy and a method of inquiry which seeks to explore and describe an experience from the perspective of those who lived the experience . It is a qualitative method of enquiry which is interested in what appears in individuals' consciousness about their experiences in their everyday life, namely what they think, feel, see, hear and taste. As further articulated by van Manen (1990), Moustakas (1994) and Giorgi and Giorgi (2003), its goal is to describe a lived experience to uncover the deeper meaning and significance of the socially constructed reality of those who experienced the experience. Phenomenology is a form of inquiry that seeks to understand human experience (Moustakas, 1994), to explore phenomena and how it is perceived and experienced by individuals.

1.3.2 User-led Interventions

User –led interventions are services driven by consumers of such services. Identifiable features of user –led services are a clear infrastructure and resources which enable them create, design and implement a service or project in collaboration with other healthcare workers. For such service to be effective, Morolake et al. (2009), WHO (2010), Paterson, Ross and Gaudet (2014), Gray and O' Hagan (2015) as well as Berg, Gamst, Said, Ass, Songe, Fange and Rysstad (2015) concur that such interventions should be locally appropriate, feasible, empowerment-oriented, sustainable, evidence-based and cost-effective.

1.3.3 Lived Experience

A lived experience is a recollection of the experience by those who lived through it. This first-hand account of the experience reflects how the experience influences how those who lived it perceive, respond and react to people, things and circumstances. According to Suwisith (1996), Gallagher and Zahavi (2008), van Manen (2002) as well as Rich, Graham, Taket and Shelly (2013) asserted that a lived experience is that which appear to the individual as real in everyday life, and it is a subjective account of living through an experience which is natural and untainted. For purposes of this study, lived experience shall refer to lived experiences of PLWH who are engaged in daily interactions and activities in communities in Vhembe District, Limpopo Province South Africa.

1.4 RESEARCH PROBLEM

HIV and AIDS as reported by Seckinelgin (2009), Obi, Okangba, Nwanebu, Ndubuisi, Mgbemene, Braide (2010), Lakshmi (2017) and UNAIDS (2018) is clearly the biggest tragedy of the present time. Since it was discovered, it resulted in many negative consequences in millions of people around the world, and there is neither cure nor

vaccine for the epidemic. The first clinical cases of AIDS as found by Maldonado, Gore - Felton, Duran, Diamond and Koopman and Spiegel (1996), the Kaiser Family Foundation (2014) and Idler (2014) were discovered in 1981 in the United States (US) in a group of gay men. The source of its discovery had significant implications for the World AIDS response as Stephenson (2009) and UNAIDS (2012) confirmed that Global AIDS response was slow. This response pace as found by Tan and Wu (2005), Gohain and Halliday (2014) and Sultana (2014) was influenced by the fact that HIV and AIDS has been linked to a behavioural component which was viewed as voluntary and avoidable such as gay sex, intravenous drug use and sex work. According to Piot, Russell and Larson (2007), this response exposed the interplay between HIV and AIDS, politics and legislation. Consequently, to date Rohleder, Swartz, Kalichman and Simbayi (2009), Edwards, Irving and Hawkins (2011) and UNAIDS (2011, 2012) confirmed that this was the source of the HIV related stigma and discrimination towards PLWH. The component of psychosocial care for PLWH as discovered by Mbonigaba (2013), Mackintosh (2009) and Fourie and Meyer (2016) was compromised from the onset. Furthermore, as alluded by Idler (2014), it served as a justification for communities of the world to conduct their healthcare business as usual.

The complacency did not last for too long as a few years later it was discovered by the WHO (2004) and Idler (2014) that the world communities' stance on HIV and AIDS worked against the general population. The HIV infection evolved from a concentrated epidemic into a generalised epidemic. Poor health outcomes among PLWH became a reality which came to haunt the healthcare system of the world. The UNAIDS (2018) and Kaiser Family Foundation (2014) reported that the world communities started to channel resources to stigma eradication programmes and other various campaigns were intensified to improve poor health outcomes. There are reports shown by UNAIDS (2013), Habib and Rahman (2010) and Yi et al. (2015) that there is progress with regard to the meaning of living with HIV as it has now been redefined as a chronic illness which is preventable, manageable and treatable but it appears this change in meaning was effectively used in the official language and documents as there was no significant change in the communities' narratives of HIV infection. Lee, Nezu and Nezu (2014) and

Human Sciences Research Council (2015) found that the concept of stigma and discrimination is still entrenched into people's understanding of HIV transmission. As a result, they emphasised that there is still a need to continue with stigma eradication programmes in that as observed by Lee et al. (2014) and Norcini and Steca (2015) despite the anti-stigma legislations to protect PLWH, disclosure by well-known figures that they are living with HIV, widespread availability of antiretroviral treatment (ART), information dissemination on how HIV is and is not transmitted, many PLWH still encounter a variety of stressors from within themselves and their social environment. In addition UNAIDS (1999, 2004), Gray and Vawda (2017) and Duby, Nkosi, Scheibe, Brown and Bekker (2018) confirmed that PLWH do not enter into HIV care as they fear to be identified with the marginalised subpopulation from which HIV was first discovered. Due to this discrepancy between the continuous poor health outcomes among many PLWH and what should have been, a qualitative phenomenological study is proposed to find solutions from the lived experiences of PLWH in communities. A phenomenological study was proposed to access personal experiences of PLWH. These data shall provide a blueprint upon which an evidence informed user – led intervention model for HIV care shall be developed.

1.5 AIM AND OBJECTIVES OF THE STUDY

1.5.1 Aim

The aim of this study was to explore and describe the lived experiences of PLWH in order to develop a user-led intervention model in Vhembe District, Limpopo Province.

1.5.2 Objectives

The objectives of the study were:
- To establish factors which compound poor health outcomes of PLWH.
- To assess a variety of stressors (intra-personal) from within PLWH.
- To appraise various stressors from their social environments.
- To establish what coping challenges PLWH experience.

- To determine the type of support system they have.
- To establish PLWH coping strategies.
- To develop a user-led intervention model with and for PLWH.

1.6 SIGNIFICANCE OF THE STUDY

An explicit benefit of the proposed study is that it captured 'lived experiences' of PLWH. This data was used to develop a user-led intervention model which is characterised by an elevated psychosocial care and support component at different levels of HIV care. The user-led intervention model augmented the current HIV care model which appears to be mainly disease-based. Specific areas of contribution of the study are the following:

1.6.1 Significance for Policy

HIV care interventions in SA is provided through the PHC system in collaboration with NGOs. The approach is fragmented and not easily accessible as these structures operate separately. The study recommended the implementation of a psychosocial user-led intervention model to be implemented at the point of entry into care in the local health facility. This requires that PLWH be employed as personnel in operational and management levels to consolidate accessibility of HIV care services. Currently, PLWH who provide user-led HIV care services do so on a voluntary or contractual basis. They do not enjoy similar conditions of services like other healthcare, and consequently have an impact on the quality of service delivered. The study designed a seven-step bio-psychosocial model, identified the location of the user-led service unit in the district healthcare organisational structure, intervention activities, lines of communication, referrals and reporting. The job descriptions, training and remuneration may be determined based on intervention activities outlined in the model. Consequently, this requires Vhembe District to facilitate and advocate for policy realignment so that PLWH be appointed and managed by the same Human Resource Management Policies as other healthcare workers.

1.6.2 Significance for HIV Care Practice and Related Disciplines

The study alerted healthcare workers on the need for a paradigm shift from a disease-based interventions to a bio -psychosocial dimension of HIV care. The study discovered that many PLWH are more afraid of being talked about than living with HIV, then followed by fear of imminent death, which is a primary source of poor health outcomes, especially self-stigma. It was found that they are well informed about the medical component of the disease. Consequently, the pre and post-test HIV counselling and testing (HCT) should pay special attention to self–stigma in order to empower PLWH fight off external stigma.

Furthermore, the study recommended a family focused approach than an individual one as it is primarily practised. It was established that many family members also experience emotional turmoil similar to those experienced by a diagnosed family member. In some families, the diagnosis disorganised family relationships and thus had an impact on the quality of support they provided to a family member who is living with HIV. In particular, healthcare workers and related disciplines should provide families with psychological education and support on HIV and AIDS, strategies to fight stigma and discrimination from communities, provide medical equipment and guidance on infection control, among others.

1.6.3 Programme Development

The study findings may be included in the continuous professional development of healthcare professionals so that their interventions are aligned with the bio-psychosocial needs of PLWH. As also acknowledged by Primary Health Care Systems [PRIMASYS] (2017), the training of health professionals in higher education institutions is still hospi-centric and curative. Consequently, the study contributed to the design and approach for individual, family interventions and community mobilisation on health promotion matters, especially HIV and AIDS.

1.7 LIMITATIONS OF THE STUDY

The study captured experiences of PLWH in order to design a user-led based model. Due to the nature of the research problem, recruitment of participants focused on particular participants who could give rich narratives of their experiences of living with HIV and AIDS. It was thus carried out as follows:

1.7.1 Sampling Procedures

The study used the purposive sampling procedure as it was intended to gather a rich data which could assist to bring out clearly the phenomenon of living with HIV and AIDS. There is a chance that the sampling procedure could have created a bias in the study findings in that it is not representative of the population.

1.7.2 Participants' Selection

The study captured individuals' personal experiences of living with HIV and AIDS. It relied on known and available participants from rural and semi-rural areas. Findings may not be generalised to urban and semi-urban areas as their social interaction patterns, culture, value system and general quality of life in their communities are different from other settings. As such, it may be a source of another bias with findings. Consequently, findings may not be generalised to other community settings.

1.8 OUTLINE OF THE THESIS

The report is presented in eight chapters as follows:

- CHAPTER ONE - GENERAL ORIENTATION

It is a presentation of the background of the study, research problem, problem statement, aims and objectives of the study, significance of the study into HIV care practice, limitations and outline of the report.

- CHAPTER TWO – THEORETICAL FRAMEWORK OF THE STUDY

It is a presentation of phenomenology as a philosophy and method of inquiry which informed the study. The two major frameworks – the descriptive and interpretive phenomenology, their relevance, applicability to the study and their convergence to bring out one approach which ultimately guided the study were discussed. The six steps of enquiry which were carried out were presented in this chapter.

- CHAPTER THREE - GLOBAL OVERVIEW ON HIV AND AIDS

The chapter is the first part of the literature review which displays global statistics on the prevalence of HIV and AIDS. A section was dedicated to the South African history's AIDS response in order to track factors which contributed to its current HIV care model.

- CHAPTER FOUR– SOCIAL WORK INTERVENTION IN THE CONTEXT OF HIV AND AIDS

The chapter consists of two parts. The first one presented common presenting problems experienced by PLWH and their families. They include but not limited to the impact of poverty on PLWH and family reactions to the diagnosis, stigma and discrimination, alcohol and drug abuse, and mental health problems. This was followed by the second part which presented specific Social Work intervention activities to empower PLWH and their social systems for better social functioning.

- CHAPTER FIVE – RESEARCH METHODOLOGY

The chapter presents an account of how the research was conducted from the beginning to the end. The chapter presented the research approach, research design, preparation of the research site, locating participants and sampling, data collection, procedures and processes of data organising.

- CHAPTER SIX – FINDINGS OF THE STUDY, ANALYSIS AND
  INTERPRETATION

Individual interviews with participants, field notes, observation of nonverbal messages and focus group discussion sessions were condensed into a research report. Verbatim extracts were also tucked into the report to illuminate participants' experiences of living with HIV and AIDS in their families and other social environments. This was followed up by linking the findings with prior research on the phenomenon.

- CHAPTER SEVEN – A SUMMARY OF THE MAIN FINDINGS, CONCLUSIONS
  AND RECOMMENDATIONS

The chapter opens with a snapshot of the restatement of the problem, aim and objectives and an indication of how each objective was achieved. This is followed by a summary of findings per theme. The chapter ends with conclusions and recommendations

- CHAPTER EIGHT – THE USER-LED INTERVENTION MODEL

A psychosocial user-led intervention model which was developed is presented in this chapter. Different levels of interventions and specific activities to be carried out were outlined.

1.9 CONCLUSION

The cost of the meaning of HIV and AIDS and subsequent complacency on HIV transmission is borne by many generations. These major costs include stigma and discrimination, lost lives, human suffering and continuous poor health outcomes experienced by PLWH and their families, which to date HIV care struggles to eradicate. Emphasis on the behavioural and medical strategies saved many lives but stigma and discrimination lives on and refuses to disappear. The Adoption of the GIPA principle which sought to involve service users into their care was not uniformly implemented. It was either inadequate or tokenistic. Consequently, many PLWH continue to experience

unmet needs which are psychosocial in nature. Hence, the study intends to locate psychosocial user-led service within the current model of HIV care.

CHAPTER TWO

PHENOMENOLOGY: A THEORETICAL FRAMEWORK OF THE STUDY

2.1 INTRODUCTION

The intended research is a phenomenological study on lived experiences of people living with HIV and AIDS. The research problem guided the selection of a theoretical framework of the entire research process. The fundamental goal of a theoretical framework as elaborated by van Manen (1990, 1994), Moustakas (1994) and Mapp (2013) is to give frame to research as it shows that it occurs within certain concepts and theories, gives research direction in different stages of research, provides justification of the research as it shows that it is based on grounded a scientific theory. In addition, Van Manen (1990, 1997) and Groenewald (2004) confirmed that a theoretical framework proves that there is an existing theory which supports the research.

The aim of the research is to explore and describe experiences of living with HIV and AIDS. According to Munhall and Boyd (1993), Moran (2000) and Gallagher and Zahavi (2008), an experience is constructed from feelings, thoughts, memories and opinions of the meaning of living with HIV and AIDS. As shown by Groenewald (2004) and Kafle (2011), a phenomenon refers to things or experiences as human beings are aware and experience them. It may be any object, event, situation or experience that a person can see, hear, touch, smell, taste, feel, know, understand, or live through. In this context, HIV and AIDS is neither measurable nor quantifiable. On this basis, the most suitable and applicable theoretical framework of the research is phenomenology. A significant number of authors such as van Manen (1990, 1994), Groenewald (2004) and Mapp (2013) agree that phenomenology in research is used to fully describe a person's experience of an event or experience, search for meaning and not measurements, focus on the wholeness of the experience rather than its individual parts in order to

understand perceptions and perspectives of a phenomenon. Phenomenology is interested in the lived experience. A lived experience as explained by van Manen (1990, 1994) as a subjective account by the first person of what it is like to experience the experience.

Van Manen (1990), Moran (2000) and Gallagher and Zahavi (2008) found that phenomenology as a theoretical framework comes from the academic disciplines of psychology and philosophy. The discipline of phenomenology as shown by Finlay (2009) and Padilla–Diaz (2015), is anchored on two major frameworks. The first one originates from the work of the German mathematician Edward Husserl developed in the 20th century, and is referred to as the Husserlian, transcendental or pure phenomenology as its aim is to describe a phenomenon. Husserlian phenomenology as discovered by Moustakas (1994: 85) is a philosophical approach to qualitative research methodology seeking to understand human experience, and is grounded upon setting aside all preconceived ideas to see phenomena through unclouded glasses, thereby allowing the true meaning of phenomena to naturally emerge with and within their own identity. Sheehan (2014) identified the tenets of Husserlian transcendental phenomenology, namely epoche, noema and noesis. Moustakas (1994: 85) described epoche as a conscious process of identification and subsequent quarantine of naturally occurring thought patterns. In addition, Blum (2012) described epoche as "the suspension of the natural attitude allowing things, events, and people to enter anew into consciousness, and to look and see them again, as if for the first time." Moustakas (1994) concludes that it is through epoche that one becomes able to perceive and receive that which is communicated without tainting its purity with preconceived beliefs, thoughts or judgments.

Sheehan (2014) confirmed that the noema is the 'what' of the experience while the noesi is the 'how' of the experience. The focus of descriptive phenomenology is articulated by Sheehan (2014), Sloan and Bowe (2014) and Yüksel and Yildirim (2015) as the correlation of the noema of the experience (what is experienced) and the noesi (how it is experienced). Moustakas (1994) and Giorgi and Giorgi (2003) indicated that

convergence of the noema and noesis results into what is referred to as the embodiment of the phenomenon. Furthermore, the authors indicated that once the things themselves have been identified or otherwise analysed, descriptive phenomenology considers its work done.

Gallagher and Zahavi (2008), Moustakas (1994) and Padilla – Diaz (2015 showed that the work of Husserl was later expanded by his student Heidegger from 1889 to 1976, who rejected the notion of bracketing. He argued that interpretations are all we have and description in itself is an interpretive process. Consequently, he introduced the framework referred to as the Heideggerian or the hermeneutic phenomenology. The hermeneutic phenomenology focuses on the interpretation of the subjective experience of an individual. It is further argued by Polkinghorne (1989) and Giorgi (1997) that adding an interpretive element on phenomenological experience is a benefit for the research as it allows for data to be used as a basis for a theory, or used to challenge or support policies or actions related to a particular experience or phenomenon.

Heidegger's central concept with this framework is the 'Dasein or Being there", which was further enhanced by the works of Jean Paul Sartre (1905–1980) and Maurice Merleau-Ponty (1908–1961), who believed that individuals are interrelated with their world. As further supported by Shosha (2010), Rich, Graham, Taket and Shelly (2013) and Tembo (2016), a subjective experience about a phenomenon is not an isolated process, but has reference to the physical, social and cultural environments in which individuals live. The focus of the hermeneutic phenomenology is thus the understanding of the meaning of the experience in different environmental contexts, by searching themes, engaging with data interpretively, with less emphasis on the essences which are important to the descriptive phenomenology.

The differences between the two frameworks as articulated by Yüksel and Yildirim (2015) is that the focus of the Husserlian transcendental approach is to describe the 'lived' experience to gain an understanding of deeper meaning, while the Heideggerian hermeneutic approach focuses on interpretation to discover the hidden meanings of a

phenomenon. However, the general purpose of phenomenology as confirmed by Welman and Kruger (1999), Groenewald (2004) and Christensen, Johnson and Turner (2010) is to describe as accurately as possible the experience of a phenomenon refraining from any pre-given framework but remaining true to the facts for the purpose of understanding the social and psychological phenomenon from the perspectives of people involved.

2.2 PHENOMENOLOGY AS A PHILOSOPHY

Suwisith (1996: 16) defined a philosophy as a statement of beliefs and speculation about the nature of value of views. In support, van Manen (1990) articulated that phenomenology is viewed as a philosophy which believes in human nature and individual experiences. In addition, Merleau–Ponty (1962), Gallagher and Zahavi(2008) as well as Moustakas (1994) indicated that throughout the history of the phenomenological movement, phenomenology attempted to explain beliefs and speculation about human nature and individuals' lived experiences, and consequently postulated five key concepts of philosophical phenomenology, namely consciousness, embodiment, natural attitude, perception and experiences.

Munhall and Boyd (1993) and Suwisith (1996) elaborated that consciousness is a sensory awareness of, and response to, the environment which shapes reality around an individual. Van Manen (1990, 1994) and Gallagher and Zahavi (2008) concurred that when one is aware of the experience, then one understands what one constructs about the experiences. Then the experience matures into a natural attitude about what appears in consciousness (Gallagher and Zahavi, 2008). One's reality in the environment may be conveyed by what one sees, feels, tastes and hears. This consciousness connects the mind and body, which is referred to as embodiment. The recognition and interpretation of one's reality generates a natural attitude or a mode of awareness. One's current experience is shaped by past experiences and interpretations stored in the natural attitude. From this chain, an individual is then able to present experiences and perceptions about a phenomenon

Phenomenological research is interested in awareness of what appears in their everyday life. Van Manen (1997) and Subramoney (2015) introduce the concept of lifeworld existentials to understand the frame of daily existence. Phenomenology as a philosophy investigates what van Manen (1997), Rich et al. (2013) and Tembo (2016) call lifeworld existential. They concurred that lifeworld existentials are a frame of lived experiences which help to understand the lived experience. They are important in the formulation of research questions, and help the researcher to know how to go about finding out what one is curious about such as the experience of PLWH and the meaning attached to the experience. In the study on the lived experiences of living with HIV and AIDS, the proposed research will operationalise the four lifeworld existentials through the administration of individual and group interviews.

Rich et al (2013) indicated that although the four lifeworld existentials have different focus, they are intertwined in their explanation of a lived experience. The four lifeworld existentials are the lived space, lived body, lived time and lived human relations.

- Lived space (spatiality)

Rich et al. (2013) and Tembo (2016) articulated a lived space as a felt and subjective experience in the space in which individuals find themselves. People living with HIV and AIDS spend their everyday lives in different spaces such as community, home, work, and school, among others. The research sought to find mutual interaction between PLWH and their lived spaces, how their spaces influence how they feel, and how their feelings affect the way they experience a particular space. The lived space is experienced through the lived body.

- Lived body (corporeality)

Benner and Wrubel (1998) and Fredriksen and Ringsberg (2007) affirmed that it is through the body that individuals experience the world. In addition, van Manen (1997) showed that it is through our body that we communicate, feel, interact and experience the world. Phenomenological research seeks to understand the way in which PLWH

discuss and describe their bodies, and what they think their bodies communicate to others. Tembo's analysis is an exploration of the participants' experiences of living with HIV and AIDS through their bodies, whether they understand their bodies to be functional, especially with sexual reproductive matters now that they are living with HIV and AIDS.

- Lived time (temporality)

A lived time as seen by van Manen (1997), Rich et al. (2013), Subramoney (2015) and Tembo (2016) is a subjective experience of time as opposed to the clock time. Of interest in phenomenology with regard to the lifeworld existential of lived time is what constitutes their past, present and future as it relates to the experience of living with HIV and AIDS. What one encountered in the past, which remains as memories which may leave traces in one's present thoughts and behaviour, determines the present and influence the future. The interplay of the past, present and future can influence one's interpretation of the experience.

- Lived other/ human relations (rationality)

Rich et al (2013) refer to 'lived other' as lived human relations, and concur with Leder (1990) that life is about the relationships we make and maintain in the interpersonal space we share with others in our lifeworld. Furthermore, Leder (1990) asserted that life revolves around being and dealing with relationships. These relationships, as asserted by van Manen (1997), include the communications and interactions we experience with others through the spaces.

2.3 PHENOMENOLOGY AS A METHOD OF INQUIRY

Phenomenology is a qualitative method which, according to Husserl (1970) and Creswell (2007), found that it overlaps with other qualitative methods such as ethnography, hermeneutics and symbolic interactionism. However, van Manen (1990), Moustakas (1994) and Giorgi and Giorgi (2003) established that phenomenology differs from other qualitative research methods because, as a method of research it is

associated with the socially constructed nature of reality. Its goal is to describe a lived experience to uncover deeper meaning and significance of human behaviour and experience from the perspective of those who lived the experience. It was also shown by Marashe (2014) that it is a qualitative method whose distinctive feature is to take into account the consciously experiencing person.

The research project is a phenomenological study of the experience of living with HIV and AIDS. Consequently, phenomenology as a research method is appropriate for the study. A significant number of authors such as van Manen (1990), Creswell (1998), Lester (1999) and Padilla-Diaz (2015) agree that the best criteria to determine the use of phenomenology as a research method is when the research problem requires a profound understanding of human experience common to a group of people. As a method of inquiry, Krueger (1998) and Moustakas (1994) confirmed that phenomenology seeks to describe what is given to us in experience without obscuring preconceptions or hypothetical speculations. Its aim is thus to return to the concrete slogan of 'Back to the things themselves' (Eagleton, 1983:56).

Although phenomenology does not test a hypothesis nor the results are predictive or reproducible, Moustakas (1994) and Subramoney (2015) cautioned that such does not render it unscientific in that the central feature of phenomenology is what van Manen (1990,1994) and Kafle (2011) referred to as 'epoche' or bracketing. As described by Moustakas (1994: 85), Epoche or bracketing is a Greek word meaning to stay away or abstain. This means that the researcher is required to consciously set aside current thoughts, beliefs, and judgments which lend themselves to bias. It is a quarantine of one's attitude by the researcher about the phenomenon under study so that one looks and sees the phenomenon as if it is for the first time. It was established by Moustakas (1994), Groenewald (2004) and Blum (2012) that quarantine assists the researcher to avoid taking sides but instead goes back to things in their pure form. Groenewald (2004) advised that bracketing may be effected in two ways. First, the researcher allows the participants to describe the lived experience in a language as free as possible from the constructs of the intellect and society as possible. Secondly, the researcher sets aside

one's preconceived ideas and enter into the world of the individual's lifeworld and use the self as an experiencing interpreter.

Van Manen (1990) and Suwisith (1996) explained that phenomenology is the study of human lifeworld which focuses on human experiences whose goal as identified by Moustakas (1994), Suwisith (1996) and Giorgi (1997) is to uncover the meaning of lived experiences through bracketing, intuition, analysis and describing a phenomenon from an individual who lived it in the way it appears without preconceived ideas.

2.4 MAJOR CHARACTERISTICS OF THE PHENOMENOLOGICAL METHOD

Phenomenology as a method of enquiry is different from other qualitative research methods as it bears the following features:

- Bracketing

Giorgi and Giorgi (2003) understand bracketing to be the process of keeping and checking one's ideas, opinions and beliefs about the phenomenon. An important technique identified by Suwisith (1996) and van Manen (1990) for bracketing is reductionism, which is a process of isolating the phenomenon and separating it from what is already known about it. Bracketing assists the researcher to prevent bias from intruding into the findings.

- Intuition

Penner and McClement (2008) articulated that intuition or grasping in phenomenological study requires the researcher to be immersed in the study, be open to the meaning of the phenomenon as described by those who experienced it, and advised that the researcher should vary data collection methods and questions until a level of understanding emerges. The main techniques for intuition identified by Streubert and Carpenter (1995) are that the researcher should avoid criticism, evaluation and opinion, but instead pays strict attention to the phenomenon under study.

- Analysis

Hycner (1985), Penner and McClement (2008) and Shosha (2010) acknowledges that a phenomenological study generates a large amount of data from audio recordings, interview notes and observations which need to be analysed. Hycner (1985), Shosha (2010) and Tembo (2016) found that the best way to initiate analysis is for the researcher to be immersed in data collected through face to face interviews to get a fee of what is being said, and then interrogates the text, codes and creates categories which emerge into themes. Effective analysis in phenomenology requires the researcher to put together the textual and structural data. As explained by Padilla–Diaz (2015:105), textual analysis refers to the description of what is expressed by participants while structural analysis refers to the interpretation of how it is expressed by the participants. Furthermore, Giorgi (1997) advised that during analysis, the researcher should include all relevant aspects of the experience such as the surrounding, social and personal interactions, emotions, beliefs, value systems and attitudes.

- Description

This is the last phase of the research process in which Hycner (1985) and Starks and Brown Trinidad (2007) allow the researcher to use one's understanding of the phenomenon, locate it within the scientific context and communicate it to others

- Sampling

Phenomenology is an in-depth study, and may be conducted with a single case or a smaller deliberately selected sample. Groenewald (2004) advised that sample size should be between 2 and 10 participants, while Padilla–Diaz (2015) settled for a sample size of between 3–15 participants as adequate to reach data saturation. The outstanding feature of phenomenology as a method of research is that the research engages in an in-depth interview with participants and may reach data saturation with fewer participants.

▪ Data collection

Van Manen (1990; 1994) argues that phenomenology seeks to describe and clarify the immediate experience with everyday language rather than scientific vocabulary. As a result, it requires data collection tools which allow the participants to articulate their experiences with minimal hindrance. Van Manen (1990) showed that data collection methods that are often used in phenomenological research are interviews/speech, diaries/ written, drawings/ nonverbal and observation/ visual.

2.5 APPLICATION OF PHENOMENOLOGICAL RESEARCH ACTIVITIES IN THE STUDY

The aim of this study is to explore and describe the phenomenon of living with HIV and AIDS. As shown earlier, 'describe' is central to the transcendental phenomenology, while explore is central to hermeneutic phenomenology. As a result, the study utilised the combined approach from the descriptive and interpretive phenomenology as it is vital for the study to interpret the phenomenon so that it can be utilised to develop a model. The combined descriptive and interpretive phenomenology was founded by van Manen (1990) who developed a phenomenological philosophy using the elements of both Hurssels and Heidegger's philosophy. He proposed six activities of conducting such research. As a methodology, this approach is both descriptive and interpretive and thus leads the researcher to uncover meanings and the essence of the experience. The researcher operationalised Van Manen's six steps of inquiry as follows:
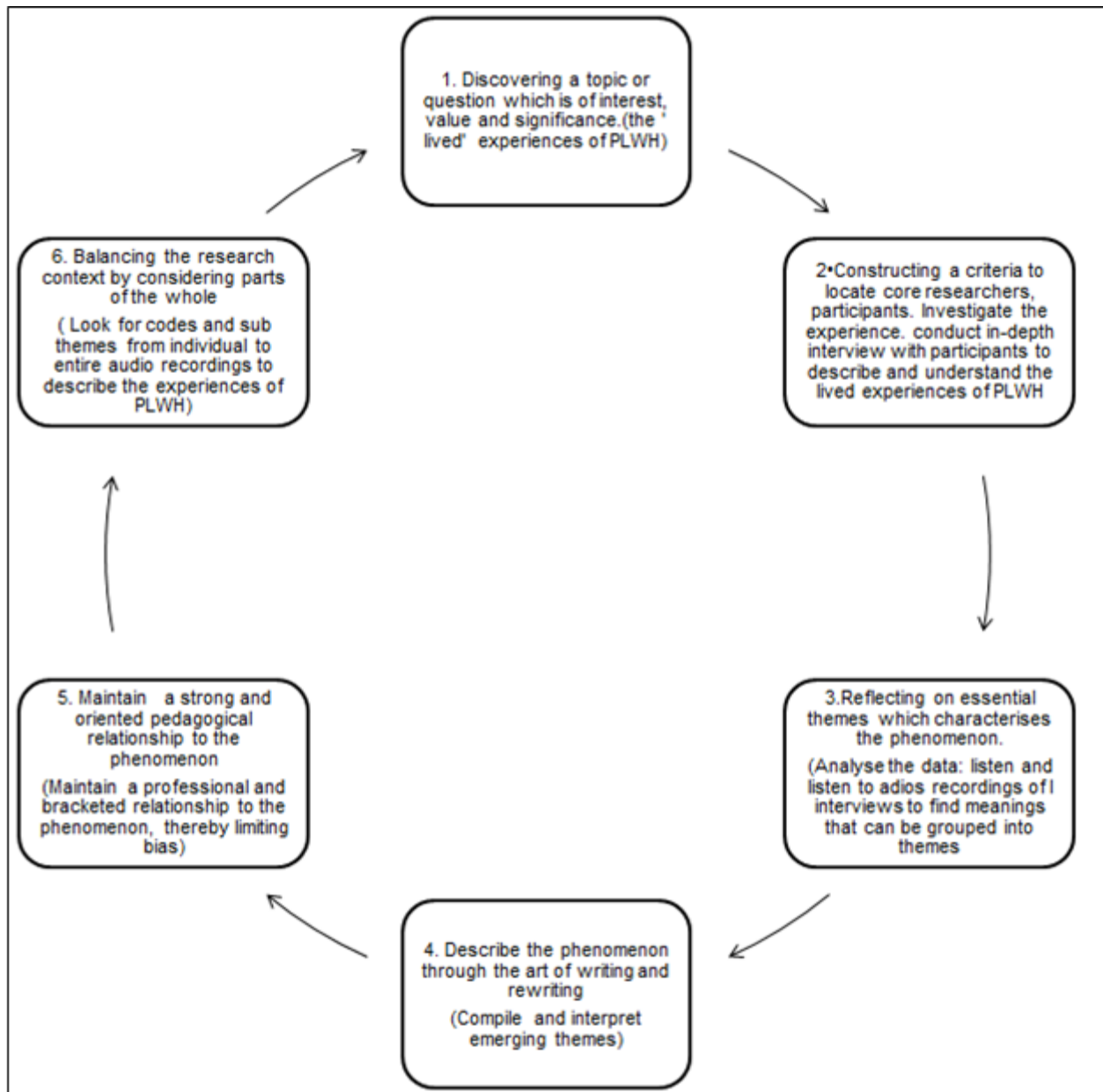
Figure 1:: Van Manen's six steps of enquiry

Adapted from Subramoney (2015: 83)

- ▪ Activity one: Discovering a topic or question which is of interest, value and significance.

In this first activity, the researcher is committed to make sense of the phenomenon. In this study, the researcher is interested in 'lived' experiences of PLWH. A lived experience may be revealed and understood in the expressions of those who lived the

experience. According to van Manen (1990), the four aspects of 'lived' experience that are of interest to phenomenologists is what is referred to as the 'lived space', 'lived body', lived time', lived other/ human relations of (intentionality).

In phenomenology, Subramoney (2015:67) indicated that 'Lived space' may be interpreted as a sense of belonging and 'lived body' represents that one is always represented in the world, 'Lived time' addressed the past, present, and the future that affects a person's perception about the future. 'Lived intentionality' refers to how individuals maintain relationships in space that they share. In a quest to understand PLWH experiences of living with HIV, the four lifeworlds have been covered as participants answered questions as contained in interview guide and focus group discussion questions (Appendix 2 and 3, respectively).

- **Activity two:** Constructing a criterion to locate core researchers, participants. Investigate the experience

In this activity, the researcher delved deeply into the lifeworld of those living with HIV and AIDS. This is what Heidegger (1962, 1996) refers to as "Dasein or 'being in the world". Instead of conceptualising what it would be like living with HIV and AIDS, the researcher seeks to understand it from those who lived it. In this activity, the researcher conducted in-depth individual interviews with PLWH and conducted a focus group session to understand their experiences.

- **Activity three:** Reflecting on essential themes which characterise the phenomenon

This activity is characterised by the researcher's reflection on making sense out of lived experiences of PLWH. However, Van Manen (1989) cautions that this activity is not about drawing generalisations of the data, but identifying themes which illuminate the phenomenon. In this activity, the researcher listened to audio recordings of interviews to find meanings which were grouped into categories, subcategories and themes.

▪ Activity Four**:** Describe the phenomenon through the art of writing and rewriting

In this activity, significant detected themes from transcribed audio recordings become words. This is the writing stage activity in which the researcher presented both the verbal and nonverbal data on the lived experiences of research participants. In this study, this activity is presented in chapter 6 on findings of the research report.

▪ Activity five: Maintain a strong and oriented pedagogical relationship of the phenomenon

This is a knowledge generating activity from the experiences of participants. Of significance is that the researcher should not allow false data to compromise the research. The researcher maintains a professional and bracketed relationship of the phenomenon, thereby limiting bias. A report which bears direct quotations by participants is presented in Chapter 6

▪ Activity six**:** Balancing the research context by considering parts of the whole

This activity is characterised by what Shosha (2010: 34) refers to as putting it all together. Themes which have been identified lead to essence of the phenomenon which, according to van Manen (1990), "makes a thing what it is". The researcher chose a phenomenological approach as it allows participants to describe an experience as it is. In this activity, the researcher presented the research report which captured the lived experiences of participants in the study, and presented the developed user-led intervention model in HIV care.

2.6 CONCLUSION

The two phenomenological frameworks seek to explore and describe the meaning of the experience from the perspective of those who experienced the experience. The frame of locating the experience is through the four lifeworld existentials, namely the 'lived space', 'lived body', lived time', and 'live other human relations'. Human beings are spiritual beings and their experience is significantly shaped by their relationship with

the Higher Power. Consequently, in striving to explore and describe the lived experience of PLWH, phenomenological inquiry should go further into their spirituality as it is the source of faith and hope.

CHAPTER THREE

GLOBAL OVERVIEW ON HIV AND AIDS

3.1 INTRODUCTION

Prior to the discovery of HIV and AIDS, Ashton and Seymour (1998) and Piot (2006) noted that the world experienced outbreaks of other epidemics such as tuberculosis, and in no time the epidemic subsided because the world responded promptly with appropriate synergy between leadership and science. However, it was not the same with HIV and AIDS as van Dyk (2005, 2010) and Piot et al. (2007) found that when it was first discovered in 1981, the world reasoned about where it came from and turned a blind eye probably as it was discovered from gay men. Consequently, the epidemic spiralled from being concentrated to a generalised epidemic. Reports by the UNAIDS (2017, 2018) revealed that no region was spurred from the epidemic since its discovery as 77.3 million people have become infected with HIV, while 35.4 million people have died from AIDS-related illnesses. The WHO (2010), UNAIDS (1999), Piot (2006) and Coates et al. (2008) asserted that if we had had the level of leadership and level of funding for AIDS in the past, we would not be where we are now. Piot et al. (2007) and Gow (2006) concurred that the discovery of HIV and AIDS among gays, and subsequent World AIDS response exposed poor integration between HIV, politics and healthcare system policy.

3.2 REGIONAL PREVALENCE OF HIV AND AIDS

Since the discovery of HIV and AIDS three decades ago, Gallo (2006), Kaiser Family Foundation (2014) and Subramoney (2015) discovered that there is still neither a vaccine nor cure. Consequently, Ezeokana, Nnedum and Madu (2009), Obi et al. (2010), Islam, Minichiello and Scott (2014), Subramoney (2015) and UNAIDS (2016, 2017) referred to HIV and AIDS as a tragedy of the century which devastated many

lives and continues to bear negative consequences on individuals, family and communities. In support of this, the UNAIDS (2018) Global statistics report is evidence of the impact of HIV and AIDS on the human race. The statistics revealed that since the discovery of HIV and AIDS,

- 77.3 million people have become infected with HIV.
- 35.4 million people have died from aids-related illnesses since the start of the epidemic.
- 21.7 million people were accessing antiretroviral therapy.
- 1.8 million people became newly infected daily.

The above report confirms that despite the medical breakthrough which afforded 21. 7 million access to antiretroviral treatment, people are still infected daily. To further indicate its hold on people, UNAIDS (2014, 2018) presented a comparative global picture of the prevalence of HIV and AIDS of 2013 and 2017 statistics in different regions. There has been an increase in each region, but it also shows that the prevalence rate is decreasing steadily as shown in the table below.

Region	No of people living with HIV in 2013 in millions	Number of people living with HIV in 2017 in millions
Eastern and Southern Africa	24. 7	19.6
East Asia and the Pacific	4.8 million	5.2
Western and Central Africa	6.2	6.1
Latin America	1.6	1.8
The Caribbean	250 000	310 000
Middle East and North Africa	230 000	220 000
Eastern Europe and Central Asia	1.1	1.4
Western and Central Europe and North America	2.3	2.2
Totals	35 million	36.9 million

Table 1: A comparative report on global HIV prevalence of people living with HIV

Sources: UNAIDS 2014 and UNAIDS 2018

As shown earlier, communities of the world did not immediately pay much attention to fighting HIV infection as they viewed it as a health condition which could stay as a concentrated epidemic. As confirmed by Mackintosh (2009) and the Kaiser Family Foundation (2014) it was not until the HIV infection spread from the marginalised subpopulations into the general population that worldwide AIDS response began to surge. Piot et al. (2007) acknowledged that one driver for spread of HIV is its long incubation period which allows it to go unnoticed and unchecked at a point which decisive political action could have seriously reduced its spread and impact.

According to the UNAIDS (2012) and the Kaiser Family Foundation (2014), the US government first provided funding to address the global HIV epidemic in 1986. The initiatives included Leadership and Investment in Fighting an Epidemic (Life) in 1999 for 14 countries in Africa and India, the 2002 International Mother and Child HIV Prevention Initiative for 12 African and 2 Caribbean countries, and the 2003 President's Emergency Plan for AIDS Relief (PEPFAR). The timelines of World AIDS response is summarised by Gallo (2006) in the table below;

Activity	Timelines
Silent spread	1970 – 1981
Recognition	1981 – 1982
Intense discovery	1982 – 1985
Global mobilisation	1986 – 1988
Ending the problem by	
blood testing	1984
Public education (1986)	1986
Antiretroviral treatment (1986)	1986
Development of a vaccine (?)	?

Table 2: A History of World AIDS response

Source: Subramoney (2015: 70)

When the world ultimately engaged in active AIDS response, UNAIDS (2004) and Tan and Wu (2005) found that they prioritised the behavioural change communication programmes and medical intervention as people began to get sick and others died of AIDS related illnesses.

Since the early days of the epidemic, the Asian Development Bank (2004) indicated that the worldwide AIDS response has been aligned to a standardised best practice model which countries were expected to follow. Equally important, Tan and Wu (2005), WHO (2006) and Seckinelgin (2007) established that countries were still expected to tailor their AIDS response to address the unique challenges posed by the epidemic. However, Sanchez (2010), UNAIDS (2012), Pope, White and Mallow (2014), Gohain and Halliday (2014), Shisana, Labadarios, Simbayi, Onoya, Zuma, Jooste and Zungu (2015) and Yi et al. (2015) found that many countries adopted a generalist model in their AIDS response.

While the world mainly focused on the two components of the epidemic, van Dyk (2005, 2010) and Keniston (1989) noted that minimal attention was given to the impact of faulty language and scary symbols which depicted HIV and AIDS as fatal. The AIDS response with the medical component of HIV care yielded good outcomes because as confirmed by UNAIDS (2011, 2012), Mbonigaba (2013) and Yi et al. (2015), many PLWH accessed ARV, the quality of lives among PLWH improved, the HIV prevalence decreased, and many deaths were averted. The UNAIDS (2014) report revealed that HIV-related deaths decreased by 35% due to antiretroviral treatment since its peak in 2005.

This pattern was evident in many continents but the same report revealed that the prevalence remained high in sub–Saharan Africa. As shown by Lugalla, Madihi, Sigalla, Mrutu and Yoder (2008), Wekesa and Coast (2013), the region is the hardest hit by the epidemic because although it constitutes 12% of the world population, it still accounted for 70% of new HIV infection. The WHO (2010) attributed the high HIV prevalence in

Africa to the many predisposing factors, in particular the East and Southern Africa and Western and Central Africa. This was confirmed by the UNAIDS (2013, 2017) statistics which showed that in 2013, people who were living with HIV in the region were 24.7 million and 25.7 in 2017, which shows an increase of 1 million. The extent of the prevalence in the sub-Saharan region is presented below:

East and Southern Africa (2016)
19.4 million people living with HIV
7% adult HIV prevalence
790,000 new HIV infections
420,000 AIDS-related deaths
61% adults on antiretroviral treatment
51% children on antiviral treatment

Source: UNAIDS Data 2017
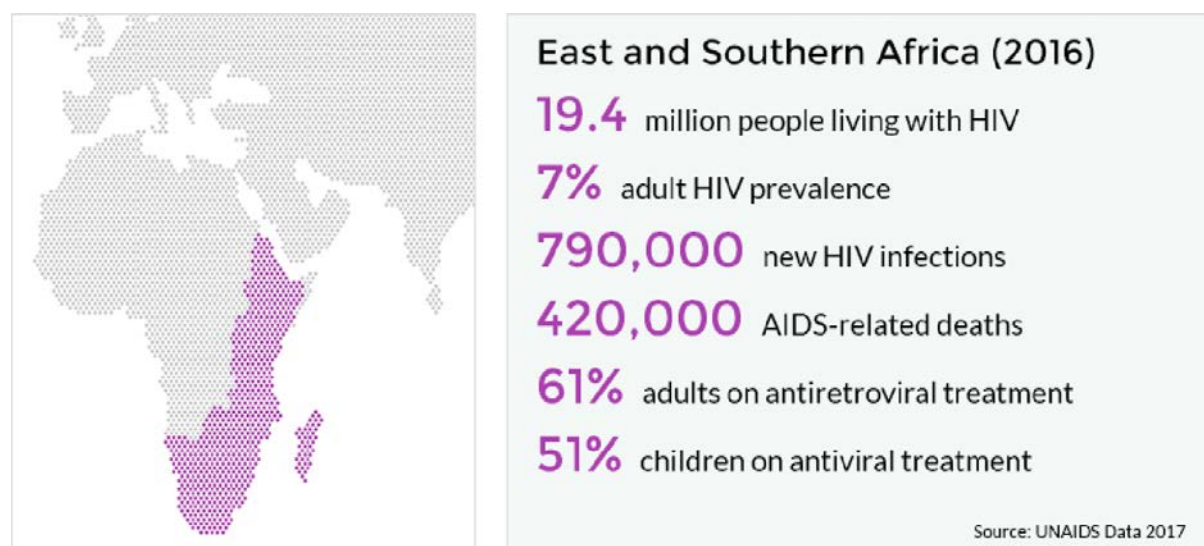
Figure 2: The extent of the prevalence in the sub-Saharan region

Out of 36.9 million who were living with HIV worldwide, 19.4 are from sub-Saharan Africa. The many predisposing factors in Africa which account for a high HIV prevalence rate, especially Sub–Saharan Africa have been identified by Epstein (2007), Lugalla et al. (2008), WHO (2010) and Johnson, Dorrington and Moolla (2009) as those of poverty, natural disasters, displacement, conflicts, mobility, migration, inequality, socio-cultural practices and status of women. In addition, Chitereka (2009) asserted that the pandemic escalated in the region mainly due to the denial of the existence of the disease by most African leaders so that by the time they acknowledged its existence, many people had been infected. Haacker (2002) and Ogunbodede (2004) discovered that the impact of HIV and AIDS in Africa is also evident in sectors such as agriculture, education, corporations, workplaces, health and others.

The report by UNAIDS (2017) revealed that scale-up of ARV surpassed expectations in that the global coverage reached 46% at the end of 2015. Gains were greatest in the world's most affected region, Eastern and Southern Africa as coverage increased from 24% in 2010 to 54% in 2015, reaching a regional total of 10.3 million people on ARV.

The prevalence of HIV determines funding priorities in the country's healthcare system. The UNAIDS (2017) and PRIMASYS (2017) showed that the impact of HIV and AIDS in the healthcare system is felt in expenditure and human personnel costs. Due to the HIV prevalence rate and the discovery of ARV, Beck, Miners and Tolley (2001) echoed that it meant the need for more budget allocation for medical treatment and more personnel to care for PLWH and their families. As estimated by UNAIDS (2017) in South Africa in 2016, nearly 3.4 million people were on ARV, more than any other country in the world. It is the largest government funded programme. After South Africa, Kenya has the largest treatment programme in Africa, with nearly 900 000 people on treatment at the end of 2015, followed by Botswana, Eritrea, Kenya, Malawi, Mozambique, Rwanda, South Africa, Swaziland, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe, which all increased treatment coverage by more than 25 % between 2010 and 2015.

3.3 HIV AND AIDS IN SOUTH AFRICA

The Global AIDS Review Report (UNAIDS, 2012) found that South Africa is the country with the highest number of people living with HIV in the world. Earlier, Gow (2006) and UNAIDS World Report (2011) attributed the escalation of HIV prevalence in South Africa to counter productivity activities which the leaders initially engaged in ever since HIV and AIDS was discovered. The General Household Survey by Statistics South Africa (STATSSA) (2017) estimated that the SA population is 56, 522 million. Out of the population, UNAIDS (2017) estimated that 7.1 million people in SA were living with HIV.

Like in the US, Mackintosh (2009), Rohleder and Gibson (2006) and Fourie and Meyer (2016) confirmed that the first case of AIDS in SA was reported in December 1981 from

a homosexual man, and the first AIDS-related death was recorded in 1983. Through the analysis of McNeil (2002) and the South Africa Civil Society and AIDS (2017), HIV and AIDS was determined to be much more prevalent amongst the homosexual population before 1990 as under 1% of the population had the disease. In 1996, the percentage of those infected rose to 3%, and just four years later, the numbers jumped to 10%. By 1995, AIDS infection began to reach a pandemic level.

Ever since the discovery of HIV and AIDS in SA, Simelela and Venter (2014), Subramoney (2015) and The South African Civil Society and AIDS Response (2017) concurred that the country paid very limited attention to the epidemic, and just three years later, 46 more cases of AIDS were diagnosed. As reported by the UNAIDS World report (2011) and the Kaiser Family Foundation (2014), the HIV infection spiralled from one person in 1981 to 5.6 at the end of 2011. The South African UNAIDS Global AIDS response AIDS Report (2012) established that SA was rated as the country with the highest number of people living with HIV in the world by the end of 2011. HIV continued to spread as the UNAIDS (2017) confirms that in 2016, 7.1 million people in SA were living with HIV.

When HIV and AIDS was discovered in South Africa in 1981, Kon and Lackman (2008) and Subramoney (2015) discovered that the SA political struggle for a democratic dispensation was at its peak. Consequently, the SA AIDS response should be understood against the background that it ran parallel with the quest for a political struggle for a democratic dispensation. This position was further confirmed by Fassin (2007), who showed that even the early warning by the late Chris Hani of the threat posed by the emerging virus at the 1990 Maputo AIDS conference, it did not seem to have any impact on the subsequent government response. When the government ultimately got to focus on fighting HIV and AIDS (Gow, 2009; Simelela & Venter, 2014), the South African Civil Society and AIDS Response (2017) established that it was not an easy road as it was marred by political, scientific debates and controversies. Such engagements were counterproductive as it generated harmful omissions and commissions, inactions, interference, pseudoscience, conflicts between political leaders

and organisations which is attributed to human suffering and loss of lives (Mackintosh, 2009; Mbonigaba, 2013; Fourie & Meyer 2016). This is confirmed by the Statistics South Africa (Statssa) (2013), which released a mortality report based on death notification forms which revealed a massive increase of AIDS related deaths by 93% between 1997 and 2006. The same report revealed a decline by 11% in AIDS related deaths between 2006 and 2010, which attributed it to availability of ARV.

The SA HIV prevalence and the AIDS response was driven within the two political dispensations, namely the apartheid and the democratic governments. The SA AIDS response is thus informed by political leadership and healthcare policy. The road map of the SA AIDS response is presented below per political leadership from 1981 to date.

3.4 THE SOUTH AFRICAN AIDS RESPONSE PRE 1994

- The Period from 1981 – 1994

During this period, the SA government was ruled by the apartheid policy which Downing (2004) and Subramoney (2015) established that it segregated Blacks and Whites on every aspect of life, including health matters. When HIV was discovered, McNeil (2002) established that it was accompanied by racial connotations, and the HIV infection was characterised by formalised stigma and discrimination as regulations were passed to quarantine for fourteen days those who were infected or those suspected of suffering from AIDS. Furthermore, the quarantine could be extended indefinitely if one was confirmed to be infected, and HIV infection was reduced to the disease of people with 'deviant' sexual behaviours and the racial connotation were attached to the disease. It is estimated by the South African National Department of Health [NDOH] (1990) that by 1990, 74 000 people in SA were living with HIV. An AIDS response of this nature is viewed by (Ashton & Seymour, 1998; Piot et al., 2007, Coates et al., 2008) as a contemporary display of poor synergy between politics, HIV and policy and public healthcare.

The first SA National Department of Health [NDOH] (1990) antenatal survey conducted in 1990 found that 0.8% of pregnant women were living with HIV. These findings significantly challenged the prejudices, stigma and discrimination levelled against PLWH as people suffering from a 'gay disease'. A decade later, NDOH (2011) found that HIV infection prevalence trends increased from 0.8% in 1990 - 29.5% in 2011. A caution is that poor leadership is not good for AIDS response (Piot et al., 2007; Chitereka, 2009; Obi et al., 2010; Dennis, 2010).

3.5 THE SOUTH AFRICAN AIDS RESPONSE POST-1994

▪ The period 1994 – 1999

This period was a democratic era wherein the ruling party, the African National Congress had to start to implement their election manifesto to improve the lives of South Africans. The PRIMASYS (2017) established that post-1994, the SA government adopted the 1978 Alma- Ata Declaration on health services to guide the SA healthcare system. This was followed by the introduction of Primary Health Care (PHC) as the foundation of SA's post-apartheid national health system. The PHC infrastructure is nurse-based nurse doctor–supported supplemented by other allied professionals, and is free at point of use. The PRIMASYS (2017) found that nongovernmental organisations is one significant component of PHC which emerged in response to the HIV and Tuberculosis (TB) epidemics.

Post-1994 era, Mackintosh (2009) and the South African Civil Society and AIDS Response (2017) established that the administration responded promptly as combating HIV and AIDS was one of the priorities. Significant commitments were made as fighting HIV and AIDS was made one of the 22 leading projects of the new government's reconstruction and development projects. Three structures were established to work with civil societies in combating HIV and AIDS, namely, the HIV and AIDS and Sexual Transmitted Disease Advisory, the committee on non-governmental organisation (NGO) funding, and the committee of HIV and AIDS and Sexually Transmitted Diseases research.

As discovered by Subramoney (2015) and the South African Civil Society and AIDS Response (2017), the SA government linked with the international communities and secured funding for HIV and AIDS programmes. However, Simelela and Venter (2014), Subramoney (2015) and the South African Civil Society and AIDS Response (2017) established that strategic challenges were experienced with the funding criteria when in 1995 a grant of R14.27 million was contracted by the Department of Health to create Sarafina II, a musical sequel to target AIDS awareness towards younger people. The challenges were further reiterated by the South African Civil Society and AIDS Response (2017) as the project led to much controversy, eventually causing the contract to be nullified as the activists and civil society experienced it as unclear and inappropriate. This was followed by the funding of the Viroden project, which the South African Civil Society and AIDS Response (2017) showed that it proved to be a false discovery of the ARV. Despite the funding drawbacks, the SA President fought against HIV related stigma and discrimination, campaigned and advocated for HIV and AIDS to be recognised and treated like other chronic diseases.

- The period 1999 – 2007

Piot et al. (2007) established that a poor synergy between political leadership and science is the root of poor public health policy. This was the case as Simelela and Venter (2014) and the South African Civil Society and AIDS Response (2017) showed that during this era, the SA AIDS response proved to be a challenge on both structural and scientific levels as leaders doubted the science behind HIV and AIDS and (ARV). As they argued and debated, the HIV infection continued to spiral swiftly and ravaged people's lives. A significant number of authors (Mackintosh, 2009; Fourie & Meyer, 2016; Subramoney; 2015 and the South African Civil Society and AIDS Response 2017) confirmed that this period was commonly referred to as the 'AIDS denialism' era. In support of the existence of aids denialism, Coates et al. (2008) and Chitereka (2009) discovered that a major setback with the AIDS response in Africa is that many leaders did not acknowledge the existence of HIV and AIDS until many people got affected.

The first SA National Strategic Plan (NSP) for HIV/STI/STD 2000-2005 was developed and promoted two primary goals, namely reducing new infections, particularly among the youths, and reducing the impact of HIV and AIDS on individuals, families and communities. The biomedical component was conspicuously absent from the NSP which, according to Kaida, Laher, Strathdee, Janssen, Money, Hoggs and Gray (2011) and the South African Civil Society and AIDS Response (2017), showed that the SA government downplayed the importance of antiretroviral drugs that had proved to be effective in reducing HIV transmission. HIV prevention requires a combination of the behavioural, biomedical and structural strategies to effectively respond to the epidemic (Bor, 1990; Piot et al., 2007; Coates et al., 2008; Bekker, Beyrer & Quinn, 2012).

It is not uncommon for the civil society to react to the omission of the biomedical component in the AIDS response as Coates et al. (2008) confirmed that it triggered the formation of the AIDS Support Organisation in 1987 in Uganda to support those who were affected by HIV before ARV was available. The South African Civil Society and AIDS Response (2017) found that the same approach was adopted in South Africa by activists, civil society and the Treatment Action Campaign (TAC) when they drove mass action campaigns for ARV roll out. Consequently, in 2002, a South African (SA) high court ordered the SA government to make available the ARV drug nevirapine available to HIV positive pregnant mothers.

The second NSP 2007-2011 HIV and AIDS and STI was developed through the initiative of the South African National AIDS Council (SANAC). The NSP focused on treatment, care and support, human rights and access to justice, monitoring, research and surveillance. The SA Review AIDS Response report (2011) on the implementation of the NSP of 2007-2011 found that among plans which were not adequately achieved, one of them was lack of adequate provision of psychosocial care and support for PLWH.

During this era the ravaging effects of HIV and AIDS in South Africa was evident as Matjila, Hoosen, Stoltz and Cameron (2008) and Chibango (2013) estimated that in

2007, there were about 350 000 people believed to have died from AIDS in South Africa. They attributed this to many factors, including but not limited to, South Africa's high population prevalence of HIV infection, high-risk heterosexual behaviour, the practice of having multiple concurrent sexual partners, unprotected sex and sexual relations with persons whose HIV status is not known, and high levels of sexually transmitted infections, among others. The gaps and successes of the NSP informed the development of the next NSP.

- The period 2008 -2018

The presidential announcement on World AIDS Day of 2009 on ARV was identified by Chibango (2013) as government commitment to fight HIV and AIDS as it had major pronouncements on HCT and treatment. According to the NDOH (2010), the SA President launched the HIV Counselling and Testing (HCT) campaign in 2010 to provide the general public with the opportunity to be tested for HIV, screened for TB, and other chronic diseases. As established by NDOH (2010) and Abbas, Glaubius, Mubayi, Hood and Mellors (2011), the campaign yielded good results in that by the end of June 2010, over 13 million had tested for HIV.

The third National Strategic Plan was developed, and named HIV, STIs and TB, 2012-2016 and was referred to as 'a national battle plan' against HIV, STIs and TB. The NSP is a comprehensive approach in that as established by Abbas et al. (2011), its development was guided by various reports such SA Global AIDS Response Progress Report (2012), the Know Your Epidemic (KYE) report, and the situational analysis of TB and other epidemiological studies. Those reports identified gaps, mismatches and missed opportunities regarding the previous NSPs. Consequently, it was anchored on five goals, which were to reduce the number of new infections by 50%, ensure that at least 80% of people eligible for treatment are receiving it, reduce the number of new TB infections and TB deaths by 50%, ensure that the rights of PLWH are protected, and to halve stigma related to HIV and TB. The review report on the implementation of this NSP could not adequately highlight the implementation of psychosocial care and support component in HIV care.

The South African National Strategic Plan on HIV, TB and STIs 2017–2022 was developed based on the review reports. According to the UNAIDS (2010), Abbas et al. (2011) and the South African Global AIDS Response Progress Report (2012: 21), TB-HIV co-infection is extremely common in SA. This was corroborated by the WHO Global Tuberculosis Report (2015), which found that SA is a country with the second highest incidence of TB in the world. The PRIMASYS (2017) confirmed that the level of HIV TB co- infection in SA is high with as many patients as 61% having both HIV and TB. Hence, the inclusion of TB in its name NSP for HIV, TB and STIs 2017-2022. As shown by the UNAIDS (2018), the South African National Strategic Plan on HIV, TB and STIs 2017–2022 aims to accelerate progress towards meeting the Fast-Track Targets by 2022 by reducing new HIV infections; improving treatment, providing care and support; reaching key and vulnerable populations; and addressing the social and structural drivers of HIV, tuberculosis and sexually transmitted infections. The plan shall be implemented through nine provincial implementation plans.

As reflected in the timelines of different political administrations, the SA AIDS response focused mainly on the establishment of AIDS response structures, protection of human rights for PLWH, and accessible medical treatment. The provision of a coherent, sustainable psychosocial support structure remained at the periphery of the AIDS response. Prior to 1994, the AIDS response lacked commitment to explicitly provide a strong well-coordinated psychosocial care, especially at the entry level into care, while post-1994, the AIDS response mainly commanded a human rights and disease-based approach. The psychosocial care and support component is implemented in a piece meal approach either by health professionals or by PLWH in nongovernmental organisations, and in many instances, PLWH are involved as tokens. PRIMASYS (2017) confirmed that the training of healthcare professionals is still hospi-centric and curative. The SA Stigma Index Report (HSRC, 2015) confirmed worrying levels of stigma and discrimination, in particular self-stigma which warrants access to adequate psychosocial component in HIV care. It also established its negative impact on HIV care. This study delves deeply into experiences of PLWH in that they can give direction

on what and how interventions need to be done for better health outcomes among PLWH.

3.6 CONCLUSION

When HIV and AIDS was first discovered, communities of the world generated a meaning of HIV and AIDS, and in the process, created a social problem, namely stigma and discrimination. To date stigma and discrimination is a problem which undermines the bio-psychosocial developments and breakthroughs achieved in HIV care. Communities had internalised the meaning accompanied by negative connotations about HIV and AIDS. Effective campaigns to fight stigma and discrimination should go beyond information dissemination, but engage people in dialogues in different settings so that they can actually talk it out.

The South African AIDS response post-1994 adopted an access model for the provision of healthcare services as it is free at point of entry into care. The prerequisite for the model to be effective is the provision of adequate resources, namely infrastructure, financial and human resources. The gap in the healthcare system is the healthcare workers training which is still mainly hospi-centric and curative. Due to the nature of complex needs of PLWH, healthcare workers should receive continuous professional training which empowers them to work in a user-led service environment.

CHAPTER FOUR

SOCIAL WORK INTERVENTIONS IN THE CONTEXT OF PEOPLE LIVING WITH HIV AND AIDS

4.1 INTRODUCTION

There are many developments and medical breakthroughs achieved in the quest to fight the epidemic, but PLWH still experience significant coping challenges in their everyday lives. This is evident from the nature of request for services to alleviate their vulnerability. Stigma and discrimination, which is as old as the discovery of the epidemic and pre-existing conditions such as poverty, mental health problems, and alcohol and drug dependence, among others, escalates the difficult experiences of living with HIV. Social Work interventions in the context of people living with HIV is a presentation of common problems and intervention activities which are carried by social workers in the generic as well as in public health settings. Intervention activities are rendered for the individual, family, group and community to counteract feelings of hopelessness and powerlessness which are experienced by PLWH in their day to day lives.

4.2 COMMON PRESENTING PROBLEMS AMONG PEOPLE LIVING WITH HIV AND AIDS

The HIV epidemic created new and complex human needs. Some are a combination of pre-existing needs which are worsened by living with HIV or vice versa, while others are new ones which arise as a result of the HIV diagnosis. Social Work intervention receive requests by PLWH, which include but not limited to poverty, post-HIV diagnosis reactions by individual PLWH and their families, stigma and discrimination, mental health problems, among others. Consequently, Social Work interventions focus on the empowerment of individual, family, groups of PLWH and the community.

4.2.1 Poverty and Living with HIV AND AIDS

Poverty in certain circumstances is older than HIV and AIDS. A significant number of authors, including Bloom (2002), UNAIDS (1999, 2004, 2018), Lwelunmor, Airhihenbuwa, Okoror, Brown and Belue (2006) and Obi et al. (2010) concur that globally, HIV prevalence is higher in poorer countries than in richer countries, and further established that poorer countries also suffer from other infectious diseases, experience food insecurity, and other serious problems. They concur that in general, regionally, the higher the prevalence rate, the lower the economic performance. This is supported by Mbirimtengerenji (2007) and UNAIDS (1999, 2004, 2017), who showed that this comparison between HIV prevalence and economic performance at the regional level is conclusive as Africa constitutes 12% of the world's population but accounts for 70% of global HIV infections.

However, Bloom (2002) and UNAIDS (2005) argued that there are exceptions to the relationship between HIV and AIDS and poverty at a country level, in particular in Africa where some countries with very high HIV prevalence rates are also among the richest such as South Africa and Botswana, but poorer countries such as Malawi, Kenya, Uganda, and others have lower HIV prevalence than South Africa. A similar finding was made by Statssa (2011), who compares HIV prevalence among SA provinces. National Department Of Health (2011) survey among women attending ante-natal clinic survey revealed higher HIV prevalence among women attending antenatal clinics in richer provinces and lower HIV prevalence in poorer provinces like Limpopo. This suggests that there is more to the relationship between HIV transmission and poverty alone, especially on a country level.

An argument advanced by Bloom (2002), UNAIDS (2004, 2005) and Coates et al. (2008) is that the difference in HIV prevalence is due to weaknesses in strategy, policy and programme implementation, and poor institutional response, which causes some countries in the same region to have higher prevalence rates than others. The

interpretation of the relationship between poverty and HIV transmission is neither simple nor simplistic. However, Mbirimtengerenji (2007), Coates et al. (2008) and Iravani, Esmaeilzadeh and Parast (2014) discovered that the relationship between HIV and poverty at the household level is conclusive. This was also confirmed by Steiner, Black, Rees and Schwartz (2016), UNAIDS (2005, 2016), Ezeokana et al. (2009) and Lakshmi (2017), that there is a bi-directional relationship between HIV and AIDS and poverty at a household level.

Firstly, UNAIDS (1999, 2004), Coates et al. (2008) and Iravani et al. (2014) found that poverty worsens the impact of living with HIV and AIDS in that people living in poor conditions do not have access to better services such as employment, proper housing, food, clean water, sanitation, and educational opportunities. These areas are usually socially and politically marginalised with poor infrastructure. The quality of lives of people who are poor is undernourishment, poor health and compromised immune system from other health conditions. Iravani et al. (2014) established that when they acquire HIV while living in an environment with poverty as a pre-existing factor, they struggle to thrive as compared to other PLWH who reside under better living conditions. Coates et al. (2008) and Iravani et al. (2014) asserted that the capacity of individuals and households to cope with HIV and AIDS depends on their initial endowment of assets – both human and financial.

As confirmed by Statistics South Africa (STATSSA) (2014), estimates of poverty in South Africa range from 46% to 65%, and is particularly severe among one third of the population that live in rural areas where poverty exceeds 70%. The onset of a health condition such as living with HIV for the poor creates a double burden as they have to make ends meet with their meagre resources, which includes providing for new financial needs which arise out of a family member living with HIV, and require additional resources which have to be provided by families. In addition, Lwelunmor et al. (2006) Chitereka (2009) and HSRC (2015) established that care of a person who is sick with AIDS is both an emotional and a financial strain on household members as they incur care related expenses, prevents carers from working as they take some time off work to

provide care, mounting medical bills, and burial expenses which ultimately push families into deeper poverty.

The second dimension is that HIV worsens poverty. A significant number of authors such as Bachmann and Booysen (2003), Makoae (2005), Li, Wu, Wu Z, Sun, Cui and Jia (2006), Lwelunmor et al. (2006) and Coates et al. (2008) concur that HIV is the fastest way for families to move from relative wealth to relative poverty .as families are forced to channel financial resources to support family members living with HIV and AIDS. It was established by (Seeley, 1993; Katapa, 2004; Chitereka, 2009) that HIV wears down family resources. People living with HIV and their families are desperate for a cure. Consequently, they pursue all avenues to find a cure for the loved one. Pursuant to find a cure for HIV, they usually pay exorbitant prices in the hope that they shall find a cure for HIV infection. They exhaust even their most vital financial reserves as they even sell cars, livestock, property, get into loan sharks and even retire early from employment so that they can access their pension pay-out to pursue other treatment options. As shown by Bor (1990), caretakers may even lose income as they stay away from work to care for a sick family member.

In this way, poverty worsens HIV and AIDS. Secondly, HIV and AIDS impoverishes families when they usurp their financial resources and become poor; they are unable to afford bare necessities such as to buy food, provide proper housing, and pay medical expenses. Consequently, PLWH become locked in living with HIV and poverty circle.

4.2.2 Individual Reactions to the HIV Diagnosis

There is a general consensus by Kübler-Ross (1969), Kübler-Ross and Kessler (2005), Baingana, Thomas and Comblain (2005), Sikkema, Watt, Drabkin, Meade, Hansen and Pence (2010) and Breet, Kagee and Seedat (2014) that HIV diagnosis evokes intense emotions similar to those experienced by those who lost their loved ones through death. Common emotional reactions have been identified by Van Dyk (2005, 2010), Catalan, Harding and Sibley (2011) and Agrawal, Jain, Agrawal, Singh and Yadav (2015) and

Zeligman (2018) as those of shock, disbelief, anger, shame, self-blame, guilt, anxiety, and depression. Iravani et al. (2014) confirmed that such emotional reactions make a person physically, psychologically and socially disabled. The disabling effect of the diagnosis is experienced in some of the following reactions.

- Shock and denial

Due to the devastating nature of HIV diagnosis, fear of stigma and discrimination, Bourne et al. (2011), Supriya (2013) and Zeligman (2018) found many people are reluctant to outrightly admit their diagnosis. UNAIDS (1999), Bekker et al. (2012) and Zeligman, Barden and Hagedorn (2016) indicated that shock and denial may stem from the assumption that one is not susceptible to HIV infection. The diagnosed may believe or convince themselves in different ways such as that the HIV test came out wrong, it is not accurate or that there has been a mixed up of test results.

Secondly, a significant number of authors (Theuninck, Lake & Gibson, 2010; Peters, 2013; Zeligman, 2018) concur that denial is a common and normal reaction which works as a form of defense mechanisms to protect oneself from intense mental pain. Derlega, Winstead, Oldfieldand and Barbee (2003) cautioned that while this reaction is natural and normal at first, if it is used continuously to cope for living with HIV, it ultimately defeats its purpose and may be a source of maladaptive coping behaviour.

Service users who seek intervention are usually caused by their loved ones to seek intervention as they become concerned about PLWH level of denial which, consequently fail them to seek HIV care. Actually, when they ultimately seek Social Work intervention, they are found not to be coping either at home, work or both settings.

- Anger

Kübler-Ross (1970), Wright (2011) and Peters (2013) showed that the inability to manage negative feelings about HIV diagnosis may lead to frustration, which in turn may evolve into anger. Prolonged anger as shown by Lakshmi (2017) and Zeligma (2018) impedes rational thinking about diagnosis disclosure, especially to partners,

starting on ARV and adherence to treatment, among others. Many sources such as Kübler-Ross and Kessler (2005), Peters (2013) and Zeligman et al. (2016) revealed that anger among PLWH is either directed towards the self about how one got the virus or angry that one did not know that one is living with HIV. They further indicated that anger is also directed at the person who is suspected to be the source of infection, and even against God for not protecting them. When they ultimately seek intervention, usually they experience poor health outcomes.

- Self-blame and Shame

Fear of Stigma and discrimination makes living with HIV difficult as UNAIDS (2004), HSRC (2015) and Zeligman et al. (2016) established that post-diagnosis, many PLWH try to imagine what other people think of them. It hurts people to be diagnosed with HIV UNAIDS (2004) as they feel that they acquired a disease which is viewed to be a disease of bad people. Consequently, van Dyk (2005, 2010), Zeligman et al. (2016) and Lakshmi (2017) argue that post-HIV diagnosis, many PLWH think poorly of themselves, experience feelings of nothingness and guilt about the self, and self-blame. UNAIDS (2004) and Zeligman (2018) asserted that the source of feeling of self-blame and shame is the societies' persistent negative perceptions, misinformation, and prejudices about HIV transmission, which cause many PLWH to react to an HIV diagnosis with a lot of pain and shame. Damar and de Plessie (2010), Peters (2013), Sultana (2014) and Lakshmi (2017) cautioned that when these reactions are not resolved, they are known to give rise to deep feelings of unhappiness which may be difficult to manage, and which interfere with the day to day life, which may lead to maladaptive behaviours.

4.2.3 Post-Diagnosis Reactions by Family Members

When a family member experiences intense emotional reactions about the diagnosis Makoae (2005), Linsk and Mason (2004), Muula and Mfusto-Bengo (2005) and Nkosi, Kipp, Laing and Mill (2006) established that family members too, experience similar feelings and concerns faced by PLWH, such as worrying about progression of the disease, fear of losing a family member, anger, shame, sadness, stigma and

discrimination, among others. Children in particular worry when their parents get sick. It was established by Sherr, Cluver, Betancourt, Kellerman, Richtere and Desmond (2014) and Islam et al. (2014) that a parental disclosure of the diagnosis has been found to have either positive or negative impact on children. They may experience stigma by association with their parents, and may even be teased by their peers. Richter (2010) Chi and Li (2013) found that children experience social, psychological and physical challenges such as fear, isolation, depression, anxiety, grief, low self-esteem, and trauma. Furthermore, Rotheram-Borus, Flannery, Rice and Lester (2005) and Lwelunmor et al. (2006) found that some children find it difficult to cope with the diagnosis of their parents, which may manifest as bullying others, poor school performance, school dropout and uncontrollability, among others. A study in the United States by van Empelen (2005) and Lyons (2008) showed that HIV-negative children experienced stress when their mothers are living with HIV. In addition to physical and psychological reactions to parent's diagnosis, Coates et al. (2008) showed that it impacts on their childhood as some children are forced to assume parental roles in the family to support a sick parent. This role reversal robs children of their childhood and quality parent-child relationship. They further indicated that such stress is reduced when children receive social support from others, such as parents and teachers.

It is known by Gachanja, Burkholder and Ferraro (2014) and Iravani et al. (2014) that HIV diagnosis alters family relationships, in particular spousal relationship. There are reports by Tshweneagae, Oss and Mgutshini (2015) that some of these PLWH were deserted or abandoned by their spouses. Thomas (2006) and Iravani et al. (2014) attributed it to exhaustion from providing care to a sick partner. In addition, UNAIDS (2004) indicated that it may happen as caregivers who are mainly spouses experience a reduced life satisfaction or even feel burnout as they care for loved ones living with HIV and AIDS. The family is the first strong line of care and support for family members in distress. As a result, Levine (1990), Ankrah (1993) and Lyons (2008) advocated that PLWH and their family members should be provided with support to assist them continue living together to uphold commitment, and to provide mutual dependence among its members.

4.2.4 Stigma and Discrimination

HIV related stigma is as old as the discovery of HIV and AIDS and is singled out by (Green et al., 2003; Khan & Lowenson, 2005; Lawson, Gardezi, Calzavara, Husbands, Myers & Tharao, 2006; Rohleder & Gibson 2006; Yi et al., 2015) as the most important factor which produces and worsens the psychosocial effects of living with HIV in that its intention is to isolate, disadvantage, belittle, discredit, label, exclude, cause discomfort, cast doubt and shame, among PLWH. Many PLWH who seek Social Work interventions experience stigma and discrimination mainly from the family and workplace.

▪ Stigma and discrimination in the family

The family is a refuge for its members when they experience relationship challenges. But Bor, Miller and Goldman (1993) and Rotheram-Borus et al. (2005) noted that the HIV and AIDS epidemic put the role of families to a test as some families are reported to have actually stigmatised and discriminated PLWH.

Social workers are inundated with PLWH who seek intervention when they are dissatisfied with the treatment they receive from their families. The family in many societies is identified (Lohmann & Lohmann, 2008; Li, Lee, Thammawijaya, Jiraphonsa & Rotheram-Borus, 2009; Lyons, 2008; Ssali, Atuyambe, Tumwine, Segujja, Nekesa, Nannungi & Wagner, 2010; Madiba & Matlala, 2012; Idler, 2014) as a critical source of support for their close family members in distress. But some families are known to have subjected PLWH to different forms of stigma and discrimination. A significant number of sources, such as Parker and Birdsall (2005), UNAIDS (2006), Cairns (2008), Sultana (2014) and HSRC (2015) identified common forms of stigma and discrimination experienced by many PLWH in their families, namely they are blamed for the infection, ostracised, deserted, abandoned, made to use separate dwellings, allocated separate utensils, refused permission to prepare food with other family members, forced to conceal their HIV status, disowned and disinherited, among others. The HIV epidemic puts a family to a test with regard to its protective role.

- Stigma in the workplace

Workplaces for many PLWH have proven to be a stressful environment. They interact with colleagues, managers and the consumer of their services. It has been established by the SA Stigma Index Report by HSRC (2015) that PLWH fear being talked about than any aspect of living with HIV. The ILO (2010) also discovered that many PLWH usually fear that their colleagues and managers talk about them. This was also established by Odetoyinbo, Stephens and Welbourn (2009) and Morolake et al. (2009), that this problem is also found even in developed countries in that in the United Kingdom (UK), many staff living with HIV employed by the National Health Service are still terrified of their colleagues and managers finding out their HIV status. Basset-Jones and Loyd (2005) and Kaur (2013) concurred that employees who experience real or anticipated harm or threat in the work environment are less likely to be productive, and such denies them the opportunity to maximally use their potential and be the best they can be.

Social Work intervention records reveal that due to such discomfort, PLWH usually seek assistance to change work stations, transfers, contemplate early job exits and resignations, among others. Those PLWH who keep their jobs present common reports which include dissatisfaction with reallocation of duties to a lower grade without consultation, perception that one is set up for failure due to lack of support from management and colleagues, allocation of duties which one is not trained to carry out, and resentment by colleagues after being away from work due to ill-health, among others. The International Centre for Research on Women (ICRW) (2006) and the International Labour Organisation (2010) noted with concern about the prevalence of stigma and discrimination and its negative impact on the quality of life of many PLWH. The prevalence of stigma and discrimination was further confirmed by the Stigma Index survey UNAIDS (2017), which also found that more than 1 in 10 people living with HIV reported that they had been refused employment or a work opportunity because of their HIV status in the 12 months before the survey.

4.2.5 Interfacing of Alcohol and Drug Abuse Treatment and HIV and AIDS

Meyer, Althoff and Altice (2013) discovered that alcohol consumption in sub Saharan Africa is high as compared to other regions such as Europe and Western Pacific regions. They confirmed that in Africa, the rate of episodic drinking per drinker is 25.1%, Europe is at 11.0% per drinker while in the Western pacific it is at 8% per drinker. The high alcohol drinking pattern in Africa and the high HIV prevalence is a worrying combination which Hahn, Woolf-King and Muyindike (2011) and Morojele, Nkosi, Kekwaletswe, Saban and Parry (2013) identified as areas which need special attention in that it worsens the impact of living with HIV and AIDS on the individual, family and community.

The relationship between alcohol and HIV infection is twofold. Firstly, Gallego, Victoria and Catalan (2000) and National Institute on Drug Abuse [NIDA] (2012) reported that alcohol and drug abuse may precede acquiring HIV, and may have increased chances of acquiring HIV due to unsafe sexual behaviour following intoxication. Thereafter, Kalichman, Simbayi, Kaufman, Cain and Jooste (2007), Woolf-King and Maisto (2011) and Morojele et al. (2013) established that once they are living with HIV, they may delay to test for HIV and related services. When people ultimately get diagnosed, they may not adhere to treatment, and alcohol consumption may interfere with the efficacy of ARV treatment.

Secondly, as alerted by Baingana et al. (2005), WHO (2008), NIDA (2012) and Supriya (2013), in the post-HIV diagnosis, some PLWH may slip into alcohol and drug abuse to numb the trauma of living with a stigmatised health condition which neither has a vaccine nor cure. UNAIDS (2007) found that those PLWH who dependent on alcohol and drugs are living with twin epidemics which do not enjoy support from the general community in that they are both stigmatised health conditions. Hence, UNAIDS (1999), Gray and Vawda (2017) and Duby et al. (2018) confirmed that people who used drugs may delay entrance into care due to fear of arrest, feelings of guilt, low self-esteem,

fear, stigma and discrimination. Duby et al. (2018) further indicated that they may also delay HIV testing as pretest assessments often involve questioning about substance use histories. They may feel uncomfortable. Consequently, they are a hard to reach group by HIV prevention services.

Consequences of living with HIV, dependence on alcohol and drugs were singled out by Meyer et al. (2013) as chronic health conditions which, if left untreated, may result in negative medical, psychological and social consequences. The drug most commonly used by PLWH are cocaine, alcohol, cannabis, tobacco and opioids. According to Altice, Kamarulzaman, Soriano, Schechter and Friedland (2010), WHO (2010) and Abbas et al. (2011), drug abuse among PLWH is associated with delayed HIV diagnosis and care, poor treatment adherence, increased risky sexual behaviour and HIV transmission, morbidity and mortality from HIV and non HIV related diseases. Furthermore, the National Institute on Drug Abuse [NIDA] (2012) reported that drug abuse can also worsen the progression of HIV and its consequences, especially in the brain as HIV positive drug users have been found with high rates of HIV Associated Dementia (HAD) compared to HIV positive non-drug users, and tend to have more rapid neurological progression than non-drug users.

4.2.6 Mental Illness among People Living with HIV and AIDS

A significant number of authors such as (Green et al., 2003; Yoska, Kaliski & Benatar, 2008; Stephenson, 2009; Feyissa et al., 2012; Yi et al., 2015). Contributory factors for the high prevalence have been identified (Chandra, Desai & Ranjan 2005; Baingana et al., 2005; Joska, Kaliski & Benatar, 2008; Li et al., 2009; Li & Liang, 2009; Yi et al., 2015; UNAIDS, 2016, 2017) found that mental illness among PLWH is higher than in the general population These scholars concurred that the high mental health prevalence is due to psychological pressure, HIV medication side effects, the effect of HIV infection on the central nervous system and mental illness as a predisposing factor.

- Psychological pressure

Due to fear of stigma and discrimination, many PLWH experience psychological pressure, which Khanna and Madoori (2013) warned that if left attended, it may escalate into poor mental health functioning. This is supported by a significant number of authors (Baingana et al., 2005; Joska et al., 2008; Yi et al., 2015; UNAIDS (2016, 2017) who confirm that psychological pressure and psychiatric problems among PLWH are a consequence of lack of support due to stigma and discrimination, and the psychological pressure of copying with a serious medical illness which neither has a vaccine nor cure. Chandra et al. (2005), Zeligman et al. (2016) and Zeligman (2018) identified depression as the most common psychiatric condition among PLWH.

- HIV medication side effects

There are unintended consequences of some anti-HIV drugs which many authors such as Rihs, Begley, Smith, Sarangapany, Callaghan, Kelly, Post and Gold (2006), Carter and Hughson (2012) and Nebhinani and Matoo (2013) concur that they are known to induce mental health disorders. In particular, Carter and Hughson (2012) reported that Rilpivine (Edurant in the combination pill Eviplera) is known to cause nightmares, depression and mood swings, while interferon, which is used for the treatment of hepatitis C, can also cause depression. Another anti-HIV drug which is attributed to unintended mental health consequences is Efavirenz (sustiva in the combination pill Atripla), which Rihs et al. (2006) reported that it can cause psychological problems such as dizziness, headache, confusion, impaired concentration and abnormal dreams. Furthermore, Nebhinani and Mattoo (2013) showed that Zidovudine causes mania, depression, insomnia and headache, while nevirapine and Abacavir can cause psychosis, AIDS related Dementia (HAD) and psychosis, among others.

- The effect of HIV infection on the central nervous system

It was established by the International Foundation for Alternative Research in AIDS [IFARA] (2008), WHO (2010) and Nebhinani and Mattoo (2013) that HIV has a direct effect on the central nervous system. Consequently, as discovered by Owe-Larsson, Säll, Salamon and Allgulander, the British Psychological Society, the British HIV

Association and Medical Foundation for AIDS and Sexual Health (2011) and Yi et al. (2015), HIV infection can masquerade as a serious mental illness as it causes neurological changes and the structures of the central nervous system which result in some complications. It was particularly found by Nebhinani and Mattoo (2013) that such effect causes complications in the functioning of the brain, and consequently, affects thinking, judgment, attention and the ability to deal with emotional situations. They further indicated that some complications which are a consequence of the HIV infection on the central nervous system are neuropsychiatric disorders, HIV encephalopathy, depression, mania and cognitive disorders, among others.

- ▪ Mental illness as a predisposing factor

Among many PLWH, mental illness is a pre-existing condition. The British Psychological Society and the British HIV Association and Medical Foundation for AIDS and Sexual Health (2011) confirm that psychological and psychiatric conditions are more prevalent among PLWH than in the general population in that mentally ill people are likely to be infected with HIV infection as they are vulnerable to sexual molestation; they are likely to engage in risky sexual behaviours due to impaired judgment; and they are unable to understand and use information about HIV prevention or negotiate for safer sex relations.

4.2.7 Common Mental Health Conditions

Common mental conditions which are overrepresented among PLWH which may cause them to seek intervention have been singled out by Chandra, Ravi, Desai and Subbakrishna (1998), Baingana et al. (2005) and Owe-Larsso et al. (2009) as depression, demoralisation disorder and anxiety, among others, These conditions are known to have an impact on the day to day social functioning of PLWH and significant others.

▪ Depression

Depression is seen by Chandra et al. (1998), Chandra et al. (2005) and Strydom (2017) as a disabling state of sadness caused by too much worry which, on a physical level, can be a medical illness caused by injury to brain cells. It is the most common psychiatric diagnosis in people living with HIV/AIDS (Chandra et al., 1998; Eller, 2014). Furthermore, Chandra et al. (2005) found that the prevalence of depression among PLWH is twofold than in the general population, with a range of 5%-25% or even higher.

The impact of depression on the day to day functioning of an individual Chandra et al. (2005), baingana et al.(2005) as well as Khanna and Madoori (2013) could result in poor self-care, poor nutritional state, medical neglect, loss of interest in work, loss of interest in the future, loss of interest in work, experiences of severe fatigue, poor concentration, experience flight of ideas, feeling sad, anxious, irritable, or hopeless, gaining or losing weight, sleeping more or less than usual, feeling worthless or guilty, and thinking about death or giving up on the spiritual level, among others.

▪ Demoralisation disorder

According to Baingana et al. (2005), demoralisation disorder has many symptoms similar to depression, such as sadness, feelings of helplessness and sleep disturbances. They asserted that it is better treated through psychotherapy and not medication.

▪ Anxiety

Anxiety is described by Agrawal et al. (2015) and Strydom (2017) as persistent worry. When it relates to HIV diagnosis, it is caused by not knowing what to expect now that one is diagnosed with HIV; not knowing how one will be treated by others when they find out about the diagnosis; not knowing how to disclose the diagnosis to significant others; and suspecting that others are talking, gossiping or spreading rumours about one's diagnosis, among others.

4.3 SOCIAL WORK INTERVENTION FOR PEOPLE LIVING WITH HIV AND AIDS

HIV diagnosis is a traumatic event which Schonnesson and Ross (1999), Khanna and Madoori (2013) and Maina, Mill, Chaw-Kant and Caine (2016) confirmed that it may draw an individual into a realm of hopelessness and powerlessness. The advice by (Coates et al., 2008; Bekker et al., 2012; UNAIDS, 2013; Iravani et al., 2014) is that to recover from the disabling effect of the diagnosis, PLWH require multidisciplinary interventions to restore and empower them for better functioning, and Social Work is one discipline whose focus is empowerment of the vulnerable.

As further elaborated by the International Federation of Social Workers [IFSW] (2000), Marsh (2003), Chitereka (2009), Iravani et al. (2014) together with Chandrika (2015), the mission of Social Work as a profession is to empower vulnerable groups, fight social injustice, restore and enhance social functioning, and to promote social change in social conditions to reduce human suffering. Many PLWH who seek Social Work intervention bear a disabling effect of the diagnosis on many levels. Due to the complex needs of PLWH, Block (1991), Anderson, Wilson, Mwansa and Osei-Hwedie (1994) and Iravani et al. (2014) recommended that Social Work interventions should focus on helping and empowering PLWH on five dimensions, namely the personal, social, economic, political and educational dimensions.

- ▪ Personal empowerment

Despite the disabling impact of the diagnosis, Chernesky and Grube (2000) acknowledge that PLWH still have strengths and capacities to change their circumstances, and recommended that any intervention should assess those strengths and build on new ones to help the user to achieve a better life. PLWH may have myths, misconceptions and prejudices about HIV Social Work interventions. As advocated by Krisberg (2006) and Linsk and Keigher (1997), a social worker's role is to enable, teach

and support an individual to change from misinformed thinking about HIV and AIDS for better health outcomes.

- Social empowerment

As echoed by Block (1991), personal empowerment precedes social empowerment. Social empowerment entails that PLWH are empowered to influence transformation in institutions which provide them with service, fight for group freedom, dignity and self-governance. Midgley (1981) asserted that Social Work interventions in this dimension teaches PLWH about activities and processes within institutions which increase a sense of responsibility and self-governance.

- Economic empowerment

Social Work intervention focuses on empowering an individual to provide for basic needs such as food, housing, shelter and clothing. Krisberg (2006) and Linsk and Keigher (1997) asserted that social workers should be better informed about government, private and community based organisations which alleviate financial hardships and those which focus on income generating activities.

- Political empowerment

The UNAIDS (1999, 2004), Morolake et al. (2009) and Piot et al. (2007) affirmed that politics, HIV and AIDS and healthcare is a lifeline for PLWH. Krisberg (2006) and Linsk and Keigher (1997) highlighted that political empowerment for PLWH is a vehicle for them to attain social justice and equality. Social Work should educate and empower PLWH to participate at different levels of political systems to influence decisions and change which affect their lives.

- Educational empowerment

Educational empowerment is acknowledged by Shernoff (1998). Coates et al. (2008) is a vehicle which ensures that one is able to compete in the open labour market. Furthermore, a higher level of literacy as seen by French, Greeff, Doak and Watson (2014) probably determines the manner in which HIV is perceived. Social Work

interventions focuses on encouraging vulnerable people to acquire better educational levels in order to improve chances of better economic opportunities. Social Work as a discipline provides interventions to individual, family, group and community.

4.3.1 Work with Individuals

Components of Social Work with individuals have been identified by the International Federation of Social Workers (IFSW, 2000), Marsh (2003), Chitereka (2009), Iravani et al. (2014) and Chandrika (2015) as intake, assessment, counselling, linkage with other services and support. They asserted that a social worker and service users enter into an intervention contract and provide an environment which encourages them to work at identified needs, problems and challenges.

- Intake, assessment and counselling

Initial Social Work intervention for every service user is intake, assessment and intervention contracting. This phase is intended to establish strengths and weaknesses within the service user and the environment. Khanna and Madoori (2013) and Maina et al. (2016) established that a pre-ARV era belief that HIV transmission is fatal is still prevalent among PLWH, and consequently, advocate for the newly diagnosed to receive immediate care to disentangle them from such thinking. During individual interventions, Iravani et al. (2014) noted that social workers conduct intake and initial assessment whose aim is to understand the needs and concerns of service users in different aspects of life in relation to the HIV diagnosis, such as current knowledge of HIV and AIDS matters, current health status, mental health, alcohol and substance use, job security, family relationship functioning, religious affiliation, source of support and sexual reproductive health, among others. Subsequently, an intervention contract is drawn for subsequent interventions. Yadav (2010), Marashe (2014) and Zeligman (2018) emphasised that subsequent interventions even after PLWH has stabilised are significant as they facilitate acceptance of the diagnosis, teach coping skills, promote assertiveness, reduce isolation, and consequently set PLWH on a path to attain post-traumatic growth. Furthermore, Bartlett and Finkbeiner (2001), Nott and Vedhara

(2000), Lau, Tsui, Li, Chung, Chan and Molassiotis (2003) and Chandrika (2015) recommended subsequent Social Work counselling, care and support sessions as they help PLWH to restore their capacity to experience wholeness; help them to be aware of inner strengths to help them cope with living with HIV; support with adherence and medication side effects; assist them with disclosure decisions; and empower them with strategies to fight stigma and discrimination. Based on the nature of the presenting problems, a social worker may link service users with others.

▪ Linkage with other services and systems

The second component of HIV case management involves linkage with other services and systems, and requires that social workers take on the role of a services broker. Krisberg (2006) and Linsk and Keigher (1997) alerted that the most common overlapping systems that clients and workers interface with are governmental, medical, and legal systems as PLWH may require services other than those provided by social workers.

▪ Medical and legal service linkage

Shernoff (1998) noticed that the medical system provides PLWHA referrals to physicians, specialising in infectious diseases and related conditions, while the legal system also provides relevant services to PLWH by assisting them in the preparation of living wills, estate planning, power of attorney orders, and documentation of domestic partnerships. Also, living with HIV and AIDS can make PLWH to be targets of stigma, discrimination and harassment. Consequently, PLWH may require help with legal proceedings.

▪ Alcohol and drug abuse interventions for PLWH

Treatment of alcohol and substance abuse is a major component of HIV prevention because (Kalichman et al., 2007; Coates et al., 2008; Bekker et al., 2012; NIDA, 2012) heavy alcohol use and drugs remain major drivers of HIV transmission. In support of this assertion, UNAIDS (2007) and Altice, Bruce and Lucas (2011) advocated for medical treatment as a strategy for PLWH who are alcohol and drug dependent as it

improves HIV treatment outcomes, retention into care, quality of life socioeconomic status and social functioning.

Social Work interventions for alcohol and drug dependence in South Africa is guided by the National Drug Master Plan (2012-2016), which is a national strategy to combat substance abuse. It is also informed by the Prevention and Treatment for Substance Abuse Act. No 70 of 2008, in particular, section 3(1) b, which focuses on harm reduction. The section provides for the holistic treatment of service users and their families to mitigate the social, psychological and health impact of substance abuse. Consequently, Social Work interventions provided are biopsychosocial in nature and include assessment, detoxification, family psychosocial care and linkage with other recovering service users.

As shown by the UNAIDS (2007), the first medical treatment is for one who is alcohol and drug dependent is detoxification, which is the first step towards recovery and the first door through which service users enter treatment. According to UNAIDS (2007), Bruce, Kresina and McCance-Katz (2010) and Pollack and D'Aunno (2010), the main aim of detoxification services is to manage withdrawal in a safe and comfortable environment by medical and non-medical interventions. Furthermore, Bruce et al. (2010) and Pollack and D'Aunno (2010) emphasised that on its own, medical detoxification is unlikely to be effective in helping individuals achieve lasting recovery. Consequently, Wolfe, Carrieri and Shepard (2010) and King, Vidrine and Danysh (2012) asserted that detoxification should be accompanied by psychosocial interventions as further preparation for maintaining   abstinence and promoting rehabilitation. Morojele et al. (2013) advised that for such interventions to be effective, long term sessions should be offered to PLWH either as individuals or in groups.

- ▪ Mental healthcare interventions

Psychosocial and medical interventions as emphasised by Sikkema et al. (2010) are important for the individual as well as family caregivers. They require support to cope with the diagnosis of a loved one, and face reactions to the diagnosis of mental illness.

This intervention is guided by the provisions as outlined in the Mental Health Care Act, No. 17 of 2002 on protocols for working with voluntary, assisted, involuntary and emergency mental health patients. The role of the social worker is to educate the individual on the interface between ARV and mental health treatment and the significance of adherence to both medications.

4.3.2 Work with Families

Social Work intervention for families of PLWH is a cornerstone for better health outcomes among PLWH as they are a social system, and should receive tangible and intangible services. As cautioned by Maina et al. (2016), people living with HIV and AIDS do not only need medical care, but also social care, including food, housing, finances, employment and food, which is referred to as a social protection package (Sabates-Wheeler & Devereux 2008; Miller & Samson, 2012; Bateganya, Dong, Oguntomilade, Chutima & Suraratdecha, 2015). Sabates-Wheeler and Devereux (2008) elaborated that social protection package is all public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks, and enhance the social status and rights of the marginalised, with the overall objective of reducing the economic and social vulnerability of poor, vulnerable and marginalised groups of people affected by HIV and AIDS, who need tangible assistance such as food, housing, finance, employment and exemption schemes.

The South African Government strategy push frontiers of absolute poverty through social grants. According to PRIMASYS (2017), sixteen million people are recipients of social grants in SA. The UNAIDS (2004) showed that although the Social Security System does not explicitly target PLWH or those who are affected by HIV and AIDS, many households have access to disability, foster care and child support grants. Bateganya et al. (2015) found that the improvement in economic status of households has an impact on the quality of life of PLWH.

▪ Family counselling, support and education on HIV and AIDS

Families are a frontline support structure for PLWH. Hence, Bor et al. (1993), Derlega et al. (2003) and Li et al. (2006) strongly advocated for the inclusion of family in interventions for PLWH in that when one family member is diagnosed, its impact radiates on the entire family system. Families need to be empowered for better coping as PLWH need informed and empowered families because they provide PLWH with psychosocial support, financial matters, assist with diagnosis disclosure, support them with daily activities, provide medical assistance and protect them from stigma and discrimination, among others (Pequegnat, Bauman, Bray DiClemente Di-Iorio & Hoppe, 2001; Lau et al., 2003).

Family education and support involves social workers to educate PLWH and their support network of family and friends about the disease. Bekker et al. (2012) advocate for comprehensive HIV care for families to empower and support families to regain social functioning as a unit post-diagnosis. Furthermore, among couples, Social Work intervention should thus focus on the provision of information on HIV counselling testing, management of post-diagnosis reactions, diagnosis disclosure, treatment decisions, sexual reproductive health, future planning, and disclosure of couple status to their children. When needed, social workers could assist families with diagnosis disclosure to children. Gachanja, et al. (2014) suggest that disclosure of parents' diagnosis to children should take into account level of knowledge of HIV and AIDS. Due to possible reactions, families are assisted to engage in a thorough preparation of disclosure to their children. In such preparations, they may decide who they choose to be present or be available later when they disclose their diagnosis. Depending on their choice, Social Work intervention activity may render psycho education to the family supporter.

▪ HIV Counselling and Testing for couples

Social Work provides awareness and education and couple counselling on HIV prevention. Bekker et al. (2012) discovered that people are known to have changed their risky sexual behaviours and protected their partners after HCT uptake. Although

HIV and AIDS is recognised as a chronic, preventable and manageable, UNAIDS (2013) argues that preventing transmission, as well as decreasing morbidity and mortality and improving the quality of life for PHAs remains a major need. Coates et al. (2008) established that in sub-Saharan Africa, most transmission occurs between heterosexual cohabiting partners, with estimates of 60-95% of new infections. Furthermore, it was discovered by Dunkle, Stephenson and Karita (2008) that cohabiting couples in Africa represents the world's largest HIV high risk group. Social Work intervention targets all population groups. However, Coates et al. (2008) asserted that couples' HIV testing should be popularised as a significant HIV prevention strategy.

- Family psychosocial care for PLWH who are dependent on alcohol and drugs

The lives of people who are alcohol and drug dependent are often chaotically disorganised around substances. Wolfe et al. (2010) and Thompson, Mugavero, Amico, Cargill, Chang, Gross and Beckwith (2012) noticed that such disorganisation rearranges family social functioning as members attempt to respond to their needs. Broadhead, Heckathron, O'Connor, Selwyn (1998) and Daley and Miller (2001) discovered that families of recovering drug users have needs which should be provided for throughout the recovery process in that when a family member gets on the recovery process, families also need to be supported to change their relationship patterns in order to create an environment which supports the recovery process. Families play an important role in the treatment and recovery process of anyone living with comorbid diseases of drug abuse and HIV. It is important for intervention programmes to help families understand the drug dependence and recovery process, and learn about HIV and AIDS. Morojele et al (2013) indicated that interventions may be provided by professionals or lay counsellors, but they strongly advocated that to realise the benefits of treatment, clinical and social service should be offered in ways that are flexible, meaningful and convenient.

- Support families of mental healthcare users

Education and support on the improvement of nutritional status, treatment literacy and adherence to treatment of a mental healthcare user who is also living with HIV are

central to Social Work intervention activities. Families are assisted to recognise mental healthcare problems, risk factors, significance of adherence to both HIV and mental health needs, and when the need arises, families are assisted to secure admission of their loved ones into a mental health facility. This intervention is guided by the provisions as outlined in the Mental Health Care Act, no.17 of 2002 on protocols for working with voluntary, assisted, involuntary and emergency mental health patients.

4.3.3 Work with Groups

Social workers work with PLWH as service users or as HIV care partners in different settings, namely support groups for PLWH and stigma eradication programs

- Support groups for PLWH

As shown by Hyde (2013) and Steinberg (2010), working with groups is one method of Social Work intervention which encourages service users who experience the same circumstances to help one another until they feel better. In addition, Agrawal et al. (2015) reported that support group discussions help PLWH to improve self-efficacy, teaches active coping skills and expand social networks. Furthermore, it provides a non-threatening environment for PLWH, which is efficient in reducing internalised stigma as PLWH get to be in the company of other PLWH. Support group activities delivered by social workers include but are not limited to self-awareness and assertiveness and confidence building, stigma eradication skills, networking with other PLWH, activities, among others. They are intended to enhance cognitive and social functioning. Many outcomes from belonging to support groups are increased acceptance of one's diagnosis, diagnosis disclosure outside support group, social networks and assertiveness which are indicators of better coping.

- Involvement of PLWH in stigma eradication

Reports by UNAIDS (1999, 2001, 2004) show that people are more likely to hold stigmatising attitudes when they do not perceive that they know anyone living with HIV and AIDS. The UNAIDS (1999), Coates et al. (2008) and WHO (2010) advised that to

overcome this, programmes should use the creativity and energy of those living with HIV and those most affected by the epidemic to develop messages and strategies to promote knowledge and attitude regarding HIV prevention. This strategy was singled out by Cornu and Attawell (2003), UNAIDS (2004) and Morolake et al. (2009) as a promising strategy to tackle stigma and discrimination in that PLWH make HIV and AIDS more relatable. People living with HIV may be involved an individual, group and community levels.

4.3.4 Work with Communities

People living with HIV and AIDS are part of the community and maintain social interactions with other members of the community and need to feel that they belong to others (Subramoney, 2015; Tembo, 2016). Work with communities to eradicate community stigma and discrimination is significant in HIV care practice. Maina et al. (2016) acknowledged that although HIV transmission is a chronic disease, it is still a major destabilising experience for PLWH as they experience stigma, trauma and rejection. Due to such experiences, working with communities to eradicate stigma and discrimination is significant in HIV care. They advocated successful programmes, especially HIV prevention should be based on a combination of strategies which include behavioural, biomedical and structural strategies.

- HIV prevention

A recommendation by Coates et al. (2008) and Bekker et al. (2012) is that HIV prevention should not focus only on the individual, but rather on all factors which exacerbate vulnerability to HIV transmission such as behavioural, biomedical and structural factors.

Behavioural strategies identified by Coates et al. (2008) and Bekker et al. (2012) are aimed at motivating sexual behaviour change, including but is not limited to, delay onset of first intercourse, decrease the number of sexual partners, increase the number of

sexual acts that are protected and provide counselling and testing for HIV. Hence, Social Work with communities are awareness raising, information and education.

According, to Reynolds, Makumbi and Nakigozi (2011), Bekker et al. (2012) and Brooks, Kawwass and Smith (2017), the Biomedical HIV prevention strategies include but is not limited to the provision of equipment and services to prevent HIV transmission, encourage adherence to ARV treatment, uptake of HCT, condom use, male medical circumcision, treatment of alcohol and substance abuse. Special emphasis of biomedical prevention as seen by Bekker et al. (2012) is adherence to ARV as it reduces viral levels and thus chances of HIV transmission to sexual partners.

Structural prevention strategies as seen by Gupta, Parkhurst, Ogden, Aggleton, Mahal (2008) and Degenhardt, Mathers, Vickerman, Rhodes, Latkin and Hickman (2010) are aimed at reducing conditions such as physical, social, political, cultural, organisational, community, economic, legal, or policy aspects of the environment that fuel or impede the prevention of HIV transmission. Specific prevention activities include policy shift from exclusion to the promotion of access to services such as the 1978 Alma Ata Declaration on health services, the development of one NSP with explicit political support, revoking of discriminatory laws, establishment of national, provincial and local structures to drive the HIV and AIDS agenda (Hallman, 2006; Degenhardt et al., 2010; Bekker et al., 2012). Structural strategies seek to change the context that contributes to vulnerability and risk. Examples of structural Social Work interventions as provided by the NSP 2017-2022 and the Children's Act 38 of 2005 are family preservation services, women empowerment, school retention, eradication of child labour and prostitution, among others.

▪ Discussing about the stigma itself in the workplace

The workplace is an important social environment for PLWH. Consequently, the ILO, UNAIDS (2001) and Dipeolu (2014) recognised the significance of active stigma eradication programmes in the workplace to improve quality of life for those employees living with HIV and AIDS. A workplace is regarded as an ideal setting for stigma

eradication programmes for HIV prevention as its population mainly consists of men and women of reproductive age. Consequently, Brink and Pienaar (2007) and Oppenheimer (2007) regarded it as an efficient place to promote HCT, couple and family centred HIV services, as employees who are breadwinners may have concerns about their ability to provide for their families in the future. It is important for leaders to understand the needs of employees. Social workers' intervention empower employees living with HIV to understand their workplace HIV and AIDS and related policies so that they are able to fight stigma and discrimination.

Stigma and discrimination which accompanied the discovery of HIV and AIDS is entrenched into the minds of those living with HIV and those affected by the disease. To improve health outcomes dialogues need to be intensified at all levels to access the long stored narrative about HIV and AIDS. Social Work as a discipline is well located in the public healthcare system to encourage people to talk issues out for better social functioning.

4.4 CONCLUSION

Stigma and discrimination is the source of many poor health outcomes which compels PLWH to seek Social Work intervention. The HIV diagnosis disempowers individuals and their families on significant dimensions, namely personal, social, economic, educational and legal dimensions. Consequently, any intervention which aims to improve health outcomes among PLWH should invest in the empowerment of PLWH in those dimensions. Furthermore, due to the complex nature of living with HIV, HIV practice should close knowledge, skills and practice approach gaps of healthcare workers through continuous professional development.

CHAPTER FIVE

RESEARCH METHODOLOGY

5.1 INTRODUCTION

The chapter presented an account of how the research was conducted from the beginning to the end with special reference to the research approach, research design, methods and procedures of the research, ethics and study trust worthiness.

5.2 RESEARCH APPROACH

A research approach is a plan to conduct research. As shown by Walliman (2011) and Creswell (2013), the choice of a research approach is based on the type of problem to be studied, the researcher's personal experiences and the audience for whom the researcher writes. In addition, Moustakas (1994), van Manen (1990, 1997) and Giorgi (1997) concurred that a research approach is the convergence of three components, namely the philosophical worldview which the researcher brings to the study; the design; and research methods. Walliman (2011) and de Vos et al (2012) concurred that the three components result into a research approach which may be quantitative, qualitative or mixed approach. The difference between the approaches as singled out by Mouton (2006), Walliman (2011) and de Vos et al. (2012) is that the quantitative approach focuses on testing relationships among variables, while the qualitative approach focuses on exploring and understanding the meaning individuals ascribe to a social problem. The mixed approach resides in the middle of the quantitative and qualitative approaches.

The research in question is: what are the lived experiences of PLWH in Vhembe District? The phenomenological study on lived experiences of PLWH aims to explore and describe feelings, thoughts, memories, attitudes and behaviours. These are socially

constructed realities about participants' experiences of living with HIV and AIDS. Due to the nature of the study, a suitable research approach is exploratory descriptive qualitative in nature. Walliman (2011) and de Vos et al (2012) argue that the qualitative research approach is associated with the Social Constructivist perspective often combined with interpretivism. A research approach is closely intertwined with the research design. In the study, the researcher planned to access experiences of living with HIV and AIDS through certain procedures of inquiry, namely a research design.

5.3 RESEARCH DESIGN

A design is a procedure of inquiry which Creswell (2013: 9) indicated that it depends on the nature of problems posed by the research aims. Each design has common methods used to collect and analyse data. Common research designs for qualitative research designs identified by Welman and Kruger (1999), Walliman (2011) and de Vos et al. (2012) are narrative, grounded theory, ethnography, case study and phenomenology. These designs are commonly based on social constructivism perspective whose focus is the meaning of the experience. The aim of the proposed study is to explore and describe the meaning of the phenomenon of living with HIV and AIDS. This cause the study to be exploratory, descriptive and phenomenological in design.

Exploratory research as discovered by Kumar (2011), Neuman (2011) and de Vos et al. (2005, 2012) is fuelled by curiosity, the need to understand or get basic familiarity of a phenomenon under study. They showed that the main objective of exploratory research is to find out the thoughts and ideas, gain a better understanding of the issue, to determine if some research would be practical. The main feature of exploratory research is flexibility as it is a drive to find new ideas, revelations and insights about the issue under study. Usually the research use different data collection methods such as personal interviews, case analysis, focus group discussion, and others. Through contact with PLWH who are in care, case study analysis as well as contact with healthcare professionals provided clues on phenomenon under study. Such an exercise gave bits

of knowledge into and comprehension of the issue. The exploratory data laid a foundation for a descriptive research.

Descriptive research puts into frame the exploratory data as it uses such data to get into deeper examination and understanding of the phenomenon. A significant number of sources such as Welman and Kruger (1999); Walliman (2011), de Vos et al. (2012) and Creswell (2013) concur that exploratory research guides descriptive research in the selection of participants , setting of priority issues, framing and asking questions as well as setting the time and place for the participants like when and where to ask questions. The focus of descriptive research is more on the 'what' and 'how' of the phenomenon rather than the 'Why'. Descriptive research goes for portraying something, for the most part characteristics and functions. Descriptive research is more structured than exploratory research. The proposed study is a phenomenological study on the experiences of people living with HIV and AIDS. Hence, the third research design for the study is phenomenology.

Phenomenology is a method of enquiry coming from philosophy and psychology, which Welman and Kruger (1999) and Gallagher and Zahavi (2008) discovered that it is concerned with the understanding of social and psychological phenomena from the perspectives of people involved. Furthermore, as analysed by van Manen (1990), Giorgi and Giorgi (2003), Sloan and Bowe (2014) and Gallagher and Zahavi (2008), phenomenology consists of two parts, namely 'phenomenon' and logic. According to these authors 'phenomenon' refers to an occurrence or experience, and 'logy' refers to a path towards understanding.

The path taken by the study to understand the phenomenon of living with HIV and AIDS is interaction with participants through in-depth interviews, observations and focus group meetings. As discovered by Kumar (2011) and de Vos, Strydom, Fouche and Delport (2012), these paths of inquiry allow the researcher more time to establish rapport, which is vital to access participants' inner world, pay attention to details beyond purely quantitative details, and gather rich data on how participants make sense of their

social and personal experiences. It also provides an opportunity to gather both verbal and nonverbal data.

The study focussed on adult people living in the communities in Vhembe District. Individual interviews were conducted with PLWH. This was followed by a focus group discussion with nine participants. According to Welman and Kruger (2002), Sanchez (2010), Larsson and Sjöblom (2010) and Yüksel and Yildirim (2015), this design allows the researcher to have access to other peoples' experiences in order to explore and describe accurately their lived experiences. Selected methods, processes and procedures were followed to study the phenomenon as presented below.

5.4 RESEARCH METHODS AND PROCEDURES

The point of phenomenological research as viewed by Welman and Kruger (2002), Sanchez (2010) and Larsson and Sjöblom (2010), is to have access to other people's experiences and their reflections on those experiences in order to come to an understanding of the deeper meaning or significance of an aspect of human experience in the context of the whole experience. Consequently, methods and procedures should be relevant and suitable to access the experience. Three methods of data collection, namely in-depth interviews, field notes and focus group discussion were selected for the study. Data was audio-recorded and data was analysed using Collaizzi's seven-step data analysis strategy. Study procedures secured the approval of the study, study site preparation, population and sampling, adherence to research ethics and safeguarding study trustworthiness.

5.4.1 Preparation of Study Settings

Preparation of study settings was done to ensure that the researcher's activities are ethical. It was emphasised by Walliman (2011), Wellington (2015) and Hickey (2018) that securing approval before the commencement of a study is a fundamental ethical

requirement which Foster (2001) and Spitz (2005) established that approval to conduct research protects both the researcher and participants.

The study commenced after approval was granted by the Provincial Limpopo Department of Health (appendix 4). Then, approval was also sought and granted by Vhembe District Department of Health to start conducting research in their health facilities (appendix 5). Approvals from the Provincial and District DOH were preceded by the Ethics Clearance Certificate number TREC/61/2017/PG from Turfloop Research and Ethics Committee (appendix 6).

After the approvals, operational managers were contacted to secure appointments for research briefings so that they may facilitate the recruitment of participants for the study. Walliman (2011), Wellington (2015) and Hickey (2018) asserted that every step of the research should be informed by ethical standards. Recruitment of participants should take into account confidentiality concerns. Furthermore, Anthony, Lee, Barry and Kappesser (2010) and Rugkåsa and Canvin (2011) advocated that recruitment should be done in such a way that participants feel that they had enough time to freely choose to participate. In qualitative inquiry, Skloot (2010), McCormack, Adams and Anderson (2013), Roulston and Martinez (2015) and Martínez-Mesa, González-Chica, Duquia, Bonamigo and Bastos (2016) showed that recruitment is the process whereby the researcher identifies and invites participants into the study. As recommended by Thomas, Bloor and Frankland (2007) and McCormack et al. (2013), a researcher may directly recruit participants or indirectly through colleagues or other people who could assist with recruitment of participants and refer them for participation. For purposes of this study, research participants were recruited through healthcare professionals who Hickey (2018) refers to as gatekeepers. The briefing meetings were sought with managers of the two major health centres situated in Thulamela and Makhado municipalities. Each health centre convened a meeting where the researcher presented the proposed study as contained in briefing notes marked appendix 8. The Thulamela briefing was held in October 2017 while the Makhado one was held in February 2018.

During the meetings, major emphasis was put on the purpose of the study and ethical issues to be observed during the recruitment of potential participants for the study.

During the briefing sessions, managers sought clarifications on the sample size, the venue where interviews were to be conducted with participants and age range of participants. They were clarified that the sample size shall be determined by data saturation, venues for individual interviews are to be determined by participants while the age of participants shall range from eighteen years and above. To facilitate the recruitment of participants, the interview guide was shared with the managers. Then copies of participants' consent forms were distributed and discussed with managers so that they are aware of their contents. They were to be signed by participants consenting to participate. The health centre managers were to share the briefing with their operational nurses and social workers who are in direct contact with PLWH at service points so that recruitment processes can resume. To ensure strict confidentiality of participants' privacy, recruiters were advised that study participants should write only one name on the consent form. Furthermore, the researcher's personal details were to be shared with potential study participants in order to avoid accidental disclosure. The researcher resumed contact with participants after receipt of their signed consent forms. The first contact with the study participants was telephonic to ensure their readiness for individual interviews with the researcher. This was then followed by personal contacts in which interviews were conducted. Thereafter a focus group discussion session was held with nine participants.

5.4.2 Population and Sampling

Participants of the study was drawn from a population of PLWH who are in care in the two municipalities. Neuman and Robson (2004), Kumar (2011), de Vos et al. (2012) and Creswell (2013) refer to a population as a set of units or group of individuals with some commonality which the researcher is interested in studying. These units form a population frame from which a sample is drawn. A population frame is described by Neuman and Neuman (2006) and Walliman (2011) as a group of units or individuals

who have a legitimate chance of being sampled into the study. Sampling is described by Neuman and Robson (2004) and Martínez-Mesa et al. (2016) as the process through which units are selected from the sample frame. It is a significant milestone in research as Wellington (2015) and Hickey (2018) showed that sampling is one step of designing a study, and answers the first ethical question about the criteria of inclusion. The researcher needs to be clear about why people need to be involved, and reflect on who is left out and reasons thereof. A sample is drawn from a population frame.

A population frame of the study was the available PLWH who access HIV care services in the service centres. The proposed study relied on 'known' and available participants from the two health centres service users' health records. This makes the sampling approach purposive in nature. According to Kumar (2011) and de Vos et al. (2012), purposive sampling is commonly used in qualitative research as it allows for the selection of participants according to the needs of the study so as to bring out the phenomena under study clearly. The sample size was determined by data saturation. As recommended by Groenewald (2004) and Van Manen (1990) in qualitative research, conducting in-depth interviews with two and ten participants is sufficient to reach data saturation, while Padilla–Diaz (2015) recommended that between three and fifteen is ideal for data saturation.

Individual interviews were conducted in three days in February, March and April 2018. Five participants were interviewed on day one. They were mainly the middle age and elderly participants. Seven participants who were mainly students were interviewed on the second day. On the third day two participants were interviewed at the health centre while three were interviewed in their respective home. Age and educational levels influenced the pace of interviews. The average time for individual interviews was forty eight (48) minutes Interviews ended with the seventeenth participant as the interview no longer elicited new information. Participants were included in the study as they

- Voluntarily consented to participate
- Signed consent forms and were received by the researcher.
- Received counselling after the HIV diagnosis

- Adhered to treatment

- Disclosed their diagnosis to at least one person other than the healthcare worker

- Aged from 18 and over

- Speak or are conversant with the Tshivenda language.

The data was them organised from the individual interviews. The organised data informed the focus group session which was held in July 2018.

The above criteria for inclusion in the study was preferred as participants older than eighteen had the legal capacity to give consent independently, have the mental maturity to appreciate implications of being research participants. More, importantly, effective narration relies on language efficiency. Therefore, participants were required to be conversant with the local language.

5.4.3 Data Collection

A significant number of authors (Van Manen, 1990; Groenewald, 2004; Gallagher & Zahavi 2008; Padilla–Diaz, 2015) established that phenomenological research seeks to describe and clarify the immediate experience with everyday language rather than scientific vocabulary. Consequently, Welman and Kruger (2002), Wojnar and Swanson (2007), Larsson and Sjöblom (2010) and Yüksel and Yildirim (2015) concurred that such a study calls for exploration of a phenomenon through direct interaction between the researcher and participants and should use exploratory and open-ended questions to allow participants to freely express themselves. Unlike the quantitative approach, Kumar (2011) and de Vos et al. (2012) showed that the qualitative approach is interested in the experiencing individual. During the data collection process, the researcher is free to adapt the process midway as one may drop or introduce questions on the basis of what one learns in the process. Data is collected until no new ideas emerge from the participant. As a result, the in-depth interview, field notes and focus group discussion data collection methods were chosen for the study.

The interview schedule was piloted with the first two participants to assess the effectiveness of the tool. Their responses were not included in the report assisted to adjust the interview schedule as the question on 'coping strategies' was included in the interview guide. Subsequent to the pilot, individual interviews were conducted with seventeen participants. Fourteen participants were interviewed in the health centre on days when they came for their medication, while three chose to be interviewed in their homes. The purpose of the research was to describe and explore lived experiences of PLWH living in communities in order to develop a user-led intervention model. The interview guide marked 'appendix 2' consisted of sixteen questions which collected data on their experiences of living with HIV and AIDS.

- Interview

A semi-structured interview was used in the study as recommended by Rossman and Marshall (1999), Welman and Kruger (2002), Kumar (2011) and Neuman (2011) because it is flexible, spontaneous and allows the researcher to probe issues. Before the start of the interview with each participant, ethical issues were revised with them. In particular the purpose of the study was explained, voluntary participation was ascertained, and the interview guide was shared with participants to ensure that they were comfortable to proceed with the interview. Interviews were conducted in an office allocated by the Health Centre for research purposes. With permission from each participant, interviews were audio-recorded. Individual interviews with the seventeen participants were conducted in three days in February, March and April 2018. Data was then organised in order to illuminate areas which needed to be discussed in the focus group discussion.

Before closure of the interview, each participant was invited for the upcoming focus group discussion. They were informed of the voluntary nature of participation and possible technical diagnosis disclosure to other group members should they choose to attend. It was meant to encourage them to make an informed decision to participate with the understanding that by attending the focus group discussion (FGD), it confirms to other participants that they were living with HIV.

- Field notes

In addition to the interview, field notes were taken. As asserted by Penner and McClement (2008) and de Vos et al. (2012), during each interview brief field notes should be compiled to capture non-verbal or non-transcribable data to ensure complete and thorough findings. Non-verbal data collected during each interview focussed mainly on how participants described their experiences of living with HIV and AIDS through their body language and tone of voice. This data was tucked in the report on findings, analysis and interpretation.

- Focus group discussion

Focus group discussion was selected as a third method of data collection. The same participants were recruited for focus group discussion because as articulated by Ghazali (2013), focus groups should be made of people with certain common characteristics and similar levels of understanding of a topic, hence aiming for homogeneity rather than diversity. The size of the FGD is recommended by de Vos et al. (2012) who showed that small groups of six to ten participants is ideal for focus group discussion. Advantages of focus group discussion are that it provides participants with a permissive and non-threatening environment to share experiences, perceptions, points of views, wishes and concerns without being pressurised to reach consensus (Welman & Kruger, 2002; Bless, Higson-Smith & Kagee, 2006; de Vos et al., 2012; Creswell, 2012). Furthermore, FGD produces concentrated amount of data which encourages emergence of ideas from participants from which the researcher learns more about the phenomena (Morgan 1997; Guba & Lincoln, 1990; Krueger, 2002; Casey, 2009).

The construct of the questions for the FGD were informed by the meaning of living with HIV and AIDS, which the participants shared during the in-depth individual interviews. The focus group discussion questions are attached as Appendix 3'. Since participants' narratives strongly revealed that stigma and discrimination is rife in communities, which in turn exacerbate self-stigma, questions which were constructed for the FGD intended

to find the appropriate community education on HIV and AIDS which could fight stigma and discrimination, pre- and post-test diagnosis care and support needs, concerns and challenges. The FGD session was conducted in July 2018.

5.4.4 Data analysis

Data analysis in qualitative research is defined by Marshall and Rossman (1999:150) as "the process of bringing order, structure and meaning to the mass of collected data". The focus is thus on condensing data collected through in-depth interviews, observations and field notes into one report. Three significant activities in qualitative research identified by van Manen (1990, 1997) are transcribing, coding and creating themes. According to van Manen (1990, 1997), Shosha (2010) and Goirgi (2012), transcribing is the process of converting audio data to text for analysis; while coding is the process of reviewing notes and discovering common "themes', which describe the phenomena. Through these activities, Groenewald (2004), van Manen (1990, 1997), Shosha (2010) and Goirgi (2012) found that it make sense from research participants' views and opinions of situations.

Crafting views and opinions by the researcher about the phenomenon under study is made possible through what Giorgi and Giorgi (2003: 131) refers to as "dwelling into data respectfully and embracing the language of participants". Dwelling in phenomenological research involves more than hanging out and waiting somehow for meanings to emerge. Instead meanings have to be mined and layered themes have to be shaped up. Psychological meanings have to be detected, drawn out and elaborated.

Many sources (Wojnar & Swanson, 2007; Penner & McClement, 2008; Shosha, 2010) alluded that qualitative data collection methods result in a large amount of data which should be prepared. Colaizzi's seven-step strategy for data analysis in descriptive phenomenology was utilised to analyse and illuminate meanings and patterns of the phenomenon from the collected data. The researcher carried out the seven-step activities as shown below

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┌─────────────────────────────────────────────────────────┐
│                      Transcripts                         │
└─────────────────────────────────────────────────────────┘
                            ▼
┌─────────────────────────────────────────────────────────┐
│                  Formulated meanings                     │
└─────────────────────────────────────────────────────────┘
                            ▼
┌─────────────────────────────────────────────────────────┐
│          Categories, cluster of themes and themes        │
└─────────────────────────────────────────────────────────┘
                            ▼
┌─────────────────────────────────────────────────────────┐
│           Ehaustive description of the phenomenon        │
└─────────────────────────────────────────────────────────┘
                            ▼
┌─────────────────────────────────────────────────────────┐
│                   Fundamental structure                  │
└─────────────────────────────────────────────────────────┘
                            ▼
┌─────────────────────────────────────────────────────────┐
│  Validation of exhaustive descriptions and its fundamental structure │
└─────────────────────────────────────────────────────────┘
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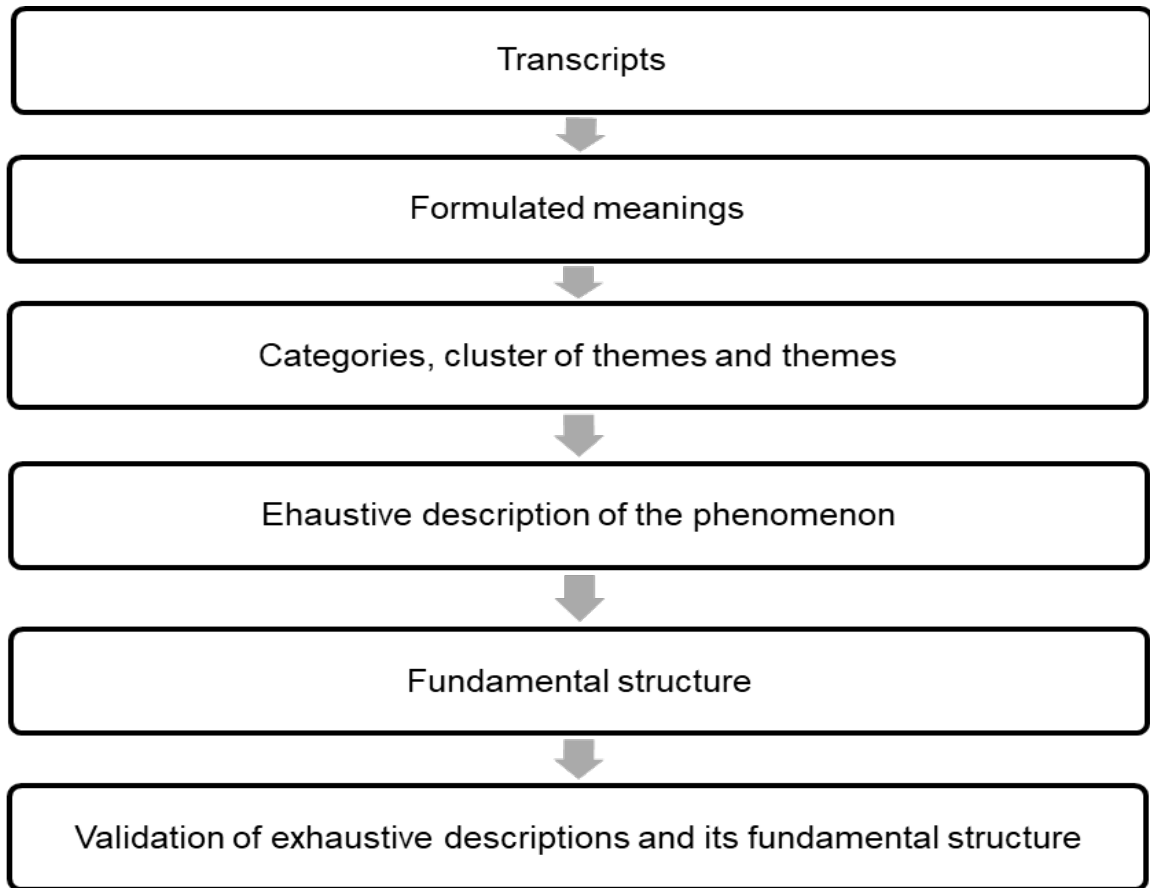
Figure 3: Colaizzi (1978) data analysis strategy

Source: Adapted from Shosha (2010: 38**)**

▪ Step one

In the first step, the researcher listened to the whole recorded interviews and re-read transcripts of each participant several times to get a sense of the whole, with particular attention to both verbal and nonverbal meaning such as pauses, posture and tone of voice, among others. Penner and McClement (2008) and Giorgi and Giorgi (2003) refer to this activity as immersion into data collected through face to face, which is followed by editing and ignoring repetitive, overlapping and irrelevant expressions. The researcher looked for similarities and differences from participants' transcripts. Then they were translated verbatim into English.

- Step two

After listening to responses of every participant in all the questions, five hundred and ninety two (592) significant statements were extracted. To reflect the data accurately, significant statements are direct quotations from the participants. An example of significant statements is presented in the table below. The question from which significant statements were extracted reads:

"*What does your community say about HIV and AIDS" Prompt: When they talk about it what do they say it is?*

Significant statements	Extracted from participant no
He says the community's understanding of HIV and AIDS is divided into three groups. He says *'the first group says HIV and AIDS is deadly epidemic which kills. The second group says 'it is a sin as it is a diseases of people with many girlfriends while the third group don't believe that it exists. The latter group believes that it is an ancestral disease which can be cured by treatment referred to as 'malombo' and this group would not even seek medical treatment for HIV disease. The latter group is the dominant one' (2)*	2
She says her *'community talks about it in a bad way. They criticise it. They say it kills. They say if you get it, it is because you are promiscuous. You never let a man pass by. A person who has it is about to die' (4)*	4
Her response was *'those who don't have knowledge say it is a sin which is brought by behaviour of running after men. They say it is a consequence of a person who has no self-control. Those who have knowledge say that it is an accidental disease'.*	17
She says her community understands it '*as a disease which comes to finish one's life. One can die at any time' (9).*	9

Her community says '*It is a killer disease for those who delay to get medical treatment (6).*	6
Her community understands it as '*a flu without cure which was predicted that it will come. They do not know how it started but it was predicted that it will be incurable*' (10).	10
She says her community says '*It is a disease which if you get it you are going to die. If they know that you have it they will talk about you 'somehow'. They say it is a big disease. They talk about it in such a way that the one who has it will not feel accepted. If one person knows about you, the whole village will know about it*' (15).	15

Table 3: Examples of extracted significant statements interviews from six participants

▪ Step three

Social and psychological meanings of the phenomenon were formulated from significant statements. This was intended to illuminate meanings hidden in various contents of the phenomenon and thereafter assigned headings to extracted data. During the creation of meaning, Giorgi and Giorgi (2003) directed that the researcher stays as close as possible to the participants' actual words. The table below provides examples of how significant statements were converted into meanings.

Significant statements	Formulated meanings
He says the meaning of HIV and AIDS in his community is classified in three groups '*the first group says HIV and AIDS is a deadly epidemic which kills. The second one says 'it is a sin as it is a diseases of people with many girlfriends while the third group don't believe that it exists. The latter group*	The participant is aware that his community understands HIV and AIDS as a fatal disease which they identify with sinful and promiscuous people. Other people in his community identify it as an ancestral disease. ' 2'

believes that it is an ancestral disease which can be cured by treatment referred to as 'malombo' and would not even seek medical treatment for HIV disease. The latter group is the dominant one' 2'	
She says her '*community talks about it in a bad way. They criticise it. They say it kills. They say if you get it, it is because you are promiscuous. You never let a man pass by. A person who has it is about to die' (4)*	She knows that her community talks about HIV and AIDS as a fatal disease which affects promiscuous people.
Her community's understanding of HIV and AIDS is *'Those who don't have knowledge say it is a sin which is brought by behaviour of running after men. They say it is a consequence of a person who have no self-control. Those who have knowledge say that it is an accidental disease. '17'*	She is aware that some community members lack basic facts about HIV and AIDS and identified its source as sinners and promiscuous women. Some talk about it as an unfortunate disease which can be acquired as an accident.
She says her community understands it *'as a disease which comes to finish one's life. One can die at any time' (9).*	She is aware of her community narratives about HIV and AIDS reveals that it is a deadly and fatal and disease.
Her community says *'It is a killer disease for those who delay to get medical treatment (6).*	She has heard that her community understands HIV and AIDS as a fatal disease but manageable with timeous medical intervention.
Her community understands it as *'a flu without cure which was predicted that it will come. They do not know how it started but it was predicted that it will be incurable' (10).*	She knows her community has minimal medical facts about HIV and AIDS as a health condition.

She says her community *says 'It is a disease which if you get it you are going to die. If they know that you have it they will talk about you somehow. They say it is a big disease. They talk about it in such a way that the one who has it will not feel accepted. If one person knows about you, the whole village will know about it' (15)*	The participant is aware that her community identified living with HIV with death. They isolate PLWH and even spread rumours about them.
They say '*it a disease and accepted it and people must support one another' (5).*	She is comforted by the experience that her community understands HIV and AIDS as a normal disease

Table 4: Examples of formulated meanings created from significant statements

▪ Step four

Formulated meanings were honed and then sorted into categories, cluster themes and major themes. This assisted to identify experiences common to all participants and to compare participants' responses collected using interviews, field notes and focus group discussions. These activities are presented in the table below.

Example of formulated meanings	Categories.	Cluster of themes	Emergent themes
The participant is aware that his community understands HIV and AIDS as an undesirable disease which is found in promiscuous people. He further understands that his community identifies it with African traditional origin. '1'	● It is a disease of poor sexual morals. ● It is a scary ● It is a killer and	Outdated meaning of HIV and AIDS in communities.	The meaning of HIV and AIDS by participants' communities

She knows that her community talks about HIV and AIDS as a fatal disease which affects promiscuous people. She is aware that her community narratives about HIV and AIDS reveals that it is a deadly and fatal and disease. The participant is aware that her community identified living with HIV with death. They isolate PLWH and spread rumours about them. '15'	incurable disease.		
She is aware that some community members lack basic facts about HIV and AIDS and identified it with sinners and promiscuous women. Some talk about it as an unfortunate disease which can be acquired as an accident.'17' She knows her community has minimal medical facts about HIV and AIDS as a			

health condition. 10'			
She is comforted by the experience that her community understands HIV and AIDS as a normal disease	HIV and AIDS is part of our lives	Community acceptance of HIV and AIDS	

Table 5: Formulated Meanings grouped into categories, cluster themes and themes

▪ Step five

The findings of the study were described and integrated into an exhaustive description of the phenomenon under study. After listening and re-reading transcripts of seventeen participants, five hundred and ninety two (592) significant statements, 59 categories, 30 sub/ cluster themes and (11) eleven emergent or major themes were extracted. The descriptions abstracted from the original data communicate and market study findings to the reader. A thematic map below communicated the fundamental structure of findings to the reader.

Table 6: A summary of the thematic map

THEME 1: PARTICIPANTS PROFILE

THEME2:THE MEANING OF HIV AND AIDS BY PARTICIPANTS' COMMUNITIES
Sub - theme I: Outdated view of HIV and AIDS with special reference to sexuality, morality, fear and mortality
● Category 1: It is a disease of poor sexual morals
● Category 2:It is a scary disease
● Category 3: It is a killer and an incurable disease
Sub –theme : 2 Lack of knowledge on HIV and AIDS in communities
● Category 1:It is an ancestral disease
● Category 2: It is a sinful disease

- Category 3:Minimal medical facts about HIV and AIDS

Sub –theme 3 Community acceptance of HIV and AIDS

- Category 1:HIV and AIDS is part of our lives

THEME 3:THE MEANING OF HIV AND AIDS BEFORE DIAGNOSIS

Sub –theme 1: Participants thoughts, emotions and feelings about HIV and AIDS prior diagnosis

- Category 1: They were not vulnerable to HIV infection.
- Category 2: Associated living with HIV with a short life span
- Category 3: Fear of physical changes
- Category 4:Did not know much about HIV and AIDS

Sub –theme 2: Participants' attitudes towards PLWH

- Category 1: Empathy towards PLWH
- Category 2 Rejection of PLWH

Sub –theme 3: Participants' knowledge of HIV and AIDS prior diagnosis

- Category 1: Lack of basic facts about HIV and AIDS

THEME:4 PARTICIPANTS, MEANING OF LIVING WITH HIV AND AIDS POST DIAGNOSIS

Sub – theme 1: The discovery of a 'new' meaning of HIV and AIDS

- Category 1: The HIV and AIDS is a human health condition.
- Category 2: Anyone may be infected with HIV.
- Category 3: HIV and AIDS is preventable, manageable and treatable

Sub – theme 2: Post-diagnosis reactions

- Category 1: Emotional reactions
- Category 2:Suicidal thoughts
- Category 3: Compressed sadness

Sub –theme 3: Benefits of HIV diagnosis.

- Category 1:Health management

THEME :5 DRIVERS WHICH CHANGED THE MEANING OF HIV AND AIDS

Sub –theme 1: Mental drivers

- Category 1:Acceptance of the diagnosis
- Category 2:Prospects of good health

Sub – theme 2: Medical drivers

- Category 1:Availability of ARVs
- Category 2:Prospects of good health

Sub – theme: 3 Social drivers

- Category 1:Family support
- Category 2:Support by other PLWH

THEME 6: SOCIAL SUPPORT

Sub –theme 1 : Emotional support

Sub – theme 2:Religious support

Sub –theme 3: Treatment support

- Category 1:Treatment support by family
- Category 2: Treatment support by healthcare workers
- Category 3: Treatment support and information by other PLWH

Sub – theme 4: Material support

- Social protection package

THEME 7: COPING CHALLENGES

Sub – theme 1: Intrapersonal challenges

- Category 1:self - stigma
- Category 2:Anticipated stigma

- Category 3: Unresolved grief, anger and resentment

- Category 4: Growing old with HIV and AIDS

Sub –theme 2: Interpersonal challenges

- Category 1: Interpersonal challenges in the family

- Category 2: Interpersonal challenges in the workplace

- Category 3: Interpersonal challenges in the healthcare setting.

- Category 4: Interpersonal challenges in the community

Sub – theme 3: Other challenges

- Category 1: Medical challenges

- Category 2 **:**Financial challenges

THEME 8: COPING STRATEGIES

Sub – theme 1: Emotion focused strategies

- Category 1:Self-convincing

- Category 2: Acceptance of the diagnosis

Sub – theme 2: Problem-solving strategies

- Category 1: Routine problem solving strategies

- Category 2: Non routine problem solving strategies

THEME 9: PARTICIPANTS ' FUTURE PLANS

Sub –theme 1: Positive living

- Category 1:Maintain good health

- Category 2: Looking forward to a long life

- Category 3: Furthering studies and career development

- Category: 4 Grow businesses and trades

THEME 10: THE MEANING OF BEING A PARTICIPANT IN THE STUDY

- Sub – theme 1: An Honouring experience
- Sub – theme 2: A down the memory lane experience.
- Sub – theme 3: A cathartic experience
- Sub – theme 4 A supportive experience

THEME 11: FOCUS GROUP DISCUSSION.

Sub- theme 1: Community education on HIV and AIDS

- Category 1: HIV and AIDS for Pastors and Prophets.
- Category 2: HIV and AIDS education for Traditional Health Practitioners
- Category 3: HIV and AIDS education for PLWH in care.

Sub – theme 2: HIV testing, Care and Support

- Category 1: Pre – HIV testing, care and support
- Category 2: Post HIV testing, care and support.

Sub – theme 3: The experience of participating in the Focus Group Act

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▪ Step six

This step is a bit similar to the previous one but no exhaustive meanings were sought. In this step redundant, misused and or overestimated descriptions were eradicated from the overall structure.

▪ Step seven

The researcher conducted what Shosha (2010) refers to as member checking by returning to participants to validate findings. The researcher returned to participants to conduct member checking through contact sessions and telephone consultations to correct discrepancies and validate findings. Then, the researcher incorporated inputs from the participants.

5.5 ETHICAL CONSIDERATIONS

Being ethical means doing the correct thing in a right way. Gelling (2011) and Hickey (2018) asserted that ethics refers to conducting research without harming anyone and

ensuring that the entire research from problem formulation to publication is anchored on ethical standards. As discovered by Foster (2001), Spitz (2005) and Gelling (2011), the development of ethics was a result of research conducted in the past without ethics which subjected participants into human suffering. They showed that such development resulted into the Nurenbeg Code or the Declaration of Helsinki which directed how participants should be treated and recruited in research. Foster (2001), Spitz (2005) and Gelling (2011) indicated that The Declaration of Helsinki culminated into ethical principles of autonomy, free and informed consent, respect for vulnerable persons, privacy and confidentiality, justice and inclusiveness, harms and benefits in research. The principles put an obligation on the researcher to ensure that no harm will be done to participants, and that the rights, needs, values and desires of participants are respected. In order to ensure that ethical principles are adhered to, the following processes and procedures were followed in the study.

5.5.1 Permission to Conduct the Study

The study commenced after approvals were granted by Limpopo Provincial Department of Health and Vhembe District Department of Health. These approvals were preceded by the Ethical Clearance Certificate from Turfloop Research Ethics Committee. Contact with participants resumed after the researcher received signed consent forms from recruiters.

5.5.2 Voluntary Participation

Walliman (2011), Wellington and Hickey (2018) advocated that participants should be treated with respect and dignity before, during and after the research. They should be made aware that they should freely consent to participate. During the study process, participants were advised on the voluntary nature of the study in individual and focus group discussions. They were advised that they can withdraw from the study or they could decline to answer questions without penalties. No incentive to participate was provided. None of the participant was enticed, deceived, misled, threatened or coerced

to participate in the study. At the end of the focus group discussion session, participants were given a 1kg coloured scented candle and a pill box organiser and a small note book as a token of appreciation for their participation in the study.

5.5.3 Informed Consent

As elaborated by Oliver (2003) and Walliman (2011), informed consent consists of three elements, namely information, voluntariness and comprehension. It is strongly emphasised by Mouton (2006), de Vos et al. (2012) and Hickey (2018) that prior to research, participants should be given detailed information so that they can arrive at a reasoned decision to participate, and that should they express the need to consult other sources before giving consent to participate, such a need should be accommodated.

The researcher provided a clear description of the purpose of the study to each participant before the interview commenced. All documents which were used with the participants in the study were compiled in the local language Tshivenda, to ensure a thorough understanding of what it is that they were being recruited to participate.

5.5.4 Privacy and Confidentiality

Privacy and confidentiality as elaborated by Walliman (2011) means a researcher agrees not to reveal the identity of the participants to anyone else. The identity and private information of participants should be protected during data collection, analysis and reporting of findings. To ensure that participants' privacy and confidentiality was safeguarded, recruitment was conducted by health centre nurses and social workers who submitted consent forms. The researcher initiated telephonic contacts to set interview appointments with participants after receipt of signed consent forms from the recruiters who Hickey (2018) refers to as 'gatekeepers'. Furthermore, to avoid accidental disclosure, it was also emphasised in the briefing sessions with managers that the identity of the researcher should be made known to potential participants so

that they are aware of who the researcher is. Furthermore, during data collection, all interviews were conducted in a separate office allocated by the healthcare centre. In the office, only one participant was interviewed at a time by the researcher. To ensure anonymity, participants were identified as P1 to P17 to protect their privacy. No study document bears the identity of participants. Research sites were only referred with their municipal names rather than specific health centre names to protect possible identification of participants.

5.5.5 No Harm to Participants

A significant number of authors, such as Wellington (2015), Hickey (2018), Mauthner (2002) and Walliman (2011) cautioned that research should not be conducted at the expense of participants. In order to safeguard this, participants were provided with the interview schedule to read before they signed the consent forms. They were also allowed to take the interview schedule home for consultation with their loved ones about their participation. This was intended to ensure that they make an informed decision. Again, in the interview office, before the interview resumed with each participant, the protocol was repeated by the researcher to ensure that participants are comfortable with the questions. All concerns and questions were addressed before each interview commenced.

Prior arrangements for immediate counselling within health centres was arranged with the nurses and social workers to ensure that such a service was promptly provided to any participant who decides to participate, but experiences distress at any stage of the research. Two participants who were in financial distress were referred to social workers for social relief assistance.

5.5.6 Debriefing

The study entered into people's lived experiences of living with HIV and AIDS. This is a sensitive subject which despite all the preparation prior to the resumption of the study, it

has risks to unravel emotions which they had stored away, hence preparations for debriefing after data collection.

According Mouton (2006), Kumar (2011), Walliman (2011) and de Vos et al. (2012), research is a learning experience for both the participants and the researcher as participants may learn something about themselves which they have not known prior to participation in the research. Subsequently, it was recommended that debriefing should be provided at the end of participation for three purposes, namely to minimise possible harm that could have occurred despite all precautions against it; to rectify misconceptions in participants' minds; and to help participants leave their engagement in the research process in a similar frame of mind as when they entered (Harris, 1998; Aronson, 1998; de Vos et al., 2012).

5.5.7 Confirmation and Publication of Findings

Prior to the presentation of the pre-final report, a member checking session was held with the participants to confirm that they were properly represented in the report, and were given a chance to make further inputs.

5.6 QUALITY CRITERIA

The researcher ensured that the study was trustworthy based on Lincoln and Guba's model in Krefting (1991), which applies the strategies of credibility, transferability, dependability and conformability.

5.6.1 Credibility

According to Guba and Lincoln (1990) and Thomas and Magilvy (2011), a study is credible when it represents an accurate description of human experience that people who share the experience would immediately recognise the descriptions. The

researcher safeguarded the study's credibility through bracketing. At the onset of the interview, all participants were informed that the researcher is learning from them. It thus encouraged them to give an account of their experiences without hindrance. Other strategies to ensure credibility were that there were no leading questions in the interview and FGD guides. Triangulation in data collection was used to minimise omissions and inaccuracies; pre-final report was shared with participants for verification; and data analysis was carried out using Colaizzi's seven-step data analysis strategy.

5.6.2 Transferability

As asserted by Krefting (1991) and Tracy (2013), qualitative research does not necessarily seek to generalise findings, but rather to ensure that if someone who was not involved in the study were to read the findings, he or she would be able to identify the story. Transferability was safeguarded by capturing each participant's perspective on the audio recorder so that it provides a dense data on lived experiences. Furthermore, some parts of interviews were extracted and used as quotes in the final report.

5.6.3 Dependability

The researcher provided detailed information on study procedures and processes from research site preparation, participants' selection, data collection, data storage, analysis and reporting. As asserted by Anney (2014), study dependability is measured by the extent to which another researcher can repeat the study guided by similar decisions and processes, and reach comparable findings.

5.6.4 Confirmability

The researcher ensured confirmability of the study by establishing a paper trail so that the study is auditable. All study records such as the supervisor's reports, summaries of correction reports, approval letters from the Department of Health, interviews, audio

recordings, signed consent forms, data collection instruments, field notes, among others, are kept. According to Krefting (1991), Thomas and Magilvy (2011) and Moustakas (1994), a study is confirmable if it can be established that it is a product solely of the participants and the conditions of the research, and not of other biases, motivations and perspectives.

5.7 CONCLUSION

The chapter detailed the methods, procedures and processes undertaken to explore and describe the lived experiences of PLWH. Details on the research design, approach, activities undertaken to prepare the research site, locating participants and sampling, data collection through individual interviews, field notes and focus group discussions were presented. Furthermore, details of Colaizzi's seven-step data analysis was presented. All the signposts of research ethics was adhered to through practice and relevant approvals. The study's trustworthiness may also be established using the paper trail. The exploratory descriptive data collected through these processes is presented in the next chapter on findings.

CHAPTER SIX

PRESENTATION OF FINDINGS, ANALYSIS AND INTERPRETATION

6.1 INTRODUCTION

The chapter is a presentation of findings of a phenomenological study on lived experiences of PLWH. The aim of this study was to explore and describe the lived experiences of PLWH in order to develop a user-led intervention model in Vhembe District, Limpopo Province. The chapter presented data collected through in-depth interviews, field notes with seventeen participants, and focus group sessions with nine participants. Of the seventeen participants, fourteen were interviewed at the health centre on days that they came for their medicines, while three chose to be interviewed in their homes. The average duration of the interviews was forty six (46) minutes per participant. The second set of data was collected through a focus group session which lasted for one and half hours with nine participants.

As a phenomenological study, data collected focussed on what van Manen (1997), Rich et al. (2013), Subramoney (2015) and Tembo (2016) refer to as the four lifeworld existentials, which are a frame which guides the researcher to locate the meaning of the phenomenon under investigation. These existentials are the 'lived space', 'lived body', 'lived time', 'lived other human relations'. When operationalised, the 'lived space' refers to how PLWH relate with their environments; 'lived body' is interested in understanding how PLWH describe their bodies or what they think their bodies communicate to others. The 'Lived time' focuses on what constitutes their past, its influence on the present and how it determines their future. The lived 'other human relations' refers to relationships that people make and maintain in spaces that they share with others.

Qualitative data methods result in large quantities of data about the phenomenon which should be organised. Colaizzi's seven-step data analysis strategy was used to analyse data from interviews, field notes and focus groups into findings, analysis and interpretations presented in this chapter. After the in-depth interviews on ten questions with seventeen participants, 592 significant statements were extracted from the recorded interviews. Meanings were formulated from the significant statements, which evolved into 59 categories, 30 cluster themes and 11 emergent themes. The following themes emerged during the course of the study:

- Profile of participants
- Meaning of HIV and AIDS in communities
- Meaning of living with HIV by participants prior to diagnosis
- Participants' meaning of living with HIV and AIDS post-diagnosis
- What changed the meaning of living with HIV and AIDS?
- Type of social support
- Coping challenges
- Coping strategies
- Participants' future plans
- The meaning of being a participant in study
- Focus group discussion report

6.2 PARTICIPANTS' PROFILE

The profile of the participants was gathered so that experiences of living can be linked to them. A summary of the participants' profile presented their ages, gender, highest educational standard passed, occupation, source of income and the number of year (s) of living with HIV and AIDS. A table about the profile of participants is presented below:

Participant name	Gender	Age	Number of years of	Highest standard	Occupation	Venue of interview

			living with HIV	**passed**		
P1	F	58	5	Grade 7	Vendor	Health centre
P2	M	48	15	Grade 12 + N3 Electrical Engineering	Self-employed Electrician	Health centre
P3	F	40	6	Grade 10	Handyman electrician	Health centre
P4	F	42	8	Grade 11	Unemployed	Health centre
P5	F	70	12	Adult Basic Education level 3	Pensioner	Health centre
P6	F	51	5	Grade 11	Shopkeeper	Health centre
P7	F	42	19	Grade 10	Clothing Trader	Health centre
P8	M	61	7	Grade 8	Self-employed Builder	Health centre
P9	F	38	10	Grade 11	Homemaker	Health centre
P10	F	30	6	Grade 11	Homemaker	Health centre
P11	F	23	1	Grade 12	Student	Health centre
P12	F	38	18	Grade11	Seasonal worker	Home

P13.	F	19	1	Grade 9	Student	Health centre
P14	M	18	5	Grade 9	Student	Health centre
P15	F	26	4	Business studies – third year	College student	Health centre
P16	F	33	5	Grade 10	Non-government al organisation volunteer	Home
P17	F	58	8	Grade 12	Domestic worker	Home

Table 7: Participants' profile

Women participants are overrepresented in the study as only three are males. This pattern may be a health indicator of many health behaviours, namely low uptake of HIV care services by males; uptake of HIV testing by pregnant women attending antenatal clinics; and the meaning of routine medical screening by both males and females, among others. The data suggests that routine medical screening by the general community, especially HIV testing is still low. Therefore, HIV prevention strategies should target males for HIV test, and improve the general communities, the uptake of medical screening, with special emphasis on HIV counselling and testing.

Fourteen participants were interviewed at the health centre (all male participants chose to be interviewed at the health centre) while three female participants were interviewed at their homes. They were not asked about the reasons for their choice of the venue. It may be that the health centre and the time are comfortable places, other than their

homes where they could be overheard by others as living with HIV and AIDS is a health condition which is still highly stigmatised.

It was found that many participants dropped out of school between grades 7 and 11. The general quality of life in their community and or poor household living conditions may have contributed to them dropping out of school. The duration of living with HIV and AIDS showed that many participants had been living with the condition since their twenties when they had dropped out of school. Being a school dropout and living possibly in poor communities may have increased their vulnerability to HIV infection. Furthermore, dropping out of school before grade 12 reduced their chance of better employment, and further locked them in the circle of poor living conditions. Hence, many participants occupy lower strata occupations. Youths out of school are a high risk group in terms of HIV infection. Keeping young people in school is a structural prevention strategy which should be intensely implemented as it may accord youths the opportunity to acquire educational qualifications which in turn improve their economic position, as well as life skills which are required in managing relationships.

All young participants are in full time studies. However, they are all behind with their school grades. It was found that they were frequently hospitalised due to ill-health before they were diagnosed with HIV. Some carers disclosed to participants their diagnosis when their health began to deteriorate. It may be that family members waited for what they thought was the right time for youth to know about their status, or they did not know how to disclose their status to participants. The carers' approach to participants' status disclosure is preferred by Gachanja (2015) and NDOH (2000), who emphasised that timing, age and knowledge of HIV and AIDS should be determining factors to disclose status to youths. Post-disclosure, carers and youths need support, especially youths born with HIV. They are a generation of young people who have complex developmental needs in that they knew of their diagnosis at the preteen or teen years. This is the age where the central theme is identity formation and the beginning of interest in members of the opposite sex. As noted by Merriam et al. (1997) and Remien and Rabkin (2001), the knowledge that they are living with HIV may limit them in their

developmental journey as it may cause them to feel different from other youths who are not living with HIV. It may also limit their social interaction circles because of anxiety over disclosure and fear of rejection by friends and potential partners; and fear of infecting others and of negotiating safer sex. Therefore, HIV care service should be customised to help them disentangle themselves from possible limiting reactions so that they look forward to subsequent stages of development.

It was discovered that some participants are above fifty years while some are approaching sixty and above. The AIDS epidemic is 'aging', hence the emergence of older groups of PLWH who are 50 years and older. It was found that some participants acquired HIV while they were still young, while a second group recently acquired HIV. In many communities, living with HIV and AIDS is still associated with immoral sexual behaviour. Older people's roles in families is to guide generations into their future. Life experience and wisdom that they gathered through life earns them that position. However, growing old and living with HIV and AIDS may drive them into feelings of loss and despair as their life journey is accompanied by HIV infection. Consequently, many older PLWH may be living with unique needs which HIV care programmes may unintentionally miss to meet as many HIV and AIDS responses are intended for younger age groups, mostly the 15-49 years old. Furthermore, older PLWH may delay entrance into HIV care as healthcare providers may not always test older people for HIV infection, or they and their families may mistake HIV symptoms to those of normal aging. There is a need for specialist care for HIV and other chronic health conditions for the aged. Where feasible, Paul and Premraj (2015) advised that older people should be provided with home based care so that they are cared in a familiar environment as it improves health outcomes.

The period of the diagnosis among participants ranges from 1-19 years. Many were diagnosed in their mid- or late twenties. Earlier diagnosis must have given them an opportunity to take care of their health. They lived through many trying experiences. It was found post diagnosis, they continued to build their families and careers. This suggests that despite living with HIV, they were optimistic with the future. The

phenomenological lifeworld existential of the 'lived' time is interested in what constitutes the past of the experience, the influence of the past into the present and how it determined their future as PLWH. Participants' experiences revealed that the three elements of the phenomenon, namely the past, present and the future are intertwined. Therefore, they have a rich experience of living with HIV and AIDS. According to UNAIDS (1999, 2004), WHO (2010), Coates et al. (2008), Morolake et al. (2008) and Marashe (2014), they have seen it all and are experts with the experience of living with HIV and AIDS. Therefore, it is justifiable to develop a user-led intervention model based on their lived experiences.

6.3 THE MEANING OF HIV AND AIDS IN COMMUNITIES

Many communities hold outdated meaning of HIV and AIDS. Some communities possess incomplete information while a few understand HIV and AIDS. It was found that many participants' communities understand HIV and AIDS to be a disease of people with poor sexual morals, while other communities are scared of HIV and PLWH. Communities' meaning of HIV and AIDS is categorised and presented below.

6.3.1 Outdated view of HIV and AIDS with Special Reference to Sexual Morality, Fear and Mortality

The meaning of HIV and AIDS in communities is outdated as it still reflects earlier phrases which referred to HIV as a disease of poor sexual morals, scary, killer, and an ancestral disease. Some participants eloquently described their communities' understanding of HIV and AIDS as follows:

> *"The community talks about it in a bad way. They criticise it. They say it kills. They say if you get it, it is because you are a slut. You go out with many people. A person who has it is about to die" (4).*

In corroboration of the above, another participant echoed that:

"Those who don't have knowledge say it is a sin which is brought by behaviour of sleeping out with men. They say it is a consequence of a person who has no sexual control, a person who does not pass any man." (17)

"They are afraid of HIV. If they know someone is positive, they criticise that person. They talk 'somehow' about it." (16)

Stigma and discrimination in communities is rife and renders the social space unwelcoming for many PLWH. Communities alienate PLWH through gossips and spreading rumours which, for many PLWH has a socially and psychologically disabling effect. Young female participants showed that their communities experience PLWH as weird. This treatment may drive them into isolation and despair. On the side of communities, such stigmatising and discriminatory treatment may deteriorate into low profile hatred of PLWH. The worst form of hatred by the community was an incident reported by Cape Argus (2003), in which a 21-year female HIV positive AIDS peer educator was beaten to death in Khayelitsha. A relationship characterised by alienation is thus not healthy for either PLWH or the general community as none of them may invest in relationships which are not rewarding. Stigma and discrimination tempered with the level of social cohesion within communities. The cost of stigma and discrimination is borne by both PLWH and the general communities as it usurps resources which are building blocks for socially cohesive communities.

Stigma and discrimination is a social problem. Communities constructed the meaning of HIV and AIDS and in the process created a problem of stigma and discrimination which the world battles to eradicate. The Social Construction theory by Hutchison (2003) sees social problems as products of claims making and labelling created from the interplay between the social, cultural, historical, medical, and religious factors about an illness. Stigma and discrimination within communities alienates PLWH, and in turn aggravates

poor health outcomes among them. The need for love and belonging are human needs, especially for PLWH. Therefore, the disconnection between PLWH and their communities should be a target by structural strategies in fighting HIV and AIDS.

Communities understand HIV and AIDS as a disease which is spread by promiscuous women. This stance disempowers women as they are reduced to scapegoats. This wrong perception about women being transmitters of HIV held in communities removes the community from being an effective stakeholder in fighting HIV and AIDS. Due some communities which blame HIV transmission on women, it may cause them to double up their coping strategies to attain similar health outcomes as compared to men. It is therefore simplistic to assume that men and women living with HIV and AIDS experience similar challenges in communities.

This was also confirmed by Marashe (2014), who found that traditional leaders in Chipinge District in Zimbabwe identified sexual promiscuity among those who were single and widowed as well as unfaithfulness in marriages as major drivers of HIV transmission. This perception generated a stigma and discrimination which has failed to disappear even when it has been proven that HIV can infect anyone after exposure (Close & Ragamonti, 2005; Subramoney, 2015; Zeligman, 2018). Therefore community education through dialogues to change thinking patterns, and improvement are core to creating a safe environment for PLWH, particularly women.

6.3.2 Lack of Knowledge on HIV and AIDS in Communities

It was found that some communities understand HIV and AIDS to be a consequence of sinful behaviours and ancestral afflictions while a few do not know its source. A worrisome view among some communities is that HIV is acquired only through heterosexual transmission. This is shown below:

> *"The first group says HIV and AIDS is a deadly epidemic which kills. The*
> *second one says 'it is a sin as it is a disease of people with many girlfriends*

*while the third group does not even believe that it exists. The latter group believes that it is an ancestral disease which can be cured by malombo (curative ancestral dances) and they would not even seek medical treatment for HIV disease. The third group is the dominant one" (*2).

In support of the above assertion, another participant said:

"It is a flu without a cure which was predicted that it will come. They do not know how it started but it was predicted that it will be incurable" (10).

Participants' experiences in their communities confirmed a socio–cultural dimension of HIV and AIDS as ancestors are viewed as the cause of the disease. It is both an advantage and disadvantage for PLWH. At an individual level, the advantage is that they may not be blamed for living with HIV and AIDS as it is an affliction by ancestors. This stance was also confirmed by van Dyk (2005, 2010), Oluduro (2010) and Peters (2013), who showed that communities are likely to be relatively sympathetic towards PLWH as they may not be seen as responsible for the infection. The disadvantage is that PLWH may delay entrance into care as they may pursue ancestral interventions which may not provide comprehensive treatment. At a community level, the understanding that HIV infection is an ancestral affliction may be a major community health risk as many community members may be unknowingly living with HIV, transmit it to their loved ones and may not seek medical intervention as they may think it is some ancestral condition. It is a threat to HIV care.

Some communities still hold onto the understanding that HIV can only be transmitted through heterosexual relations. This understanding may put many family members at a risk of infection. The PHC in SA system supports the home-based care systems for many health conditions, including HIV care. Many PLWH who are terminally ill are usually taken care of by their family members. Home-based carers are usually mothers, sisters, daughters, aunts and grandmothers. With this complacent attitude about HIV transmission, many are likely to acquire HIV in the home caring activities. Under these

conditions, women in particular are left disproportionately vulnerable to HIV infection than men.

It was found that some communities understand HIV and AIDS to be a consequence of sinful sexual behaviour. This may cause PLWH to feel uncomfortable to actively participate in church activities or may even discontinue their membership. Family, community and church are major social settings in which people find purpose in their social interactions. Attitudes such as living with HIV is a sin and may purge many PLWH from the religious spaces. These attitudes were confirmed by van Dyk's (2005, 2010) study, which was conducted among 1 352 South Africans from diverse religious backgrounds, and found that a significant number of people felt that religious institutions should condemn the 'sinful' lifestyle of HIV positive people.

Religious denominations which hold better attitudes such as some African Independent Churches should be identified so that they may mentor and coach their peers in creating an enabling social environment for PLWH in communities.

6.3.3 Community Acceptance of HIV and AIDS

Fewer participants experience relative acceptance and understanding of HIV and AIDS by their communities. This was confirmed by a participant who said that:

> "They say it is a disease and accepted it and people must support one another'" (5).

Communities are aware of the availability of ARV and its efficacy in suppressing the HIV virus. As confirmed by Kaiser Family Foundation (2014), Fourie and Meyer (2016), UNAIDS (2017), South African Society and AIDS Response (2017) as well as WHO (2018) ARV treatment was rolled out seventeen years ago. The effort and messaging of HIV treatment reached those affected as well as those living with HIV and AIDS However, HIV and AIDS related stigma and discrimination which is three decades old

lives on. Lessons from the ARV drive may help to orient strategies to fight stigma and discrimination.

6.4 THE MEANING OF LIVING WITH HIV BY PARTICIPANTS BEFORE DIAGNOSIS

Participants' understanding of HIV and AIDS is not different from their communities. Participants' meaning prior to diagnosis is presented into three categories, namely their thoughts about HIV infection, their relationship with PLWH in communities, and their knowledge of HIV and AIDS.

6.4.1 Participant's thoughts, Emotions and Feelings about HIV and AIDS prior to Diagnosis

Although participants were not asked about the mode of HIV transmission, it was found that many acquired HIV through heterosexual transmission. Furthermore, prior to diagnosis, they knew that HIV is a sexually transmitted infection but they still thought that they would definitely not be infected. Many of them shared that:

"I never thought I will actually get sick from this disease" (3).

"I thought 'it is a disease for those people who are not right. It is for the promiscuous. They do not pass any man. Such a person who has it is about to die" (4).

"*Eeeh…..I used to think if I get it I will take a rope and kill myself"* (10).

"Ahaaa… I told myself HIV can never infect me. I was not running around with men. When you are married it can come in different ways" (9).

"I used to think that the infection happens because a person does not listen. It is for people who are too forward" (5).

'With a frowning face he said'*, "The disease can expose you in such a way that you can no longer look at yourself. I saw Nkosi Johnson's picture on TV while I was still sighted. It taught me to respect the disease. I actually feared the disease"* (2)

Participants' had knowledge about HIV infection and feared living with HIV and AIDS, but the knowledge did not translate into behaviour change as they neither tested for HIV nor adhered to safe sexual relations, probably because they were socialised by their community that HIV infection is for 'others' and not 'them'. The 'othering' attitude fuelled a complacent attitude about HIV transmission. This demands that HIV prevention strategies should go beyond education and give information. It should intensely be geared towards changing attitudes through dialogues to fight the complacency about HIV infection.

Many female participants initially experienced HIV infection as a disease of those who are unfaithful, while male participants just experienced it as a scary and unacceptable sexually transmitted infection. The difference in the meaning of the disease between males and females is a significant factor which determines coping in living with HIV and AIDS.

Although participants were not asked about their marital status, it was found that many female participants were either married or in steady relationships. They appear to have knowledge of the Abstain, Be faithful and Condomise (ABC) strategy of HIV prevention. As shown by UNAIDS (2005), WHO (2005) Coates, Ritcher and Caceres (2008).The ABC is an earlier prevention strategy of HIV transmission. Escalators of HIV transmission have changed, so has the prevention strategies. However, it was found that Female participants held solely onto the 'B' strategy of HIV prevention, namely 'Be faithful'. They lived with the understanding that faithfulness is a definite protection from

HIV infection. They were let down as they acquired HIV while they were faithful. Of the ABC messages, they apparently adhered to the 'B' only and omitted the 'A' and 'C'. They may have adhered to the 'Be faithful' prevention strategy as a self-fulfilling prophecy, or found it difficult to introduce the 'A' and 'C' in their relationships.

The ABC HIV prevention strategy individualises and infantilises HIV prevention in that it provides protection from HIV transmission on a low scale. Many sources established that HIV infection in South Africa occurs mainly through heterosexual transmission, but a large number of participants who are sexually active thought they were definitely not vulnerable to HIV infection (van Donk, 2002; Karim, 2005; UNAIDS and WHO, 2013; Rispel, Cloete & Metcalf, 2015). They are referred to as the 'perceived low-risk group' (Abbas et al., 2011). This is the same in other African countries as Coates et al. (2008) estimated that 65%-95% of new infections in Rwanda and Zambia occurred between married couples living together and those who are cohabiting.

Communities do respond to HIV and AIDS education. Hence their adherence to their knowledge of the narrow 'ABC' strategy of HIV prevention. It is time to intensely educate and empower communities on all dimensions of HIV prevention, especially the structural prevention of HIV. Articulations by participants revealed their past about their understanding of HIV and AIDS. They did not think well of PLWH in their communities. It is likely that it influenced their present experience of living with HIV and AIDS and their future.

6.4.2 Participants Relationship with PLWH prior to their Diagnosis

Unlike many middle aged and old participants, young participants were sympathetic to PLWH long before they were diagnosed. Their reasons were:

> *"It pained me as a person when I heard about another person who has HIV.*
> *That person is like me. We are the same" (14).*

110

"I accepted that person because such a person is like any other person because nothing has changed. That person just has HIV" (15).

"I used to feel pain for PLWH. It is because one did not know that it does not kill" (16).

One's prior experiences with the meaning, understanding, knowledge and interpretation of the illness from the social environment may be a benefit to the self and others as found among the above participants. It was noted that young people who are empathetic are also in possession of higher literacy levels as compared to middle-aged participants whose literacy levels are lower. Higher literacy levels may have influenced their understanding and perceptions of medical conditions and shape their attitudes towards HIV and AIDS. This finding is similar to an assertion by Coates, Ritcher and Caceres (2008) as well as French et al. (2014). Therefore, investment in the improvement of educational levels within communities may significantly turn around the tide of HIV transmission.

6.4.3 Participants' Knowledge of HIV and AIDS Prior to Diagnosis

While the world is three decades into the epidemic, a few communities still lack basic facts about HIV and AIDS.   This is articulated by a participant who shared:

"*I did not know much about it until I was tested and told that I have it. I used to think that if you are sick and you come to the clinic, nurses can see it even if you have not tested"* (1).

There could be many people in communities who hold this view. HIV care practice apparently takes it for granted that almost all communities have basic medical facts about HIV and AIDS or had reached saturation levels on HIV and AIDS matters. The UNAIDS (1999, 2004) and Coates et al. (2008) acknowledged the existence of this gap

and thus advocated for the rigorous implementation of the biomedical, behavioural and structural prevention strategies to reduce HIV transmission.

6.5 PARTICIPANTS' MEANING OF LIVING WITH HIV POST-DIAGNOSIS

Knowing one's HIV status has changed the meaning of living with HIV as it was found that post-diagnosis participants discovered a 'new' meaning of HIV and AIDS; that it is a health condition which is preventable, treatable and manageable; and that HIV infection can affect anyone. Participants were humbled by their personal experience of HIV transmission. Hence, they shed the myths, misconceptions and prejudices they previously held about HIV infection.

6.5.1 The Discovery of a 'New' meaning of HIV and AIDS

In the post-HIV diagnosis, the participants discovered a new meaning of HIV and AIDS, and faced the reality that anyone has a chance of being infected with HIV. They learnt to embrace other dimensions of HIV transmission other than the one they held prior diagnosis. The source of the 'new' meaning of HIV and AIDS where shared by some participants as follows:

> "It is a mistake which happened as I was taking care of my younger sister. I do not blame anyone. She did not tell me anything. I accepted that it happens in a human being. In fact it can happen in every human being" (5).

> "I saw because of my own experience. I did not get it from sleeping around. I got it from the one man I have. Even those others did not get it because of running around with the whole world" (4).

"I told myself that I did not get it because I love bearded people too much. I know I do not have two husbands but one husband. I know myself. I have one husband" (7).

Personal experience with HIV transmission humbled them as they changed from being judgemental to advocates of PLWH. The HIV diagnosis changed them from being judgemental into advocates for PLWH. Through social and psychological growth, they forgave themselves for stigma and discrimination that they previously meted out to those living with HIV, and attained personal growth. Participants who prior to diagnosis understood HIV to be for those who are unfaithful discovered that there is more to HIV transmission than unfaithfulness. They learnt that HIV prevention is not solely an individual's responsibility. The HIV prevention strategy which emphasises faithfulness only sends out confusing messages because participants diagnosed are neither members of the marginalised subpopulations nor unfaithful. These two diverse meanings of HIV may be a source of inner conflict which one has to resolve successfully for a new meaning of living with HIV. When the task is positively completed, it may mark a possible onset of HIV and AIDS activism. However, if this mental task is not adequately achieved as Peterson, Hotere-Barnes and Duncan (2008) discovered, it may be a defining moment for the onset of self-stigma which may manifest as feelings of worthlessness, self-doubt, self-devalue and low self-esteem, among others.

Prejudices on HIV infection was discovered among some participants. There are participants who were infected while caring for their loved ones. It was found that the participants neither inquired from their loved ones about the diagnosis nor use universal precautions while handling sick members' body fluids. It is likely that they did not consider their family members as potentially vulnerable to HIV infection. On the other hand, those family members who were being cared for also did not disclose their diagnosis to the carers. It is a blind spot in HIV prevention which may be attributed to either ignorance by carers or stigma and discrimination from both parties. Female family members usually carry out home-based activities of PLWH who are terminally ill.

Therefore, there is a chance that many home-based carers unknowingly acquire HIV. HIV and AIDS education should focus on universal precautions, especially among family members who provide palliative care to their loved ones.

6.5.2 HIV and AIDS is Preventable, Manageable and Treatable

Personal experience and factual information gathered as they receive HIV care followed by improved health outcomes changed the meaning of living with HIV among PLWH post-diagnosis. The diagnosis forced them to be rational about HIV infection. Hence, they started to refer to living with HIV and AIDS as a human health condition. Once PLWH begin to think about HIV and AIDS as a human health condition, it is an indicator that they are on a journey to post-traumatic growth (Braye, 2000; Miller, Nash & Fatty, 2014; Zeligman, 2018). It was found that post-diagnosis, many participants experienced the following:

> *"It is an acceptable disease. It is manageable by doctors and hospitals. It is no longer a scary disease. I accepted the disease. If you understand the disease there is no problem" (8).*

> *"I was no longer afraid of anything because I will look the same like before. I will not lose weight and become thin" (6).*

> "*No. There is no dying if one follows the instructions" (17).*

> *"I started taking treatment in 1999. By then it was not yet available in the clinics. I used to buy them. I have three children. All are negative. The youngest one was born in 2014" (7).*

Knowledge that ARV is available softens the crisis of HIV diagnosis. It a tangible solution to mitigate the impact of living with HIV. Participants who were particularly worried about what the body of a PLWH conveys to others are relieved to know that

medication shall hide undesirable physical body changes. Investment in biomedical, social and structural prevention strategies continues to better health outcomes for those in HIV care.

6.5.3 Post-Diagnosis Reactions

Participants' reactions to the diagnosis ranged from shock, disbelief, denial, shame, guilt to acceptance.

With a wide eyed expression and putting a right hand on the fontanel area a female married participant demonstrated her reaction on the day of diagnosis. She explained that

> *"When I was tested and told I was positive, I did not accept myself. I did not know what to do. I thought my life is finished. I asked myself what will happen to my children. What about this man. Must I leave him? I was so mixed up. I thought as I was walking home from the clinic people can see that I am not right" (9).*

> *"It was not easy. I knew about it in September. I wrote trial exams without reading. I wrote final exams without reading. I was stressed. I started going out smoking and drinking to take out stress" (15).*

> *"At first it was difficult for me to accept but bit by bit I told myself that it is my life. I should take medication in the way that the lady neighbour told me. I should not take a decision to kill myself" (10).*

> *"I was unable to accept. I thought everything in life is easy because I had no hope. Anything can happen" (11).*

"I accepted because I did not go out looking for it. I got it from my mother"
(13).

Participants first experienced the diagnosis as their world falling apart in their faces. Later they gathered strength and self-comforted and convinced themselves that it is not as bad as it appeared before they were diagnosed, and found reasons to support their thoughts about the diagnosis. Despite the debilitating nature of the diagnosis, they tapped into their inner strengths and weaved coping strategies. Many participants possess better problem-solving skills as they were able to identify the problem, considered possible solutions, implemented them, and were able to manage negative feelings which accompany HIV diagnosis. Ultimately, they motivated themselves to accept the diagnosis. Therefore, personal empowerment for PLWH which activates self-awareness and personal strengths should be a cornerstone to case management interventions.

Some female participants were found to have experienced suicidal thoughts on receipt of the diagnosis. It was established that most participants living with HIV first heard their diagnosis as a death sentence (Anderson, Elam, Gerver, Solarin, Fenton & Easterbrook, 2010; Kübler-Ross, 1969; Peters, 2013; Agrawal et al., 2015; Zeligman et al., 2016). It was found that participants understood HIV as a killer, but when they received the diagnosis, some participants had suicidal thoughts. The prevalence of these thoughts was found among female participants whose average age is early thirties. Suicidal thoughts may be a way of taking control from a disease which they viewed as a killer. However, suicide ideation is an infantile poor coping mechanism which may be a consequence of internalising outdated earlier images in the print and visual media which depicted PLWH as frail and undesirable. Therefore, the aim of HIV prevention should be to change people's thinking patterns about HIV and AIDS. Otherwise, the persistent stigma and discrimination which manifests in suicidal thoughts may continue to be a liability in HIV care practice.

Secondly, those participants who experienced suicidal thoughts may have experienced the HIV diagnosis as limiting. It is possible that as young women in their thirties also define themselves as wives and mothers. Hence, living with HIV may have posed a threat to these aspirations. This was supported by Merriam et al. (1997), who identified age ranges of 19-40 years as a young adulthood stage whose central theme is love. People develop intimate and committed relationships. The HIV diagnosis threatens one's plans, goals and aspirations regarding intimate relationships, child bearing and disclosure of diagnosis to partner.

A few participants experienced compressed sadness as they had to deal with difficult news one after another. In such situations, they had no chance to get out of the first one before the onset of the next one. The participants' mothers succumbed to AIDS related illnesses. While they were still experiencing AIDS related bereavement, they got diagnosed with HIV. Then they learnt that they acquired the HIV infection from their mothers. Participants experienced double grief in that they lost their mothers to HIV and lost who they may have become had they not acquired HIV from their mothers. This grief among the participants is usually deferred.

Acceptance is a common feature among PLWH, which influences better coping as one decides and actually releases oneself from being in conflict with the self. However, it does not necessarily mean that they got happy, but showed that individuals reach a stage of acceptance as they may have learnt to deal with the reality of their situation, in this instance, the HIV diagnosis. As discovered by (Kübler-Ross, 1969; Kübler-Ross & Kesseler, 2005; Wright, 2011; Peters, 2013; Agrawal et al. 2015) acceptance confirm that although they could not return to who they were before the diagnosis, they found their way forward. An enabling environment should be created within the HIV care practice for PLWH to reach the stage of acceptance

6.5.4 Benefits of HIV Diagnosis

A few participants understood HIV diagnosis as a health management strategy:

"After I was tested and told that I am positive, I felt free because now I knew what was eating me. I was happy. I knew there are people I know who have HIV and they are alive. I will also live" (1).

"I was sick for some time. I did not like food and was just losing weight. One day I stood up and went to the clinic for a test. When they told me that I have it, I accepted" (16).

*"I have been ill for a long time from different ailments. I was not getting better despite the clinic treatment. One day when I went to get help the nurses at the clinic told me that they have already given me all types of treatments. They said now the next best thing is to test for HIV. I tested and the results were positive. I was relieved because the clinic will know how to help me" (*17).

HIV Counselling and Testing (HCT) helped participants to regain control over their health. A common thinking pattern is that these participants self-motivated themselves and were psychologically prepared to deal with the outcome of HIV testing. They took the HCT before their health was at a terminal stage, and such gave them a chance to benefit from ARV treatment. If was found that these women were not judgemental about PLWH even before they were diagnosed. Furthermore, it was established that their communities' meaning of living with HIV was less vicious than those of other participants. Participants' environments provided them with a space to learn to appreciate a diagnosis as a benefit to their health. In order to create enabling conditions for PLWH to enjoy better health outcomes, it is important to target their social environments, especially communities as Subramoney (2015) and Tembo (2016) established that Living with HIV and AIDS is a community matter.

6.6 DRIVERS WHICH CHANGED THE MEANING OF HIV AND AIDS

Participants' personal experiences of receiving a diagnosis changed the meaning of living with HIV which they held prior to diagnosis. Some of the drivers which changed their prior meaning of living with HIV and AIDS are mental, medical and social factors.

6.6.1 Mental Drivers

The first destination of the HIV diagnosis is the mind. Consequently, changing the mindset about the diagnosis is a point of growth. Many participants carried out mental exercises and concluded that:

> "I was ill for a long time and did not know what the problem was HIV. The male prophet ordered me to go to the clinic for a test. After the test results came positive I knew I will live." (1).

> "It is like flu. You may not know that you will catch it .I told myself that it is like an accident. There is no person who can go out and say today I want to be knocked by a car. It just happens. It is an accident when it comes to you without expecting it' (7).

> "After I was tested at the hospital and told that I am HIV positive as an old person I accepted. I did not neglect myself" (5).

> "I know I did not go out looking for it. I got it from my mother" (13).

The strength of a human spirit was central to changing the meaning of HIV and AIDS among participants. All participants engaged themselves in some cognitive restructuring exercises as they disputed and tested facts that they previously held about HIV

transmission, examined and expanded their perspectives about the diagnosis and accepted it. They accepted that the HIV diagnosis is one aspect of their lives they cannot change. According to Tewksbury and McGaughey (1998), acceptance is some form of psychological ownership. Although almost all participants reached the acceptance level, it was also found that participants who acquired HIV through other modes of transmission other than sexual harboured a lot of unresolved issues or unfinished business with the loved ones from whom they acquired HIV who had passed on. Deep-seated HIV grief related issues need specialist HIV care treatment strategies as it has the potential to stir up poor health outcomes.

6.6.2 Medical Drivers

HIV diagnosis is still experienced as crisis which needs comprehensive intervention which may calm raging emotions post diagnosis. Tangible support such as the availability of ARV ranked as the highest driver of change among the participants. It reassured them of relative control over their health. Articulation by some participants highlighted that:

"*It was a difficult part. It starts by accepting. I followed part by part and understood that this medication works anyway" (2).*

"*I saw that ever since I started being under the doctors it is better than before. In the past I would feel that I have many diseases. Now I feel healed. I like food and my body feels healthy and I live like any other person. I have power. It once diminished but once I started to take medication the power came back and my body changed and became right. In the past everyone could look at me and tell that I was sick"* (8).

"*I am no longer like the old self. Before I knew I had HIV, I used to get very sick and would even be transferred to hospital. I got checked and told that I have HIV. Now I have happiness like others. I am healthy" (14).*

HIV diagnosis still evokes devastating feelings which are better mitigated by a tangible solution such as ARV. The availability of ARV changed the face of HIV and AIDS, and made the experience of living with HIV better on social, physical and psychological levels. Participants felt in control of their health and looked forward to a better 'lived body' as ARV shall support them to exist in bodies which convey good health messages to those who are in their social spaces. It is easier to cope with living with HIV when one is well.

6.6.3 Social Drivers

Social drivers consist of people who related in different social spaces, namely family, friends, church, community, community based organisations and others. It was found that participants relied on other people's responses for better coping. They were supported from post-diagnosis reactions such as those presented below:

> "*On the same day that I learnt that I am positive I told my mother and father in law about it. I told them that I don't understand because I am always at home .I do not walk around. They said we are also aware that you do not walk around, keep quiet, sit down and be still. They comforted me in many ways*' (9)

> "*My friend living with HIV told me that she was living with HIV for a long time. She told me that I must not make it a problem. The most important thing is taking medication.*" (12).

> "*My lady neighbour cum friend who is also living with HIV encourage me to take medication. They advised me to do what I am told to do by the clinic nurses*" (10)

"I do support group. I meet others. I see that I am not alone who is sick of HIV. I accepted myself" (14).

Many participants sought refuge from female family, friends and nonfamily members. Participants survived post-traumatic reactions due non-judgemental, reassuring, encouraging, caring and supportive responses from their significant others. These responses diffused the crisis as participants began to feel better and valuable. The 'Lived other human relations' lifeworld existential in phenomenology focuses on who is in the person's environment who can change thought patterns about an experience. It was found that the psychological meaning of the experience changed after family members and other significant people in the lives of participants interpreted the diagnosis to them differently. Psychosocial support provided by such sources is accessible and effective. Therefore, these sources should be empowered to provide psychosocial support to PLWH.

The family is the smallest unit of society whose stability keeps the larger society together. It was found that the structure, organisation and functionality of families played a role in changing perceptions of participants about the diagnosis as those participants who are in stable, extended and complete families enjoyed abundance of reassurance, love, care and support, which hastened their acceptance of the diagnosis. Participants from disorganised, single parent and sibling-headed families augmented care, support and reassurance from nonfamily sources such as friends, churches and support group for PLWH to recover from the impact of the diagnosis. Families are the smallest unit of society, but a major base from which individuals derive life purpose. Therefore, family preservation strategies should be purposefully integrated into the HIV prevention programmes to support PLWH. It has been established that PLWH who receive family support experience better health outcomes than those who are isolated (Ryff, 1989; Almeleh, 2006; Kim, Sherma & Taylors, 2008; Edwards et al., 2011).

Another significant social change driver is support and information provided by other PLWH. Some recently diagnosed listened to other PLWH than healthcare workers. This

may be due to the richness of personal experiences of other PLWH which provided participants with practical, relevant and appropriate responses to their new needs and concerns. Major sign posts of learning as articulated by the Social Learning theory include observation, modelling and psychological processes. It is easier to learn by observing, which entails listening and hearing how others who had a lived experience travelled the journey. Then one models or does as one observed the behaviour and learns to do as others did. Lastly, one is then motivated to model the behaviour from other PLWH as they are aware of possible health rewards. All other PLWH who provided support to participants were able to dismantle wrong perceptions, diffused what appeared to be crises and were readily accessible for support. Accessible user-led service at a point of entry into service is a right requisite for PLWH.

A third significant social change driver after support by other PLWH is participants' religion. A clear non-judgemental stance by some participants' religious leaders changed a crisis experience and settled down anxious congregants about the HIV diagnosis. Churches are well established community grassroots structures and many people are affiliated to different denominations. South Africans are religious as the 2001 census confirmed that 79.8% of South Africans are affiliated to the Christian religion, especially the African Independent and the Charismatic churches at 40.82%. Although the 2011 census did not have a question on religion, Schoeman (2017) confirmed that South Africans are very religious, and their religion plays an important role in their lives. Therefore, churches are an important health partner in HIV, and its contribution should be sought through purposeful involvement.

6.7 SOCIAL SUPPORT

According to Yadav (2010), Edwards et al. (2011) and Lakshmi (2017), social support is the physical and emotional comfort given to one by family, friends, spiritual leaders, co-workers and others. For the recipient of social support, it means knowing that one is part of a community of people who love, care, respect, value, and think well of other people.

6.7.1 Emotional Support

Despite the changing face of HIV and medical advancements for HIV Purc-Stephenson, Bowlby and Qaqish (2015) and Zeligman (2018) asserted that an HIV diagnosis still shakes the core of the self and one's mortality. Consequently, on receipt of a diagnosis, PLWH need all the support. It was found that participants received different types of support, namely emotional, religious, treatment, information and support by other PLWH. When some participants experience intense emotional reactions post-diagnosis, they were comforted by their loved ones.

"I became very tearful. Tears was just coming out but without crying out. There was no voice. Just tears. I just cried until my partner asked me about my tearfulness. I told him that at the clinic today they told me that I am positive. He said you just have to accept. He guided me to understand HIV and AIDS" (3).

"On the same day that I learnt that I am positive I told my mother and father in law about it. I told them that I don't understand because I am always at home .I do not walk around. They said we are also aware that you do not walk around, keep quiet, sit down and be still. They comforted me in many ways"" (9).

"My pastor told me that other people in the church who are positive are also drinking pills. She further told me that she has also been taking treatment for the past seven years. She asked me if I can read any tell-tale signs that she is on medication. She told me I also need to drink. Now I enjoy it" (11).

"I asked myself how I got it. My mother passed away in 2016. I found out that I am HIV positive in 2017.My pastor told me that my mother told her

that she is HIV. My mother just did not want to hurt me. The pastor said she just did not know how to tell me about it" (11).

"Do not eat your heart my child. You will heal. The most important thing is to drink your pills" (17).

This is similar to another participant's mother who told her 33 year old daughter that:
"It happens. You are not the first one" (15).

"I found myself getting into face book talking about myself with a disguised identity to look for support after I was told that I am positive but my younger sister and aunt advised me to delete what I have written. I can only talk to my younger sister and aunt. I need this support. My mother was sick. I could not tell her such a problem" (3).

Many married female participants or those in steady relationships got very devastated about the diagnosis. Many are those who prior to diagnosis definitely thought that they can never get infected. This could be attributed to prior understanding that HIV infection affects those who are unfaithful. Hence, post-diagnosis, some participants experienced profound emotional reactions, in particular feelings of profound helplessness which gave rise to depressive symptoms. Depression among PLWH has been singled out as the most prevalent mental health problem among PLWH which, if it remains untangled, may lead to further mental health deterioration (Bing, Burnam & Longshore, 2001; Nakimuli-Mpungu, Musisi, Katabira, Nachega & Bass, 2011; Agrawal et al. 2015; Zeligman, 2018).

Some participants were worried about the diagnosis, anticipated rejection by spouses while others were actually rejected by spouses and in-laws. The common feature with all the participants is that they were all comforted by family members, namely husbands, father-in-law, mother-in-law, mothers, sisters and aunts. The ages and gender of participants did not make any difference as post-diagnosis, many shared that they

sought comfort from their families. It was found that female family members, especially mothers and sisters are the greatest comforters. However, it was discovered that there is a designated female comforter, namely the aunt (father's sister) who did not appear among comforters. Fathers and uncles were either absent or were not preferred as disclosure recipients. It may be an indicator of changing traditional family structure and roles which rearrange the support structure.

Some participants were comforted by elderly people in the family, who displayed a rich wisdom and skill to calm down the raging emotions as they themselves kept calm in the face of some participants who got hysterical about the diagnosis. Family elders were not scared of the pain of their loved ones. The recently diagnosed require such a stability. With adequate HIV care support, mentoring and coaching older people in families may be an asset in the provision of home-based nonprofessional psychosocial support for family members. Stigma and discrimination can be fought within families.

6.7.2 Religious Support

The experience of living with HIV and AIDS is multidimensional, with religion as one of them. Many PLWH rely on their religions for support and guidance. It was discovered that some participants took HCT, initiated ARV and adhered to treatment through the support of their religious leaders such as these ones.

> "*You must stop the church treatment of regurgitating. Instead he instructed me to go for testing in a clinic, not the hospital. The prophet said it is also an instruction from the church leader. I was saved by my church male prophet. He did great. He told me that he knows me as a person of good body weight but I am just wasting away. He prophesised that I must stop to clean my stomach and to regurgitate. The prophet ordered me go to the clinic for testing*" (1).

"When I am in church pilgrimage and run out of medication, I go to the office to report. Then I am sent to the church clinic to get medication. Our Bishop is a doctor and encourages us to take medication. He encourages us to take care of ourselves" (5).

"One day the clinic sister said she can't help me. She told me that she needs my parents or anyone closer to me so that she can help me because I was not drinking my meds. I gave them my pastors' contact telephone no. They called and secured an appointment with her. My pastor came to the clinic with me. The clinic sister talked to the pastor. Then the pastor talked to me" (11).

Church leaders encouraged congregants to go for routine medical screening, treatment adherence and ART initiation. The significance of their actions is that religious leaders shared the spiritual healing space with medical care in a way that was of benefit to the entire system. In this way, they provided for the felt needs of congregants. The African Independent Churches and charismatic churches have been found to be proactive in HIV care issues as they translated their religious missions into a consumable product which improved the lives of their congregants, in particular PLWH. These churches never caused their congregants to feel that living with HIV and AIDS is a sin, or that seeking medical treatment is a lack of faith in divine intervention. This approach to HIV care was appreciated by Troyer (1988) who asserted that it reduces the level of stress for the congregants in question. Therefore, continuous training of religious leaders on the up to date information and integration of their doctrines and HIV and AIDS can be an asset for HIV care.

6.7.3 Treatment Support

The HIV care practice introduced the component of treatment support for PLWH to ensure that they maintain a high level of adherence of viral suppression. Treatment

supporters for the participants are family, healthcare workers, friends, neighbours and other PLWH.

6.7.3.1 Treatment support by family

Children, grandchildren, parents and spouses are the greatest family treatment supporters. Many participants were satisfied with treatment support that they receive from their families.

"When the time comes for me to take medication my grandchildren bring me water and pills for me to drink. At times I tease them and say I no longer want to drink pills. They cry and say I should not do like" Person Y" who stopped drinking pills and died. Hahaha…they and their mother care for me" (1).

"My eldest child who is in Grade 12 knows that I am positive. She reminds me to take my pills. I gave her my clinic card. She collects my pills from the clinic" (12).

"My elder sister's daughter who is in grade 4 reminds me to take my meds. She nags me if she thinks I am not drinking my pills" (13).

While in a relaxed, laid-back sitting posture throughout the interview, one participant who has been living with HIV for 19 years displayed immersed support, and shared that:

"Even when I visit my mother, the first thing she asks me is whether I brought my medication with me. If my pills gets finished while I am at her place, she accompanies me to the clinic. She actually negotiates with clinic sisters on my behalf for them to refill my meds. She gets on well with them. They do give me the pills" (7).

"My husband reminds me of the clinic follow up visits. He reminds me to take my pills at the correct time. He then reminds me to give the child her medicines. He does not miss this. When he is not at home he sets the alarm to remind me to take pills" (9).

Diagnosis disclosure within families is significantly high as each participant had disclosed the diagnosis to at least one family member, namely parents, in-laws, spouses, children, grandchildren, sisters, aunts and disclosure recipients, who surrounded participants with support. In this way, it confirmed that relevant social support is dependent on diagnosis disclosure. Advantages of diagnosis disclosure is that one accessed support and liberated oneself from living with fear of the diagnosis being found. The commitment of family members towards their loved ones confirmed that stigma and discrimination is better managed as every family treatment supporters did their best to support the participants.

Participants disclosed their diagnosis mainly to female members, who are a pillar of strength for many participants. The reasons advanced for the preference of female family members as disclosure targets are that female family members are more compassionate and supportive than male family members (Norman, Chopra & Kadiayala, 2005). Petronio (2004) showed that the choice of a disclosure target depends on liking and attraction. Female family members, especially mothers are disclosure recipients than other family members. However, this puts a burden of care on them as compared to other family members. HIV care intervention should strengthen intervention protocol which include family members in the interventions.

One significant family member who did not feature among disclosure recipients is father's sister (aunt). In the African family setting, an aunt is a counsellor and family spokesperson whose role is to give direction with well-defined instructions. An aunt is a refuge in time of need who diffuses a crisis before it escalates into emotional breakdown. Their absence could suggest that either a family structure is undergoing a tremendous change or that aunts' role is extinct. Therefore other family members

should be adequately supported to carry out the role. This is well articulated by van Empelen (2005), Lyons (2008) and Vranda and Mothi (2013) that the family as a fundamental unit of society and natural environment for growth and wellbeing of its members should be empowered, supported and afforded the protection and assistance so that it can assume its responsibilities in communities.

Parents who provide emotional support to many participants are the elderly, but their responses confirmed that they value treatment and provide a support structure for their adult children. However, empowerment of the elderly in HIV care seems to be minimal, and their availability, accessibility and wisdom appears to be an untapped resource for HIV care practice.

6.7.3.2 Treatment support by healthcare workers

As shown by PRIMASYS (2017) the PHC infrastructure consists of nurses, doctors and community healthcare workers. Participants singled out clinic nurses as their primary treatment supporters. Some of these supporters are available to participants' bio-psychosocial needs even after working hours. One participant demonstrated her appreciation of the support in that when she narrated it, she moved her upper body forward and used her hands to create a circle in front of her chest to demonstrate how they surround her with support. Then she goes on to say:

> *"Clinic 'Sister XXX" encouraged me to stay on medication. She advised me to eat lots of avocados, fruits and beetroot. I used to eat my heart a lot. Clinic Sisters XX and YY are my support. When I cry they receive my tears. I love XXX a lot. When I feel like I am falling they support me"* (6).

> *"I once decided to go to another clinic but decided to stay. Here they support me"* (11).

"You know…….hahaha…..the Clinic "Sister XXX" is my parent. She gives me medicals. My sister reminds me to drink my pills on time" (14) [With a beaming laughter].

The primary objective of PHC is to ensure that citizens have access to healthcare services. Many participants from both municipalities commended nurses' support in the health centre as they accessed healthcare workers' support even after working hours. The clinic nurses are their patients' healthcare providers as well as companions. This is a good footprint in HIV care, and contributes to the better social functioning of participants. The finding on satisfaction with the service that they receive from this public healthcare centre from the nurses is similar to a finding by the General Household Survey (GHS) by Stats SA (2017), which found that 81, 7% of households that attended public health-care facilities were either very satisfied or satisfied with the service they received. Investment in comprehensive healthcare, in particular HIV care may reduce poor health outcomes for those living with HIV and their families.

6.7.3.3 Treatment support and Information by other PLWH

Despite the changing face of HIV and medical advancements for HIV, an HIV diagnosis still shakes the core of the self, self-identity and one's mortality (Purc-Stephenson et al. 2015; Zeligman, 2018). The efficacy of guidance, support and information by those who lived the experience was confirmed by some participants:

"My lady neighbour and friend who are also living with HIV encourage me to take medication. They tell me to do what I am told to do by the clinic nurses'" (10).

"My pastor told me that other people in the church who are positive are also drinking pills. She further told me that she has also been taking treatment for the past seven years. She asked me if I can read any tell-tale signs that she is on medication. She told me I also need to drink. Now I enjoy it'" (11).

"My friend living with HIV told me that she was living with HIV for a long time. It is just that she did not want people to know. She told me that I must not make it a problem. The most important thing is taking medication" (12).

Although participants did not look up to the general community for support when they were diagnosed, they enjoyed good neighbourliness. Disclosure of private and confidential information such as HIV diagnosis happens in the social environment of trust between the owner of private information and the recipient. Strengthening small community units such as families may give rise to communities which are socially cohesive and communicate communal care to its inhabitants. Disclosure of their diagnosis to neighbours provided some participants with accessible and effective psychosocial support which is often scarce in HIV care. Receipt of information from another person living with HIV was quick to break barriers into HIV care and surpassed the psychosocial care provided by some healthcare workers. Participants initiated ARV and others were encouraged to adhere to treatment. Reinforcement of better community life is a requisite for effective HIV prevention.

The participants' quick response after they got information and support from other PLWH is a product of social learning. They could observe and identify themselves with other PLWH. The foundation of social learning as postulated by the social learning theory is that individuals learn through observation, modelling and motivation to learn a new behaviour.

Female PLWH who readily reach out to other PLWH. HIV positive and discordant couples rarely come out to support other PLWH, probably due to fear of stigma and discrimination. Marashe (2014) cautioned that this trend may perpetuate the perception that HIV infection affects the unmarried and widowed. It is necessary for HIV care to prioritise reaching out to couples living with HIV and AIDS and be involved in programmes of fighting stigma and discrimination.

6.7.4 Material Support

Members of extended families are still a source of support in time of need, especially tangible support such as food, accommodation, and clothing among others.

> *"I am unemployed. I and my daughter depend on my elder sister for food and other things. My mother passed away some years ago and left me here. My father stays somewhere. He does not help us with anything" (16).*

The participant is young, dropped out of school, unemployed and currently living with HIV and AIDS. She experiences different levels of vulnerability. The available support by her sister helps her pull through each day. HIV care should be designed to support PLWH with basic needs for better coping.

6.8 COPING CHALLENGES

Stigma and discrimination is the most painful stressor among participants. Each one of them had a story to tell about experiences of stigma and discrimination in their daily lives. Experiences of stigma and discrimination breeds both the intrapersonal and interpersonal challenges. Such challenges are summarised below.

6.8.1 Intrapersonal Challenges

Intrapersonal challenges manifest in the way one relates with the self. It was found that the most common intrapersonal challenges experienced by participants is self and anticipated stigma.

6.8.1.1 Self-stigma

Feelings of self-judgement, self-devalue, self-punishment may be a consequent of the quality of interaction with self and others in the social environment. In many instances such feelings are subjective. This was revealed by some participants who experienced self-stigma since diagnosis.

"When I am here next to the clinic and receive my treatment, I am fine. I do not need much from the community" (2).

"I was not drinking my medicines. I was collecting tablets from the clinic but I was throwing them away" (11).

"Here in my family we used to be many people, my brothers, their wives and children. I did not want them to know that I was positive. I wanted to keep it to myself. It forced me to breastfeed my child because I did not have money to buy baby formula. During that time babies were not to be breastfed. In 2000 it was shameful. I had to fetch baby formula from ZZZ (name of the clinic) then people were going to know that am HIV positive" (12).

"I want to grow up and clean my life, and not become pregnant" (13).

Self-stigma was found to be a core intrapersonal coping challenge which strikes the minds of participants daily. Gender, age and the duration of living with HIV do not make a difference on the nature and intensity of experiences of self-stigma. It was singled out by WHO (2004), Yi et al (2015) and HSRC (2015) that post diagnosis, PLWH carry a lot of shame about the infection and they think others too think poorly of them. Consequently, they develop a poor self-perception which, for some, deteriorates into self-devalue and self-ill-treatment. It was found that the most common form of self-ill-treatment among PLWH is neglect of medical treatment.

The meaning of HIV and AIDS created by communities and their members is shared through language, names, labels and symbols. Hence, when people get diagnosed, they view themselves against the shared meaning. As the shared meaning of HIV and AIDS bears negative connotations, they negated themselves, which is a source of self-stigma. Subsequent to this, many PLWH begin to be selective in their social interactions

in order to manage relationship gaps created by stigma and discrimination. The negative self-perception is located within the framework of the Social Construction theory (Hutchison, 2003), which emphasises that through interactions, individuals develop the self, learn to interpret the world around them and try to find their place in it. They live with others, for others and by others. This is what is referred to as Cooley's 'looking glass self', which compels an individual to think how one appears to others, imagine other judgements about the appearance, and develop some feelings about the self which may be pride or shame, which is the result of imagining their judgements. Consequently, HIV care preventive interventions should target stigma and discrimination at the source, namely community narratives on the meaning of HIV and AIDS

6.8.1.2 Anticipated stigma

It was found that post-diagnosis, a handful of participants anticipated poor treatment by family, workplaces and health settings. Consequently, they decided to protect themselves from possible stigma and discrimination in this way:

> *"If family members knows that you have HIV, they will write you in their funeral policies as they think you are about to die. You can't even have flu or headache. When you are ill, they will come to visit you as if they care about you when in actual fact they are coming to check if you are about to die. You will no longer have peace" (4)*

> *"People say you can't get a job when you have HIV. It causes one to lose hope. When I think of looking for a job I feel discouraged. I just sit here at home and tell myself I will eat what I eat. My children will grow up'" (12).*

> *"At some point I thought of changing to DT the clinic but I decided to stay with this clinic. You find other people talk to you somehow with an approach. Then I find myself down. Here they support me" (11).*

Some Participants regulate their social interactions with others based on the negative predictions. It was established that post-diagnosis, some PLWH trusted less of other people in their social space, and were not keen to develop new relationships due to fear of diagnosis disclosure and rejection by family, colleagues and other service providers. Hence, many participants chose to keep to themselves and in trusted familiar environments. These decisions about their social interactions suggest that they carried out a cost benefits analysis about certain relationships which they decided to sever or avoid as they concluded that they shall not add value to their daily lives. As shown by Dejman, Ardakani, Malekafzali, Moradi, Gouya, Shushtari and Mohraz (2015), this explains social relationship patterns and coping strategies chosen by PLWH in order to deal with their unique needs, problems, concerns and challenges.

As articulated by Wang, McClelland, Overbaugh, Reilly, Panteleeff, Mandaliya and Kreiss (2004) human relationships are based on the Social Exchange Theory (SET) principles, namely mutualism, reciprocity and utility. According to Wang et al. (2004) and Neuman (2011), social relationships occur in the social market place in which people give in order to get individuals relate with self-interest in mind. These individuals have the desire to maximise the benefits and minimise costs. Anticipated stigma is a proactive strategy, but it is limiting on the part of PLWH as participants lead apprehensive life based on negative predictions. It usurps resources which could be channelled into better living.

6.8.1.3 Unresolved grief, anger and resentment

Although the study did not pose a question to participants on the mode of HIV transmission, it was discovered that a few participants acquired HIV through home based caring activities and through mother to child transmission. They experience complex emotional coping challenges which may require specialist HIV care services to help them work through the unresolved grief related to HIV transmission. They shared their coping experiences.

"I do not blame anyone. She did not tell me anything" (5).

"According to me I understand that it does not come through sexual intercourse only, and when it comes you, you had not applied for it" (11).

"I accepted because I did not go out looking for it. I got it from my mother "(13)

The underlying message among these participants is anger, guilt and resentment towards their loved ones who did not protect themselves from the infection when they could have possibly done so. In the same breath, they also experience guilt for feeling the way they do towards their loved ones. They experience conflicted emotions in that on the one hand, they are good family members who cared for their loved ones. On the other hand, they feel guilty and disappointed as they are living with HIV which they acquired while taking care of those loved ones. Irrespective of the mode of transmission, society judges them for living with HIV. They experience a unique and complex relationship with what they have become due to the diagnosis. It is likely that they may experience delayed adjustment in coping as compared to those who acquired HIV through other modes of transmission. Their unique circumstances was acknowledged (Naswa & Marfatia, 2010; Wang'ondu, Samuels Andiman, Paintsil, Barakat & Langs-Barlow, 2018), and recommendations were made that there is a pressing need for sensitive approaches to provide psychosocial care for youths who perinatally acquired HIV or those who acquired it through home caring activities for them to manage latent negative emotions towards family members from whom they acquired the HIV, especially biological mothers.

6.8.1.4 Growing old with HIV and AIDS

One 70 year old participant is proud that she is still able to take care of herself. However, she seemed paralysed by the fear that one day she may have to depend on other people for her daily upkeep. With an empty stare she expressed that:

'I stay alone. 'My children and their spouses have their own separate families but they know that I have HIV. I must wake up in the morning and eat the correct food. In the future as I am growing old, I am not getting younger. There will be time when I am no longer able to prepare food for myself. I would like them to prepare me food' (5).

Some PLWH are paralysed by the thought of dependence on others when the disease progress into the terminal stage. This stage is the peak of one's life wherein individuals re-evaluates what one has become. The knowledge that one was able to parent, care and guide the next generation has been identified as the central and a form of self-actualisation but living with HIV into old age may turn it into feelings of despair. Specialist HIV care services should help old PLWH to mediate such feelings

6.8.2 Interpersonal Challenges

Many participants lost quality relationships they used to enjoy before the HIV diagnosis. This loss caused them feelings of sadness, rejection, abandonment meted out by their social environment such as the family, the community, workplaces and health, among others.

6.8.2.1 Interpersonal challenges in the family

Some participants lived through experiences of rejection and abandonment by in-laws and partners:

"*Soon after I received the news that I am positive I took my mother in law as my mother. I went to her and told her that I am positive. As soon as I left her gate house she called her other police child and told him that PP (name of the participant) was here. She told him that she is saying this and that. She*

must not dare and lie that she got it from my son. She is the one who brought it" (3).

"One time when my partner came home over the holidays, he found me very ill. He never asked me about what I was suffering from. He just brought some food and left. I think he thought I would be dead soon" (1).

"When I told my partner about it he said I must have got it somewhere. I think he was afraid that I will leave him. Then I will tell people that he is ill" (15).

One participant was baffled by her partner's response when she shared her diagnosis. With a left hand supporting her chin and an empty stare she narrated her visiting partner's 'response when she disclosed her diagnosis.

"When I told him my status He never seemed worried. I never knew his status .He passed away in 2016. I never knew his status. You know how men are" (17).

Many female participants experienced rejection and abandonment by in laws and spouses. It was found that all male participants were neither rejected by parents nor partners. Rejection is an experience of feeling unwanted, unwelcomed, isolated, baselessly blamed, withdrawal of attention and interest by a significant other. Many PLWH who are abandoned post-diagnosis are women. It was established that the most common form of emotional abandonment among participants was the severance of emotional ties, indifference about the diagnosis and general wellbeing. These experiences by female participants exposed the dimension of gender and illness, especially HIV and AIDS*.*

6.8.2.2 Interpersonal challenges in the workplace

Post-diagnosis, PLWH may have new financial needs. Consequently, looking for a job or staying in the current one is vital. However, it was discovered that some participants experienced stigma and discrimination by prospective and current employers.

> *"People give us a job to do. We do quotations but before we could start working we see another person doing that job without them even telling us they no longer want our services" (3)*

> *"I was looking for a job as a security guard in MKN in 2010. I and other job seekers brought back HIV positive results. We were not appointed. Those with negative HIV results were appointed. The supervisor told us that if it was not for the HIV positive results we could have been employed you but your life is cut short as you are HIV positive. You will not work for a long time. It means that when I go to the doctor I must bribe for a negative test result so that I can get employed" (4).*

> *"When you are a domestic worker and asks for permission to collect your medication, they think that you will bring HIV into their family" (17).*

Stigma and discrimination occurs in many workplace settings, namely self-employment, small business, entrepreneurship, domestic work and others. The manner in which stigma and discrimination surfaced in the job market for these participants suggest that prospective employers are either unaware or ignorant of the provisions of recommended good practice for HIV and AIDS in the workplace. They may not be aware that they are harming the rights of PLWH and breaking the law. This practice deters PLWH from being active in the open labour. More training for employers in terms of the Employment Equity Act 1988 (ACT 55 of 1998) and the International Labour Organisation (ILO) Code of Good Practice on HIV and AIDS in the World of Work (2010) is required to create a safe environment for PLWH in the workplace*.*

6.8.2.3 Interpersonal challenges in the healthcare setting

HIV care in South Africa is provided through the Primary Health Care (PHC) system within the access service delivery model. A handful of participants experienced some impediments to HIV care:

> *"One time I left unexpectedly to Gauteng to care for my brother who was very ill. He was ill from this same disease. When my pills got finished I went to the SSS clinic (name of the clinic) for meds. They refused to give me. I pleaded with them on my knees for meds which they later gave me. When they finished the second time I went to the DDD clinic (name of the clinic. They were very friendly and gave me the pills" (1).*

> *"Suppose I am in PKN at work and my pills get finished. When I request for medication from the clinic which is next to my workplace they said they cannot give me pills because they will be giving me another person's pills. They said I must go back to collect my pills from my home clinic" (4).*

It appears possible to refill ARV from another healthcare centre as was the case with some participants. However, healthcare workers in the same province display different ARV dispensing protocols. The impediment to HIV care can either take the form of policy provisions or attitudes of healthcare workers towards PLWH. The practice suggests indifference towards PLWH which defeats the intentions of HIV.

UNAIDS (2017) discovered that the source of indifference of many healthcare workers is compressed grief. Healthcare workers witness their patients suffer and die one after another from AIDS-related illnesses and do not have time to debriefing and mourn properly. Consequently, many healthcare workers develop indifference towards PLWH. Continuous training of healthcare workers and the provision of caring for carers may provide healthcare workers with support as HIV care practitioners.

Another challenge found in the healthcare setting is related to being served in identifiable ARV clinics. Some participants who experienced discomfort by being served in identifiable ARV clinics shared their experiences:

"When we are here to take medication and find a new patient from local. I start to be an enemy because he feels I have seen him because he does not want to be seen. He is not used that we live with it. When they teach him in the clinic he takes it I talked about him. It starts hatred" (2).

"It forced me to breastfeed my child because I did not have money to buy baby formula. During that time babies were not to be breastfed. In the 2000 it was shameful. I had to fetch baby formula from the TDZ clinic. Then people were going to know that am HIV positive" (12).

"If one person from this village sees me getting into the TDZ clinic (ARV Clinic), that person will come back and tell everybody. Separating the clinic gives pressure to people living with HIV. One has to hide so that one may not be seen by people who knows him/her. I wish medication could be delivered here in the community to all people who suffer from all other illnesses, not only HIV medication. It should be delivered by PLWH not just any person so that the patient can feel free. " (17).

Stigma and discrimination by PLWH towards other PLWH is not uncommon. A person living with HIV did not want his status to be known by other PLWH from the same village. Stigma and discrimination robbed them of the opportunity to be supportive towards one another. Instead it drew them apart.

Stigma and discrimination is a killer disease which turned caring mothers to appear negligent towards their unborn children as they omitted the prevention of mother to child transmission treatment. It later caused them enormous guilt after their children were born, even when the children in question did not acquire HIV. It stirs up anxiety among

PLWH and may be the possible cause of non-adherence to treatment. Dalton (2013) echoed that stigma segregates and puts people into categories. These categories become one's master status, overshadowing other statuses. This conditions the individual to continuously partake in the activities ascribed to the master status, good or bad.

6.8.2.4 Interpersonal challenges in communities

Communities are not safe places for some participants. Community members gossip, spread rumours and reject those who are suspected or known to be living with HIV. The pain of rejection was explicitly demonstrated by one female participant who has been living with HIV for the past years. She remembered her rejection by her neighbours. With rolling eyes and froth spitting out her mouth she said:

> *"People are sarcastic. Two lady neighbours who were standing next to my yard talked about me. I was sleeping under a tree next to my neighbour's yard fence. I pretended to be in deep sleep. Although I heard bad things they were saying about me i did not talk back to them. I pretended I did not hear what they said I heard them say look at her. She is dying. She has AIDS. This year she will not live to see Christmas'. I did not know what they were seeing in me to say those words"* (1).

> *"Students at school say they do not even want to eat with a person with HIV. They say that such a person may infect them"* (13).

Grinding his teeth and tensing up around his shoulders, he talks about the negative relationship experiences he receives from his community.

> *"They are not reluctant to hurl insults at you laden with* "AIDS" *so that you hurt most. I cannot recommend my community when it relates to AIDS. My community is not still or calm at all. What worries me is to be thrown with*

painful words in public to expose me that I have AIDS. They are not transformed. They need transformation!" (2.)

"People knew I was in a relationship with someone who has HIV. I did not know. They talked about it. I accepted I am not the only one in South Africa" (15).

Communities' outdated understanding of HIV and AIDS compound poor health outcomes among PLWH. Many communities indulge in intentional disabling interactions with PLWH, which renders them powerless. As it is, fighting stigma and discrimination should not be left to PLWH, but its source should be targeted. However, PLWH need to be empowered with life skills so that they may assert themselves when they are attacked.

6.8.3 Other Challenges

Living with HIV and AIDS give rise to new needs. Other than intrapersonal and interpersonal challenges, there are medical and financial challenges.

6.8.3.1 Medical challenges

With the exception of a few participants, it was found that many participants are doing fairly well in managing the side effects of medication. One female participant who has been living with HIV for the past five years learnt to live with it. When she articulates the experience, she presses her hands on her tummy to demonstrate the location and intensity of the sensation which is caused by one tablet, and says:

"There is one tablet which makes me very hungry. I feel it in my stomach. Then there is another one which makes me feel sleepy. After drinking it I sleep just a little bit'" (1).

Another shared that:

> *"Before I started treatment I was living well but after I started taking the pills I started to menstruate for many days. I used to menstruate for three days, then one week and then I would menstruate for the whole month since 2013.I also have a burning sensation in my stomach. When it happens the burning is intense and cause me to lay flat on my stomach. But I had to be at work. Ms MM encouraged me to stay on medication. She advised me to eat lots of avocados, fruits and beetroot. I used to eat my heart a lot. I was a size 42 but now I am size 38. In the month of February (2018) I did not menstruate at all. I resorted to use pampers as sanitary pads were not enough. I would use a pack of 20 for three days"* (6).

> *"I sometimes get very angry without any provocation. I am insulting a lot. It just happens and later goes away. I did not have this in the past. I later feel very guilty about it. It started in 2017. It just happens. I get very irritable. My younger sister now understands that I just get irritable with her. I feel I want to get away from her. When I come back I feel ok and speak well"* (10).

Despite the side effects of medication, participants are resolute about treatment adherence. Personal and educational empowerment, specifically on treatment literacy could improve the quality of lives of many PLWH. Physical and mental side effects are prevalent among participants.

6.8.3.2 Financial challenges

Economic empowerment among PLWH and their families through employment and social protection package is a precondition for better health outcomes. A handful of participants shared that they could do better financially if their circumstances could improve:

"They encourage us to eat good food. Where do I get food when I am unemployed? It gives me stress. It is better if they could find us work so that we can work. When I wake up in the morning I need to get maybe an apple or another fruit" (4).

"If your husband is unemployed don't say what I will eat. If you are a church goer believe that what you eat your child will also eat. One day God will give your husband a job" (9).

"We sometimes have shortage of food and electricity. We sleep in the dark. I tried to go to the social workers. Since then when I go to check they keep on saying it has not passed yet. I asked if there is no need for the two children to get food rations. They said no" (12).

"I am unemployed. I and my daughter depend on my elder sister for food and other things. My father stays somewhere. He does not help us with anything" (16).

No participant experience abject poverty as all participants are either recipients or administrators of social grants. Among them a few participants experience relative poverty. Although they experience financial challenges, female married participants are not in dire need, while single parent female headed families are the most affected by lack of basics. Like other participants, they are recipients of social grants, but it is inadequate. After the interview, these families were linked with municipal Social Work managers to provide them with further social assistance services in order to improve their living conditions.

Male participants were found to be better off financially because self-employment activities that they occupy may pay them a better income than those occupied by women. It was discovered that the economic vulnerability of PLWH is exacerbated by lack of multidisciplinary HIV care as participants depend on clinic nurses for almost all

their needs. It was found that there are healthcare partners who are a missing puzzle in the narratives of participants. These are dieticians, psychologists, psychiatrist and social workers, among others. This is also a finding by the PRIMASYS (2017), which confirmed that patients have access to a basic package of services within the PHC health system. However, it was acknowledged that the availability of dental, therapeutic, dietetics and psychosocial services was still low. Ineffective multidisciplinary interventions in HIV care perpetuate their vulnerability.

6.9 COPING STRATEGIES

Coping is described as the ability to engage in problem-solving, which entails knowing what needs to be done to manage the stress and the ability to regulate negative feelings emanating from stressors (Robbins, Chatterjee & Canda, 2006; Shulman, 2009; Stowers & Kohli, 2012). Participants relied on the emotion and problem focused solving strategies to deal with the challenges of living with HIV and AIDS.

6.9.1 Emotion Focused Strategies

Self-convincing and self-talk were found to be the most common form of emotion focused coping strategies. Examples of self-talk and self-convincing is reflected in some participants' responses to the question of how they coped with challenges related to living with HIV and AIDS. Some participants demonstrated a level of emotional intelligence when they convinced themselves that:

> *"In this world we are the same. People must accept us as everyone else. Living with HIV is the same as other diseases like diabetes" (1).*

> *"I started going out drinking and smoking to take out stress. But I realised that after drinking the problem comes back. I told myself I had to stop it now. I am destroying myself. I have to get someone to talk to" (15).*

"I accepted it. One will go to the clinic and find people who will counsel and get medication. You are not the first one, is that not so? One must not kill oneself, is that not so? I have a child. I live for my child. I stay alone with my child" (16).

"Dying is for everybody. You may die not of AIDS. If you are taking pills you may die of any other disease" (7).

Participants oriented themselves positively. They achieved this through cognitive restructuring exercises. They changed negative thoughts and beliefs about themselves; disputed wrong perceptions about living with HIV; self-educated themselves to expand their perspectives about living with HIV and AIDS; consciously planned to occupy a space in the social environment; and encouraged themselves to assert their new thoughts verbally and behaviourally. Cognitive restructuring reflected their ability to be kind, self-compassionate, self-calming and affirming to bounce back. For HIV care, this emotion focused strategy may be a point of departure to improve their self-efficacy, confidence and self-respect among themselves. This is a trait which, if tapped, may foster feelings of efficacy. This finding shows that despite the debilitating effects of living with HIV and AIDS, PLWH have survival skills. Personal empowerment for PLWH should focus on increasing their self-efficacy, confidence and self-respect in order to facilitate acceptance of the diagnosis.

6.9.2 Problem-Solving Strategies

Participants' problem-solving strategies focused on routine and non-routine problems. They demonstrated the ability to apply ideas and skills to solve both routine and non-routine problems which they experience as PLWH.

6.9.2.1 Routine problem-solving strategies

Routine problems are those problems which require simple solutions and do not demand complicated problem-solving strategies. Participants implemented problem-solving strategies with routine problems such as treatment adherence, treatment literacy and assertiveness, among others.

"When it is time for me to take medicines something clicks in my mind. It is now in my blood. I am not ashamed to drink my pills even when I am in community gatherings. When it is time I drink my pills. I ask for something to eat first so that I don't drink pills on an empty stomach." (1).

"Me? Forget to drink pills? I don't miss my time not even a day. Never! I drink at 21h30. When I start to feel drowsy, I go to sleep, I have no stress" (14).

Putting her right hand on her chest, one participant emphasised her commitment to treatment adherence. She said:

"Hmmm…I love beer. I go out drinking with my friends but I never leave my pills. When it is time for my pills, they remind me to drink" (16).

"I learnt from the radio talk this week that ARV and Tuberculosis (TB) medicines have affects and can cause one to be irritable. Now when it happens I know. I go out for a while and come back later. My younger sister now understands that I just become irritable against her" (10).

"I started going out drinking and smoking to take out stress. But I realised that after drinking the problem comes back. I told myself I had to stop it now. I am destroying myself. I have to get someone to talk to" (15).

"Although I heard bad things they were saying about me i did not talk back to them. I pretended I didn't hear what they said. Anyway it was prophesied that two women would do this to me" (1).

"You must forget that you have HIV. Live like everyone else. When you wake up in the morning just greet them. We are all the same" (4).

A simple act of remembering to take medication on time is a problem-solving strategy which contributes to better health outcomes. Participants are aware that adherence to treatment is their lifeline, and thus orient themselves to maintaining high adherence levels. When they go on their drinking sprees, young people take their medication and even enjoy treatment support from friends. Friendship among PLWH was found to provide a strong and reliable support network. Furthermore, it was found that drinking sites are an important social space for young people as they frequent them. Consequently, HIV prevention and treatment adherence should target beer patrons as they may be in contact with customers who may be drinking to numb the pain of living with HIV and AIDS, or those who drink excessively and increase their vulnerability to HIV infection.

Another routine problem-solving strategy practised by participants was the avoidance approach to potential conflict. This is an indication of maturity with conflict management as the approach disables the conflict surrogate.

6.9.2.2 Non routine problem-solving strategies

Participants also developed strategies of coping with non-routine problems. Routine problem-solving requires more critical thinking, skills and strategy development. Participants' major non routine problems which they had to solve post-diagnosis was to decide who to tell and who not to tell. They planned, selected disclosure recipients and disclosure strategies. It was found that participants chose disclosure, selective or partial and non-disclosure strategies.

- Diagnosis disclosure strategy

The 70 year old woman is passionate about the benefits of diagnosis disclosure. As she talks about it, she pulled her chair next to the interviewer and spoke in a whispering voice and said:

> *"People must not hide themselves because hiding kills. What happens when one day you collapse and bleed? Another person may hold me not knowing. People must not be afraid to tell people that this disease kills but people must not hide themselves. They must tell others." (5).*

> *"On the first day that I learnt that I am positive I told my mother and father in law about it. A few days later I called my husband and told him that I am positive" (9).*

> *"I no longer had parents. There was no one I could tell. I was forced to tell my friend even when I knew she may tell other people. I am telling her so that I can free my heart" (12).*

> *"I told my friends that I am HIV positive but I warned them that as long as you are still sexually active, do not laugh at the others" (16).*

> *"I told my friend that I have HIV. I told her since she knows my situation. I pleaded with her not to tell anyone" (13).*

It was found that prior to diagnosis disclosure, participants thought deeply about who and how to tell. They ultimately disclosed their diagnosis to people close to them, namely parents, children, friends and siblings. It was found that after parents, friends came second as the preferred disclosure recipients. Good friendship extends families. Female participants in stable and supportive marriages found it easier to disclose their

diagnosis to their family and partners. It was found that reasons for disclosure by participants is to protect others from HIV infection, to access support, educate others and to release oneself from the secrecy of the diagnosis. Diagnosis disclosure is investment in family and friendship as it brings affirms trust and dependability.

- Selective disclosure strategy

People living with HIV have a right to choose who they want to share their diagnosis with. Some participants selected siblings, friends and pastors as recipients of their private information. Some shared their selective disclosure strategy.

> *"When I came back from the clinic I called my sister and told her that I am HIV positive but I did not tell my partner. I was advised from the hospital that he may blame or kill me" (16).*

> *"I told my friend that I have HIV. I told her since she knows my situation. I pleaded with her not to tell anyone" (13).*

Disclosure of private information is a non-refundable valuable. Hence, individuals select certain diagnosis recipients based on trust. Trust entails to leave one's heart into the hands of another person unconditionally. Many disclosure recipients met the criteria of trust. For these participants, it confirms a sense of emotional safety within their social environment which is a pillar of good mental health. In addition, Petronio (2004) asserted that trust is one significant rule within the Communication Privacy Management (CPM) theory which guides the interaction pattern between the owner of the private information and the recipient, and requires that the recipient abides by privacy rules drawn by the owner of the private information, namely that such information may not be divulged to the third person. Secondly, the owner of private information may choose to tell some recipients due to a sense of security than with

others. The cost benefit analysis of a relationship determines who would be told private information or not.

- Diagnosis nondisclosure strategy to certain individuals

Some participants believed that it is not in their best interest for certain people to know about their diagnosis. They cited the following reasons:

"There is no problem because even in church I will not tell them what kind of a person I am because if you tell them everyone will always say sham…sham…sham! Once you have a headache, they say, that's it! (Then she banged the table to emphasise the point). They always think of the disease which you have" (4).

"I did not have anyone to share issues with. I was thinking that if someone knows that I have HIV he or she will take me somehow" (11).

"He did not know until we separated. Even my new partner does not know that I have it. He is just another person as well. He goes out with many girlfriends. I always insist that we use a condom always" (16).

Fear of stigma and discrimination is one major reason many PLWH do not disclose the diagnosis. Female participants who did not disclose their diagnosis feared violence by partners. Upon anticipation of possible problems, they selected a solution which suited their needs.

The overall finding is that many participants command a higher level of problem-solving skills. During post-diagnosis, they were aware that non-disclosure of the diagnosis may hinder their coping capacity. They chose strategies which worked for them and avoided those which had a potential to create problems, and where necessary, they sought support. As discovered by Petronio (2004) and Rodkjaer, Sodemann, Ostergaard and

Lomborg (2011) all disclosure strategies have consequences because the first disclosure strategy frees individuals from the burden of secrecy and isolation. But individuals lose control over their private information regarding their status, the partial disclosure strategy individuals relatively still have control over their private information, while the non-disclosure strategy protects individuals from stigma and discrimination but it costs them to maintain the secrecy. PLWH need to be supported to achieve a balancing act which guides their decisions without compromising their well-being.

- Informal job activities

Out of four participants who identified unemployment as a challenge one participant carries out what is referred to as 'piece jobs' Unlike the others, her family support network is poor. Consequently, she has to regularly seek opportunities for piece jobs to augment the child support grant she receives.

> 'I do some piece jobs, do washing for people so that we do not run out of food. I want to make sure I do not miss to take my pills. A few days ago I was harvesting mealies for a certain primary school' (12).

It is a strong resolve to shed potential apathy and provide for the family's basic needs, namely food, accommodation and basic children's financial needs. Families of PLWH should be supported to preserve family functioning

6.10 PARTICIPANTS' FUTURE PLANS

Participants survived the trauma of the HIV diagnosis and started to lead a positive life. This is revealed in their future plans.

6.10.1 Positive Living

Participants' plans for the future confirmed that they bounced back from the post-traumatic experience of the diagnosis and started to project their lives into the future with enthusiasm. It was asserted by Diener and Chan (2011) that although a positive

154

attitude is not likely to help people overcome illness, it does help to improve the quality of life, boost their immune system and result in other desirable benefits. It was established that all participants have plans for one or more aspects of their lives, namely their health, studies, career, family and businesses.

6.10.1.1 Good health

Some participants showed that it is easier to plan for the future when one is healthy:

> *"My future looks good. I am going back to how I looked before. Even when I walk I do not doubt myself. When I walk I feel free. I do not feel lost"' (6)*

> *"My future is better. I will not die of HIV. I will die of other diseases other than HIV. Living with HIV does not mean that one will die soon. My plan is that while I am living I must keep on using my medicines" (8).*

> *"My future is fine. After starting to take medicine I am like any other person. If you stop taking medicines you will die" (17).*

Participants are comfortable about messages which their bodies communicate to others in their social spaces.   It is a sense of feeling desirable and being in control of their health. Such a level of predictability with their health is a consequence of medication which mitigated the debilitating effect of living with HIV and AIDS. Consequently, participants feel safe to share social spaces with others without looking over their shoulders. This is referred to as the phenomenological lifeworld existential of the 'lived body'. They are confident that their physical health conveys desirable messages to people they interact with. Consequently, they experience belongingness which Kaur92013) refers to as a social need level on the hierarchy of human needs.

6.10.1.2 Looking forward to a long life

A state of good health supports participants in their roles and nurtures a sense of pride. Some participants were proud that they have a chance to carry out parenting roles. One 38 year old participant pointed at a toddler who was sitting on her lap and confidently declared that:

"*I believe that this child, I will bring her up until she passes Std10 and even start working*" (9).

"*My future is better. I will not die of HIV. I will die of other diseases other than HIV. Living with HIV does not mean that one will die soon. My plan is that while I am living I must keep on using my meds*" (8).

"*I plan everything looking at my children. I had them before I had this. Everything I do should be for my children*" (10).

A 70 year old female participant takes pride in being a grandmother, and looks forward to this task. She is happy when her grandchildren give good feedback about food she cooks for them. She shared that:

"*My grandchildren regularly visit me. They enjoy what I cook for them*" (5).

Many middle aged participants define their future in terms of parenting roles. The experiences they lived since their diagnosis encourage them to appreciate the present and motivate them to plan into the future, in particular for their children. Hence, participants are very clear about their current and future roles for their children and grandchildren. The ability to parent, care and guide the next generation and to manage one's destiny is the greatest form of self-actualisation. It may contribute to a sense of purposefulness and contentment. According to Rich et al (2013) and Tembo (2016), this

experience is referred to as the phenomenological 'lived time' and human relations' existential.

6.10.1.3 Furthering studies and career development

It was found that young participants are in full time studies and have plans for their careers. Others found career paths in HIV care.

> *"Last year I was called by the clinic sister MML that I will be trained in counselling and home based care. It has not yet happened but she promised to make a follow up" (3)*

A 23 year old who had suicide ideation on the day of her diagnosis had plans for the future:

> *"I also have a plan in life. I told myself that I will achieve what I want to achieve. Last time I was writing driving license. I completed and passed. On April 16, I am going to NW school on fire fighting. I will attend for six hours for one day then I bring back the certificate" (11).*

> *"I accomplished from 2014. I could not believe it. I have a future. I am in third year at college. Next year I am doing practical. HIV does not determine what I want to be. I thank support by my parents. I also talk to nurses in the clinic" (15)*

> *"My future is sharp. I am not the only one with HIV. There may be 100% of people with HIV. I plan to either be a social worker or a lawyer. I plan to clean my life and my future like any other children. I will not fall pregnant" (13).*

> *"I plan to give other people ideas about an illness. I will advise them to go to hospital so that they get sharp. I plan to be a doctor" (14).*

According to the human development perspective by Merriam et al. (1997) and Remien and Rabkin (2001), these participants are emerging adults (19-40 years). It is a stage of development marked by plans for family and careers. Participants are optimistic about the future. Although they should have been at the tertiary level of education, the participants appear determined to catch up with their developmental tasks as they have specific plans about their careers. They have what Diener and Chan (2011) and Supriya (2013) referred to as a fighting spirit in that they believe they can get something positive out of their experiences. Young people should be managed as an investment as they are a source of future workforce and potential taxpayers. A comprehensive HIV care Agenda on youth living with HIV and AIDS is core to nurturing interest into the future.

6.10.1.4 Grow businesses and trades

Middle aged participants have established businesses which provide them with a stable source of income. They plan to grow them further as each of them articulated that:

"I am self-employed in building houses. Although I am old it is not yet time for me to stop working. I have power. I can still climb on the scaffolding" (8).

"I am living like any other person. I even go to Mozambique or Durban for four days to stock merchandise. My business is big. I sell in streets and at the South African Social Security Agency pay points" (7).

"I am selling food at the RR clinic entrance. I have expanded it as I even go to collect veld grown vegetables and sell them" (1).

"I have all the things that I need like food and other good food. I have a trade which I learnt from the urban areas. My partner works with me as she is my assistant" (2).

Self-sufficiency provides one with a sense of pride and self-respect. Some participants enjoy good physical and financial health. They also experience a sense of pride as they are able to provide for their basic needs. Economic empowerment of PLWH through accessible finance to support their businesses and entrepreneurship may be another source of better health outcomes.

6.11 THE MEANING OF BEING A PARTICIPANT IN THE STUDY

Participants shared with the researcher their lived experiences as PLWH. This question was asked in order to find out if they had benefits from participating in the interview. Secondly, it was for purposes of assessing if any of them experienced distress as a result of talking about their lives, so that if any, they could be referred for counselling, care and support. Thirdly, it was intended to assess their readiness for participation in the upcoming focus group discussion. It was discovered that participants experienced their participation in the study as honourable, memorable, cathartic and supportive.

6.11.1 An Honourable Experience

Participants are experts in lived experiences of living with HIV and AIDS. The researcher relied on them for data. They shared their experiences in a confidential environment to an interested listener. The participation in the study was reciprocal. This was a direct benefit for them.

> "I *am not afraid to talk about it. I have encouraged many people even my local traditional leader to come to the clinic for testing and drink pills" (1).*

> *"I am thankful. You honoured us by this interview" (5).*

"The interview did not give me any problems. I would not have come if I was not interested' (7).

"The interview was good. I had no problem with the interview" (12).

"I am not selfish. I am used to helping students in their studies. When you are done with your studies let me know if this interview helped you to pass. It will make me happy" (17).

Participants' experiences with the study confirmed that research ethics were adhered to. Participants confirmed their voluntary participation and the understanding that the interview was for study purposes. An indirect benefit is that the participants contributed into the system in which they live and generate solutions to help others. Kaur (2013) refers to this as the greatest form of self-actualisation.

6.11.2 A Down Memory Lane Experience

Participants acknowledged that the interview reminded them to appreciate their inner strengths and earlier coping strategies. This was well articulated by some participants:

"I loved the interview. It was unlike the first day when I was told that I am positive, it was difficult" (9).

"The interview served me well. It reminded me to understand how I accepted myself" (10).

"I felt the interview is good because it reminded me" (13).

"The interview served me well. When you are interviewed you remind yourself again. It reminded me about the past. Had I not done the test I would be no more. I would have died" (17).

"It reminded me of the support group we once had. It was disbanded. I once lodged that we need to have it running again" (3).

Participants were not afraid of visiting their past experiences and how they gained stability post-diagnosis. However, they still need individual and group support for further growth and coping. They appeared to be longing for more engagement with their experiences

6.11.3 A Cathartic Experience

Although it was not a counselling session, participants experienced sharing their lived experiences with the researcher as cathartic. They got the value of what they gave out, in that talking and telling about oneself promotes further healing, coping and growth.

"With this interview I am covered. We must talk more about this matters. I am ready to raise other issues in the upcoming group meeting" (2).

"The interview served me well. I enjoy sharing my issues with another person. When I looked at you I was happy to share my life with you, although I do not know you" (11).

"Ha…haha (a loud laughter)…the interview was good. I am ventilating. I am happy to share with another person what I went through" (15).

The study focused on what participants feel, see and think about their experiences. Many participants acknowledged that they had not shared their experiences of living with HIV and AIDS in the way they just did in the study ever since they were diagnosed. Although the interview was not a therapy session, it provided them with a platform to share their lived experiences in a manner that was beneficial to them. A trusting participant researcher relationship is vital for a phenomenological research.

6.11.4 A Supportive Experience

Some participants experienced the interview as supportive. This could suggest that answering questions as presented to them provided an opportunity to confirm some issues about living with HIV and AIDS.

"I am happy that sister MDL told me about his interview. I could have missed to talk about it. 'The interview means a lot. It encouraged me not to be afraid of myself". (6)

"The Interview served me well because it supported me in my thoughts" (14).

"The interview was fine for me. Young people should know and be helped to tell so that they must stay shrunk" (16).

"The interview is fine. Remember I do not want to hear the interview being broadcast in the radio" (8).

Articulation by participants confirmed that research ethics was adhered to as participants reaffirmed voluntary participation in the study, while others reminded the researcher of their privacy and confidentiality. It was discovered that young participants need more psycho - education on living with HIV and AIDS. Furthermore, it was discovered that the individual interviews with the seventeen participants captured their individual lived experiences while the focus group discussion session rekindled a sense of belonging and togetherness as PLWH. This was confirmed by their closing remarks at the end of the focus group discussion when they actually identified their relevance and resourcefulness for other PLWH. They benefited from being participants of the study

6.12 FOCUS GROUP DISCUSSION

The focus group discussion was selected as a third method of data collection of the study. Each participant was individually recruited at the end of the interviews. Again, the voluntary nature of participation was emphasised. Nine participants turned up for the FGD session. The FGD was facilitated by the researcher in the small boardroom of the healthcare centre. The brief of the session was that all ideas were of value and that participants should respect each other's points of view. The session lasted for one and a half hours. The content of the focus group discussion was informed by the findings of individual interviews with the seventeen participants. Profile of the focus group participants is presented in the table below

Table 8: Focus Group Discussion Participants Profile

Participant name	Gender	Age	Number of years of living with HIV	Highest standard passed	Occupation
P1	F	58	5	Grade 7	Vendor
P2	M	48	15	Grade 12 + N3 Electrical Engineering	Self-employed Electrician
P2	M	48	15	Grade 12 + N3 Electrical Engineering	Self-employed Electrician
P3	F	40	6	Grade 10	Handyman electrician
P5	F	70	12	Adult Basic Education level 3	Pensioner
P6	F	51	5	Grade 11	Shopkeeper
P9	F	38	10	Grade 11	Homemaker
P10	F	30	6	Grade 11	Homemaker

| P12 | F | 38 | 18 | Grade11 | Seasonal worker |
| P16 | F | 33 | 5 | Grade 10 | Non-governmental organisation volunteer |

Table 8: Focus Group Discussion participants profile

The above FGD participants participated in the individual interviews conducted earlier. They provided for triangulation on data collection because of the following reasons:

- They contributed information which could not be extracted from them on a one –to one interview. They designed the training content on HIV and AIDS for pastors, prophets, PLWH in care. Furthermore, they contributed a psychosocial approach to HIV testing care and support. These components are core to the seven step user – led intervention model presented in Chapter 8.

- The researcher established through the FGD with participants what accounts for their similarities and differences with ARV protocols. They were not reluctant to reveal their position on the like or dislike of the requirement of a treatment supporter for initiating on ARV. They may have been reluctant to the contradictions during the individual interview with the researcher.

- Focus group discussion provided a nonthreatening platform for quality interaction. As they exchange views, ideas and opinions, participants connected. This benefit could not be achieved through individual interviews

The FGD interview guide is attached as Appendix 3. A summary of the FGD is presented in three subthemes. Repetitive and overlapping response discarded from the report. The three subthemes on the FGD are the following:

- Community education on HIV and AIDS – stigma eradication
- HIV testing, care and support
- Focus group discussion experiences

A summary report in organised and reported under the three subthemes

6.12.1 Community Education on HIV and AIDS

Question 1 - If you were to teach your community about HIV and AIDS, what would you s*ay?*

Participants were from the onset sceptical about educating the larger communities or gatherings on HIV and AIDS. Such discussions revealed that communities generally no longer lead a communal care system. On the contrary, participants gave a picture that communities occupy the same residential areas but they have lost interest in the communal care system. It repeatedly came out very strongly in the discussion that generally, community members are not interested in health promotion conversations, including HIV and AIDS. Consequently, targeting to provide health promotion education to a larger community was ruled out. They showed that communities do not turn up for Headmen's meetings even when they are invited to listen to public servants such as police or nurses. Participants indicated that communities attend meetings only when they are discussing politics. Otherwise, they do not respond well to other invites. However, participants identified influential groups which should be targeted in the community to address HIV and AIDS education, in particular stigma and discrimination perpetuated in communities. The three target groups are pastors and prophets, traditional health practitioners and PLWH in care.

The researcher established that lack of social cohesion and diminishing traditional authority is a gap in fighting stigma and discrimination. The communal care system is a safety support network for those in distress, but it was found that this is diminishing in many communities. Those who need support such as PLWH are on their own within communities. This confirms that a gap exists between quality of community life and National Strategic Plans on HIV and AIDS as traditional leaders are identified as a significant stakeholder in the fight against HIV and AIDS, especially in many African countries. This was confirmed by Dlamini, Green and Naidoo (2009) in their four country

study when they found that South Africa, Lesotho and Swaziland recognise traditional leadership structures and religious groups as key implementing partners in the fight against HIV and AIDS. Traditional leaders are figures of authority and are closest to people. Based on the reports of diminishing traditional authority and poor social cohesion within communities, traditional leaders no longer command power and authority over their subjects. A situational analysis on communities' ability to mobilise for health promotion, especially HIV and AIDS should inform future planning. Otherwise, traditional leaders as partners in fighting HIV and AIDS is an operational missing link in HIV care.

6.12.1.1 Group one: HIV and AIDS education for Pastors and Prophets

Pastors and prophets have been identified by participants for HIV and AIDS education as they are either change agents or impediments to HIV care. Participants were worried that there are other PLWH whom they know who were taking treatment but stopped as they claimed that their pastors prayed for them and they are healed. Participants echoed that some have bangles on and think that they are indeed healed. Participants felt very strongly that pastors and prophets should be taught that the HI virus is in the blood. Against this background, they should be encouraged to give informed religious teachings. To emphasise the point on the convergence of spirituality and medical treatment when it relates to HIV and AIDS, one staunch member of African Independent Church stretched out her left hand. With her right hand pointing on her hand veins, she said, "Pastors and prophets must be taught that the HIV virus lives here, in the blood."

Participants concurred that after they shall have educated pastors and prophets on basic medical and religious facts about HIV, then participants could get into churches to teach congregants about HIV and AIDS, and to take testing kits with them so that those who are interested can outrightly test for HIV. The emphasis in this step is that congregants should be taught by their pastors that there is no cure for HIV infection. The FGD participants are worried that they have relatives who stopped medication who

had gone as far as Nigeria in search of HIV healing. Some of them had already passed on. They say that PLWH are desperate for a cure.

It was found that participants experience churches in their communities as helpful. This is also supported by Oluduro (2010) and Schoeman (2017) who established the impact of religion on people's daily lives. However, participants were concerned that the teaching by some pastors and prophets does not emphasise that the HIV virus lives in the blood. Consequently, such teaching sends unclear messages to communities which Coates, Ritcher and Carese (2008), Cairns (2008) as well as van Dyk (2010) cautioned that they are a major setback for HIV prevention. Furthermore, it was discovered that the church is experienced by participants as a source of faith, hope and love. Under these circumstances, it suggest that experiences of an illness may not be confined only within the four lifeworld existentials which are used to locate an experience. The thought system on spirituality and illness need to be incorporated into HIV care.

The gap that exists between HIV care and other partners, especially the church should be bridged by continuous joint training on health matters. Churches are possible vehicles of change as congregants listen to their leaders. This is attributed to the fact that religious leaders are custodians of good morals, provide guidance to congregants throughout the stages of their lives, and are held in high esteem within communities (Cairns, 2008; Oluduro, 2010; Dalmida, Koenig, Holstad & Wirani, 2013). Any partner who could provide for the needs of PLWH is a strategic partner in fighting stigma and discrimination. With better support, mentoring and coaching, working together between PLWH and the church, in particular to fight stigma and discrimination as well as mobilisation for HIV testing may be nurtured.

6.12.1.2 Group two: HIV Education for Traditional Health Practitioners

Participants expressed concern that common diagnosis for PLWH by Traditional health Practitioners THP) is that they have been bewitched with a disease referred to as 'Tshiliso', meaning to have been fed something deadly'. Participants showed that many

PLWH stopped treatment and began to take traditional medicines which, in many instances, caused them to experience poor health outcomes. One participant shared with the group about his personal experience with traditional health treatment when he indicated that before he got into HIV care, he went as far as Zimbabwe looking for a traditional cure because he believed that he was bewitched. He ultimately ended in HIV care with a severely compromised health. Now he teaches his friends, recruits and supports others to stay in HIV care. The participants felt that the THP needs to be made aware of the impact of diagnosis. It strongly emerged that THP should be continuously taught that there is no cure for HIV and AIDS and they should be encouraged to desist from making false claims, diagnoses and treatments. A strong assertion was made by participants1, 2, 3, 5 and 6 that many people in their close social circles relapsed due to such THP diagnoses.

A strong belief in traditional medicine for those living with HIV and AIDS is prevalent. It is their truth which should neither be trivialised nor wished away. It is possible many PLWH use both healthcare professionals' services and THP. Therefore, HIV care practitioners should be empowered with skills to help PLWH mediate the different thought systems about living with HIV and AIDS.

6.12.1.3 Group three: HIV and AIDS Education for PLWH in care

The participants expressed sadness about many PLWH who are in HIV care who know about HIV and AIDS but do not believe it in their hearts. The participants observed and heard worrying conversations in the waiting areas on the days that PLWH come for monitoring or to collect their medicines. They showed that PLWH in care engage in self-defeating conversations. Although they are on treatment, their hearts do not believe Participants were also worried about stigma and discrimination to PLWH by other PLWH in care. There are PLWH who do not want to be associated with fellow PLWH who are in care. Due to this, they even sneak to clinics for their monthly medication while some PLWH go to an extent of changing clinic visits from midweek days to Sundays so that they avoid being seen by other PLWH.

The second group of PLWH which participants identified as a target of HIV and AIDS education are the recently diagnosed. They need to be supported by other PLWH who were living with HIV for some time. Otherwise, when they are left to go back into the community without support, they are likely to experience delayed or poor adjustment of living with HIV.

Stigma and discrimination meted out by PLWH other PLWH is a hidden dimension of HIV and AIDS. Relating in this manner may arise from the 'us' and 'them' attitude among PLWH. Many stigma eradication programs may miss this dimension which weakens coexistence among PLWH.

It was found that Witches are experienced as powerful people by those who believe they have been afflicted with an incurable disease such as HIV and AIDS. This causes some PLWH to feel powerless in the face of sorcerers. To regain their power, they can only do so through traditional interventions. When PLWH blame sorcerers for HIV infection, it should not be casualised, ignored or wished away because this is the meaning of an illness which shall direct them to treatment options. It was discovered by Chen, Huang and Yeh (2017) as well as PRIMASYS (2017) that training of healthcare workers is mainly hospi-centred and curative. Consequently, the sociocultural needs of PLWH and the skills of healthcare workers are not complementary. Based on the findings, HIV care is complacent as they appear to hold onto the notion that treatment adherence is equivalent to sociocultural coping among PLWH. Consequently, some PLWH fall within the system.

6.12.2 HIV Testing, Care and Support

6.12.2.1 Pre HIV Testing, care and support

Question 2. *If someone in your community tells you that he/she had decided to do an HIV test, what would you say to that person?*

Participants are happy for those who decide to test because a decision to test and actually test is difficult one. They shared that there are many people who are in their close social circles who live between the thought of HIV testing and actual HIV testing. Some of them have children who appear to have perinatally acquired HIV but are not on treatment because their mothers are afraid of HIV testing. Participants 3, 6, 9, 12, 16 were very specific about care and support for HIV testing In order to provide support to the one who had decided to test, participants shared that they would:

- Reassure such a person that HIV testing is good for you and the community;
- Disclose their HIV status (as chosen by some participants) to the person for encouragement;
- Accompany the person to the clinic to reduce fear of testing and diagnosis;
- Tell them not to devalue oneself;
- Tell them not look at another person;
- Tell them that they are not lost;
- Tell them not to doubt oneself; and
- Give them post-HIV testing support.

In their pre-testing, it is likely that participants experienced mainly medically based counselling. Hence, their emphasis on the psychosocial elements of pretesting care and support. This approach is client-centred and signifies that better coping starts with the individual's thoughts and the impact of others thoughts about them, especially when they get diagnosed.

6.12.2.2 Post-HIV testing care and support

Question 3. When that person ultimately tests and is told that he/ she is HIV positive, what would you say before he/ she leaves the clinic?

Participants identified two groups of the recently diagnosed. The first group discloses the diagnosis while the second one masks the diagnosis. The second group, rather than

disclosing the HIV diagnosis, choose to say their diagnosis is TB or diabetes. The participants identified the type of support which both groups need.

They flagged out that they would want to know if the recently diagnosed actually understood the meaning of the HIV test result in that by testing positive, PLWH must understand that the whole body has changed. They are worried that many problems for the recently diagnosed are in the lack of understanding of how their bodies work. They showed that If they do not understand the meaning of the test results, participants strongly agreed that they would encourage the recently diagnosed to go back for follow up for post-test counselling until they understood the medical facts about an HIV diagnosis. They said this is then followed by working on the mind as acceptance of the diagnosis is the weapon for moving on.

They showed that those who mask the diagnosis usually say they were diagnosed with TB or diabetes. Some participants advised that when the diagnosis is masked, it is important to check the treatment which the recently diagnosed brought from the clinic. Usually they are ARV but those who are recently diagnosed may not be aware that participants know the regimens. The participants emphasised that in such circumstances, it is important to support that person to maintain adherence to treatment without necessarily confronting them about the reports of a mismatch between the masked diagnosis and the dispensed medication. They indicated that such a recently diagnosed person should be supported until one is ready to unmask the diagnosis. The participants strongly cautioned that rather than confronting about diagnosis masking, it is better to keep close to the person and provide support so that one is not lured into other treatment options.

Some participants who do not mask the diagnosis should be advised with diagnosis disclosure decision. Others felt that the recently diagnosed should keep it with themselves while others felt that they should spend a few days to calm down before diagnosis disclosure. Later, one participant advocated that they should select two

people in the family to tell about the diagnosis. She justified that anyway this is the standard protocol used in HIV care to bring one support for counselling.

This opened a fierce debate by some participants who dislike the treatment supporter protocol as they said it forces PLWH to bring a person who listens to one's private matters. They said the protocol was not right from the beginning. They said it violates one's human rights while others felt it was meant to encourage disclosure and support, especially among partners. The FGD provided them with an interaction platform where interactions was mainly among themselves than with the researcher. They were not reluctant to identify what they do not like about some treatment protocols.

Those participants who argued against violation of human rights of PLWH further argued that a person may bring a supporter to counselling but that a supporter may not be always around when one takes medication. They further showed that Anyway, there are PLWH who are in care who brought a supporter as required by the HIV care protocol just for compliance. They brought a supporter not even related to them or a distant relative who stayed far away from them. They just satisfied the requirement of HIV care standards but it did not benefit them as they went back to their immediate family members and did not disclose their diagnosis. They stuck with the argument that a person needs to have one's mind right about the diagnosis as the guard may not always be present to see them take the pills. They upheld that acceptance of the diagnosis is key. The discussion closed with the two streams of disclosure strategies, namely nondisclosure and disclosure.

In their articulation of pre- and post-care and support for PLWH, they displayed social care service values which are required for social care and support. Many of such values are provided for in the South African Council for Social Service Professions: Policy Guidelines for Course of conduct, Code of Ethics and Rules for Social Workers. They are
- Respect the individual
- Begin where the client is

172

- Work at the service user's pace

- Client self-determination

- Non-judgmental attitude

- Client-centred social care

- Awareness of the areas of collaboration for service user-interventions

The FGD brought out conceptualisation of violation of human rights of PLWH. This never surfaced during individual interviews. Some participants, especially male ones strongly felt that the HIV care requirement to bring a supporter violates confidentiality and their privacy.

6.12.3 The Experience of Participating in the Focus Group Discussion

Question 4: What is your experience of participating in the focus group discussion?

The participants experienced deliberations in the focus group discussion as encouraging, interesting and thought-provoking. Actually, they felt it is possible even without the researcher to take the discussion to the next level. Firstly, they discussed that each participant could recruit other PLWH who are in care in the health centre who are interested in attending monthly meetings. Secondly, they alerted one another that there are people who are diagnosed in the health centre who need support daily. They (participants) actually thought that they could stand in as volunteers in clinics and help the recently diagnosed with their concerns or needs. However, they acknowledged that they also need to be strengthened before they can support other PLWH. At the end of the FGD session, participants nominated three participants to approach the clinic sister who recruited them into the study for the provision of support to other PLWH, especially the recently diagnosed.

Participation in FGD rekindled belongingness and feelings of usefulness, possibly in the healthcare centre. In closing the session, the researcher thanked them for their participation and contribution to the study. They were encouraged to engage the health

centre clinic sister with their intended meetings of PLWH. As a token of appreciation, each participant was given a pill box, I kg scented candle and a clinic visits record book to encourage self-care for better health outcomes.

6.12 CONCLUSION

The data presented in this chapter are findings from the individual, field notes and focus group discussion with PLWH in Vhembe District. The problems, needs and challenges experienced by PLWH in different settings shall be addressed by the psychosocial user-led intervention developed and presented in the next chapter.

CHAPTER SEVEN

SUMMARY OF THE MAIN FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

This chapter presented summary of findings collected from in-depth interviews with seventeen participants on their experiences of living with HIV and AIDS, field notes gathered from each interview as well as focus group discussions conducted with nine participants. The summary of findings is presented per theme. Prior to the discussion of summary of findings, a restatement of the problem and objectives are presented so as to confirm the achievement of the study objectives. Based on the findings presented in chapter six, conclusions and recommendations were presented to provide a blueprint of what needs to be done in HIV care to ensure better health outcomes among PLWH and their social systems.

7.2 RESTATEMENT OF THE PROBLEM

Ever since HIV and AIDS was discovered three decades ago, it has been a highly stigmatised health condition as it was discovered from a marginalised subpopulation. Although the epidemic transformed from a concentrated to a generalised epidemic, the stigma and discrimination did not change to date, and it undermined many efforts to fight HIV and AIDS. Consequently, many PLWH still experience poor health outcomes to date. Despite the anti-stigma legislations to protect PLWH, disclosure by well-known figures that they are living with HIV, widespread availability of antiretroviral treatment (ART), information dissemination on how HIV is and is not transmitted, many PLWH still encounter a variety of stressors from within themselves and their social environment. Due to this discrepancy between the continuous poor health outcomes among many PLWH and what should have been, a qualitative phenomenological study was proposed

to find solutions from the 'lived' experiences of PLWH in communities. Such data shall provide a blueprint upon which an evidence informed user-led intervention model for HIV care shall be developed.

7.3 RESTATEMENT OF OBJECTIVES

As presented below, the study confirmed that study objectives were achieved. These objectives were:

- To establish factors which compound poor health outcomes of PLWH.

In this study, it was found that communities' outdated understanding of HIV and AIDS is accompanied by stigma and discrimination which in turn alienates PLWH in communities. Communities isolate, reject, ostracise, gossip and spread rumours about PLWH. This treatment socially and psychologically disables them. Lack of safe and supportive communities compounds poor health outcomes among PLWH.

- To assess a variety of stressors (intra-personal) from within PLWH

The study established that many PLWH are not kind to themselves post-diagnosis as they worry about what others will think of them. To manage the anxiety, many resort to self-isolation or self-exclusion, self-devaluation and self-ill-treatment. These are some forms of self-stigma which limit PLWH to live a fuller life. Furthermore, some PLWH lead their lives based on negative predictions. Hence, the anticipated stigma phenomenon discovered among them. Some experience unresolved HIV related grief, guilt and despair. These are internal unresolved issues which revolve within them.

- To appraise various stressors from their social environments

It was found that a major stressor from their social environments is stigma and discrimination generated from outdated, incorrect knowledge, attitudes and wrong perceptions about the meaning of HIV and AIDS held by those that they interact with in their daily lives. Stigma and discrimination from social spaces, namely family, community, workplaces and the health settings undermines HIV care.

- To establish coping challenges experienced by PLWH

This study found that despite the support system and medical breakthroughs in the treatment of HIV, many PLWH still experience coping challenges arising from living with HIV and AIDS. In particular, females experience abandonment, rejection, isolation, ostracism from family, school and community. In addition, it was found that some were denied job opportunities. A finding related to the health setting is that some PLWH experienced disadvantaged treatment due to inconsistent implementation of ARV dispensing protocols in certain PHC centres in some provinces. A few experienced a significant discomfort by being served in identifiable ARV clinics as they felt that entrance into the clinic automatically discloses their diagnosis.

- To determine the type of support system that they have

Although many communities alienate PLWH, it was found that post-diagnosis, many PLWH lived within a reasonable support system. From their system, they were able to receive different types of social support, namely emotional, treatment, religious and support by other PLWH. This study found that the support system network created by family and nonfamily sources created a safe social space to absorb the impact of living with HIV and AIDS.

- To establish PLWH coping strategies

The HIV diagnosis generates new needs, concerns, problems and challenges. Consequently, PLWH had to learn new coping strategies. The study found that common coping strategies are emotion and problem-solving focused. It was found that many command a high level of emotional intelligence as they are able to appreciate their emotions, its effects on other people and to manage negative feelings which emanate from them. They also have problem-solving skills as they are able to identify the problem, assess different and appropriate solutions, and plan and implement solutions, verbally and behaviourally.

▪ To develop a user-led intervention model with and for PLWH

Many PLWH respond better to psychosocial, information, care and support provided by other PLWH. However, in this study, it was found that many PLWH receive fragmented, poorly coordinated and collaborated psychosocial care and support in HIV care, and consequently, fall through the gaps. To respond to this finding, a user-led service which is available at the point of entry into HIV care was developed. A psychosocial user-led seven-step intervention model was designed to address intrapersonal, interpersonal, social support gaps and coping challenges experienced by PLWH and their system. As presented in Chapter eight, specific intervention activities were outlined for each level of intervention.

7.4 SUMMARY OF FINDINGS

The findings of the study arise from data collected through individual interviews, field notes and focus group discussions with PLWH living in Vhembe District communities. A summary of findings per theme in the study is presented below.

7.4.1 Profile of Participants

In this study it was found that out of school youths, married or people in cohabiting relationships are more vulnerable to HIV infection. It was also found that heterosexual transmission was a major mode of transmission, followed by mother to child transmission and home-based care activities. The latter mode of transmission is a hidden dimension of acquiring HIV as many HIV prevention programmes focus on other age groups than the aged. The profile of participants included major aspects of their experiences of living with HIV and AIDS. Therefore, it is justifiable to use the data as a blueprint in the development of a psychosocial user-led intervention model.

7.4.2 Communities' Understanding of HIV and AIDS

Although HIV was discovered three decades ago, the study found that many communities still hold outdated understanding of HIV and AIDS. Some have incorrect information while a few do lack basic facts about HIV and AIDS. These meanings carry a lot of stigma and discrimination which alienates many PLWH living in communities. Consequently, many PLWH feel unwelcomed, rejected and ostracised. The study established that it causes them a lot of grief. All such circumstances compound poor health outcomes among PLWH.

7.4.3 The Meaning of Living with HIV and AIDS by Participants before Diagnosis

This study discovered that many people were complacent about HIV infection before HIV diagnosis. This is a shared understanding learnt from their community. Hence, their knowledge, attitudes and perceptions were not different from the understanding of living with HIV by the general community. Consequently, when they got diagnosed they viewed themselves through the eyes of their communities, and consequently, negated themselves. This has caused many PLWH to experience stigma and discrimination. The most common problematic form of stigma is self and anticipated stigma, followed by external stigma. It was found that many participants experienced self-stigma and were rarely able to reconcile the community's outdated understanding of HIV and AIDS and correct facts about HIV transmission. Consequently, it becomes a source of poor health outcomes.

7.4.4 Participants' Understanding of Living with and AIDS Post-Diagnosis

Personal experience with HIV transmission changed many PLWH prior to understanding of HIV and AIDS, because once diagnosed, many PLWH changed their

incorrect facts about HIV infection through logical reasoning, information, care and support from other PLWH.

7.4.5 Drivers which Changed the Understanding of HIV and AIDS

In this study, it was found that post-diagnosis, PLWH discovered a new understanding of living with HIV. The drivers of change into the 'new' meaning include mental, medical and social factors. They changed their thinking patterns as they disputed facts that they previously held, and change their wrong perceptions about HIV and AIDS. In addition, the availability of antiretroviral treatment gave them control over their health, while social factors such as support by other PLWH gave them faith and hope which helped them to think positively.

7.4.6 Social Support

It was established that the HIV diagnosis is a life-changing experience which is accompanied by complex needs. Many needs were met through different types of social support, namely emotional, treatment, religious and material support. Social support created a safe space to absorb the impact of living with HIV and AIDS. It was found in this study that female family members and elders were a source of emotional support while parents, children and friends are the greatest treatment supporters. Non-family support for participants which came from nurses, pastors, friends cum neighbours and other PLWH was mainly information on better coping strategies when living with HIV and AIDS.

7.4.7 Coping Challenges

The study established that despite the medical breakthroughs, many social developments and People living with HIV and AIDS still experience intrapersonal and interpersonal challenges. The most common form of intrapersonal challenge is the self-stigma which arises from feelings of guilt, shame, hopelessness and worthlessness.

Almost every participant was found to have experiences of self-stigma. Furthermore, it was found that gender, age and duration of living with HIV and AIDS could not spare participants from experiences of self-stigma.

Interpersonal challenges emanate from external interactions with others in different social environments, namely family, community, workplaces and the health settings. Common interpersonal challenges experienced by participants from families were found to be rejection, blame and abandonment while many communities outrightly alienate PLWH. Workplace HIV related stigma is meted out in different forms such as denied work opportunity, reallocation of tasks to other workers and subtle gestures of not welcoming PLWH in the work environment. All treatment undermines health outcomes for PLWH.

7.4.8 Coping Strategies

Many PLWH are survivors of the experience of living with HIV and AIDS. It was found that they bounced back after the diagnosis. The evidence of their resilience is indicated by coping strategies, namely emotion and problem-solving focused coping strategies. They taught themselves and learnt from others to cope with living with HIV and AIDS. The study found that with regards to emotion focused coping strategies, participants engaged in cognitive restructuring exercises, looked for correct facts which assisted them to accept their situations, and integrated the diagnosis into their identity. Furthermore, they learnt to engage in actual problem-solving activities, namely treatment adherence, treatment literacy, choice of diagnosis disclosure, sharing, seeking support from other PLWH, and seeking employment and opportunities, among others.

7.4.9 User-led Intervention Model

The study found that while the biomedical component of HIV care is adequately provided in HIV care, many PLWH experience significant psychosocial challenges,

namely intrapersonal and interpersonal challenges. To respond to this finding, the seven-step psychosocial user-led intervention model, which is a locally based solution to needs, problems, concerns and challenges experienced by PLWH, was developed. The model shall be implemented in collaboration with other Primary Health Care Infrastructures. Its intervention starts with the individual level whose aim is to provide pre- and post-support for PLWH. The second level caters for families of PLWH by providing psycho - educational support on HIV and AIDS to family members. The next level creates different support groups for PLWH and their family members. Its aim is to nurture social networks, reduce isolation and improve self-efficacy for PLWH and their families. The next level is outreach to work in churches whose aim is to empower these churches on HIV and AIDS so that they can be change agents on HIV and AIDS narratives. When the four levels have been completed, then the fifth level is community mobilisation on HIV and AIDS education, with special emphasis on working with structures of authority such as civic organisations and traditional leaders. The next two levels are the administrative part of the model, which seeks to monitor, evaluate and report on the efficacy of activities which were implemented in the first five model levels.

7.5 CONCLUSIONS

Conclusions of the study are drawn from the findings presented above:

- From this study, the profile of participants revealed that HIV infection affects all age groups, and that certain conditions increase vulnerabilities to HIV infection. It was found that participants were living with HIV for a longer period, and appeared to enjoy good physical and mental health. Timeous access to HIV treatment was an opportunity to take care of themselves. It is concluded that further personal, social, economic, educational and legal empowerment may improve the quality of their lives.
- Based on the findings of the study, it is concluded that communities created the problem of stigma and discrimination. Consequently, HIV prevention strategies should be designed to change the narrative which undermines PLWH. It cannot

be left to PLWH to fight stigma and discrimination because this is deep-seated in communities' languages and gestures, which must be accessed through constructive engagements, especially through joint multidisciplinary dialogues facilitated by local authority figures, religious leaders, healthcare professionals, pastors and other PLWH. It is concluded that joint convergences of different perspectives on the meaning of HIV and AIDS can engulf communities and compel them to assess if they have stigma and discrimination, and be motivated to change.

▪ Many people were found in this study to be complacent about HIV infection prior to diagnosis. It is possible that this attitude increased their vulnerability to HIV, and unknowingly infected others. It was also found that intrapersonal and interpersonal challenges experienced by PLWH are primarily a consequence of unhealthy narratives from their communities. The better the community narrative, the better health outcomes among PLWH.

▪ In this study, it was found that many people experienced post-diagnosis challenges long after diagnosis, but immediately coped better after they got information and support by other PLWH. It is concluded that PLWH live better when they are supported by those who lived the experience.

▪ The HIV diagnosis is still a crisis. The study discovered that the available behavioural, medical and structural interventions averted the crisis before it deteriorated into possible psychosocial catastrophe. People thrive better when their basic needs such as accommodation, food and medical treatment are adequately provided.

▪ The study established that although some PLWH experienced challenges within families, many PLWH are supported within families. It is concluded that PLWH need their families for stability. On this basis, there is a need for a family-centred approach in HIV care services to reinforce their capacity to be available for family members in distress.

▪ In this study, many PLWH felt that communities interact with PLWH like outcasts and are lonely within communities. Conclusively, many communities can make or break PLWH in their communities, hence PLWH experience so much coping

challenges. Despite the status quo of living in alienation, many PLWH learnt to cope in abrasive and vicious social interactions within social environments. It is concluded that despite the magnitude of the problems, with a conducive environment and support, individuals have the capacity to activate their spirituality and inner strengths, and to participate in finding solutions for their problems.

▪ Many PLWH made better choices and decisions about HCT, status disclosure, ARV initiation, and treatment adherence after they received information and support from other PLWH. However, the service was not outrightly available as the study discovered that post-diagnosis, many PLWH stumbled into bits and pieces of such a vital service by chance. It is therefore concluded that a user-led service which is located at a local healthcare facility is a requisite for better health outcomes. Hence, a psychosocial user-led intervention model is recommended.

7.6 RECOMMENDATIONS

The study found that individuals' families and communities are complacent about HIV infection. PLWH are alienated in their communities due to outdated understanding of HIV and AIDS, which fuels stigma and discrimination. Post-diagnosis, many PLWH experience intrapersonal and interpersonal challenges; they receive different types of support from different sources but still experience some coping challenges. Due to these findings, the following study generated the following recommendations.

7.6.1 Recommendations for HIV prevention

Many people are complacent about HIV transmission. Even those who are sexually active do not get tested as they do not believe that they are vulnerable to HIV infection. Many undiagnosed people unknowingly transmit HIV to others. People are afraid to be tested for many health conditions. Systematic desensitisation through the provision of regular medical screening at an individual, family, church and community levels may

help to eradicate the fear of testing, eradicate stigma and discrimination, and normalise testing for HIV and living with HIV and AIDS.

7.6.2 Recommendations for Individuals living with HIV and AIDS

HIV is a generalised epidemic in South Africa. All age groups are either living with HIV, or their loved ones are living with HIV. Many female participants acquired HIV in steady heterosexual relationships. There is a need for specialist services for different age groups and categories, namely couples living with HIV, discordant couples, young people living with HIV and AIDS and growing old with HIV, and HIV grief related counselling, among others.

Out of school youths who are in their twenties are vulnerable to HIV infection. Improving the living conditions of communities and households to ensure that youths are kept in school may decrease HIV infection among young people.

Personal empowerment programmes by linking them with other PLWH. It is easier to learn by observing others who have been living with HIV. This could teach them to rediscover their self-respect, self-confidence, self-reliance and self-sufficiency, which they may have been depleted post-diagnosis.

7.6.3 Family Focused HIV Care Recommendations

Living with HIV and AIDS is not an individual matter. However, the dominant HIV interventions emphasise an individualistic approach. Families should be part of interventions from the onset in that they do experience emotional turmoil when one of them is diagnosed. It is recommended that HIV care healthcare workers should conduct a broad family assessment which establishes the general functioning of the family, family members' interpretation of an illness, health, coping capacities and strengths, which help them to cope with crises and external family support, among others.

It was found that participants who are in functional families cope better with the HIV diagnosis than others. Consequently, families should be provided with family support and preservation services so that it may in turn support its members in distress. Tangible, social, medical services packages and informational support is recommended.

7.6.4 Community Education on HIV and AIDS

Many communities are the seat of stigma and discrimination. Any change about the meaning of HIV and AIDS in individuals should start with community narratives. Then, it may reduce alienation of PLWH, which is a significant condition which PLWH need to enhance their social functioning.

In order to create an acceptable environment for PLWH, community narratives should be changed. HIV and AIDS education should go beyond awareness and information but should be mainstreamed through outreach activities which are aligned to community life. Alignment of HIV and AIDS education should be done by influencing entertainment activities, namely composition of storytelling, games, traditional dance songs, local radio drama and soapies, which fight stigma and discrimination.

On a community governance level, it is recommended that HIV work with civic organisation committees and link HIV and AIDS with their political activities as they can mobilise their followers. Like religious people, political followers listen to their leaders. This was also confirmed by the HSRC (2015), which found that educators know their HIV and AIDS policies more than their workplace HIV and AIDS policies. HIV care should work with politicians as effective and strategic partners.

7.6.5 Recommendations for the Implementation of the User-led Intervention Model

PLWH in care are falling through the gaps and fragmentation of HIV care services, in particular lack of access to adequate psychosocial care and support. The PHC provides

access to HCT and treatment accompanied by minimal psychosocial support, and relies on collaborative services from NGOs. Some NGOs have HIV care as one of their core mandate, while others coordinate support groups for PLWH. They are not at the centre where PLWH receive healthcare services. Of the seventeen participants, only a few attend sporadic support group meetings coordinated by NGOs. The geographic location and frequency of service of NGOs do not adequately meet the intentions of the access model into care. The user-led unit must be implemented at the point of entry into care so that the recently diagnosed as well as those in care may timeously access adequate, effective, relevant and continuous psychosocial care and support by other PLWH.

7.6.6 Continuous Professional Development of Healthcare Professionals

It is possible that caring for PLWH may be draining healthcare workers emotionally. HIV care should invest in healthcare workers through continuous professional development to raise awareness about their unconscious reactions towards PLWH, and to keep them abreast of the needs, problems and challenges of HIV care service users.

7.6.7 Recommendations for Further Research

This study could not answer all the questions relating to experiences of living with HIV and AIDS. There is a need for further research in the following areas:

- There are four national Strategic Plans (NSP) on HIV and AIDS in South Africa which were spearheaded by political leadership. The relationship between politics and health was not actively cascaded down to local political structures. Hence politics and health matters, especially HIV and AIDS run parallel in local communities. Consequently, governance community structures are likely to be part of the problem, namely stigma and discrimination. There is a need for research into politics and HIV and AIDS as continued lack of integration between politics and AIDS response programmes may threaten the National Development Goals.

- Experiences of PLWH who are congregants of the African independent Churches shared better health outcomes. There should be research on how congregants in the main line churches are coping with living with HIV and AIDS.

- Congregants confide in their pastors about their crises, including living with HIV and AIDS. There are also pastors living with HIV. There is a need for research to learn more about experiences of pastors living with HIV and AIDS.

- The growth of the spirituality in Africa is phenomenal. It is the source of faith and hope. Consequently, when providing a service to an African service user, there is a need to go a step further to understand the meaning of an illness within the context of spirituality. It is vital to decolonise philosophy with a view to Africanising the phenomenological approach.

- The study focused on PLWH living in communities. There is a need for more research on how family members cope with stigma and discrimination when one of them is diagnosed, especially children who are active treatment supporters for their family members.

- Stigma and discrimination defeats the aim of identifiable ARV clinics in healthcare facilities. Different stakeholders should be consulted on their experiences about service models of identifiable ARV clinic.

- There were worrying reports of employer practices which expose employees or prospective employees to stigma and discrimination. Knowledge and attitude gap on HIV and AIDS in workplaces should be investigated.

CHAPTER EIGHT
A USER-LED INTERVENTION MODEL

8.1 INTRODUCTION

As established by Ostrow and Leaf (2014) and Grey and O'Hagan (2015), the concept of user-led or consumer-operated services was first conceptualised in 1970 for other healthcare fields such as mental health. This was an acknowledgement that people with lived experiences may serve others who are living with the same health conditions better than traditional services. In addition Cornu and Attawell (2003) Morolake et al. (2009), Paterson, Ross and Gaudet (2014) as well as Berg et al. (2015) concurred that consumer-operated services are effective as they are based on principles of respect, shared responsibility, empowerment and mutual agreement of what is helpful.

The WHO (2010) found that user-involvement for HIV and AIDS was declared in 1994 during the Paris AIDS Summit. Forty-two countries, including South Africa, signed the Paris Declaration, referred to as the Greater Involvement of People living with HIV and AIDS (GIPA) Principle. The aim of GIPA was to realise the rights of PLWH, create a space for them within HIV service to make decisions that affect their lives, and that such involvement must be meaningful and not tokenistic (UNAIDS, 1999, 2004; Patersona, Rossa & Gaudet, 2014). For purposes of this chapter, user-led and meaningful user-involvement shall be used interchangeably. Hickey (1998), Greenhalgh, Humphrey and Woodard (2011) as well as Paterson, Ross and Gaudet (2014) asserted that the core of the user-involvement concept is involving people who receive health services in their own care. Hence, user-led and user-involvement mean that services are driven by service users who create, design and implement a service or project in collaboration with others.

8.2 BENEFITS OF GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV AND AIDS

It was established by Cornu and Attawell (2003), Paterson, Ross and Gaudet (2014) and Berg et al. (2015) that the Implementation of GIPA benefits individuals, families, organisations and communities. On an individual level, GIPA improves psychological health, self-esteem and social interaction, and provides access to information from other PLWH.

Families of PLWH benefit from GIPA because involvement improves both the psychological and physical health and reduces families' worry about their loved ones. Secondly, families benefit when they learn more from PLWH who bring more knowledge from other PLWH into the family. Thirdly, families are reassured when they realise that one of them who is living with HIV can be active and productive.

Organisations benefit from GIPA as it improves services, add credibility, and contributes to team development as it provides a critical support role which is also provided by designated personnel such as public health educators, psychologists and social workers, among others. Community mobilisation driven by PLWH helps to fight stigma and discrimination. It teaches communities that despite living with HIV, PLWH are valuable members of society.

8.3 IMPLEMENTATION OF GIPA IN DIFFERENT COUNTRIES

As a follow up study on the implementation of GIPA, Cornu and Attawell (2003) found that countries implemented the principle differently based on their interpretation, understanding, funding and the type of the epidemic. It was found by Berg et al. (2015) that since the inception of the GIPA principle, that there has been a handful of true user-led involvement in HIV care, especially in low income countries. Cornu and Attawell (2003) established that organisations mainly involve PLWH either optionally for short

periods or voluntarily in periodic campaigns. However, Doughty and Tse (2011) and Berg et al. (2015) established that there is growing political and research interest in user-involvement in care.

High income countries such as Norway, UK, Canada and US implemented true user involvement in their HIV service clinics. In particular, the Southern Norway HIV clinic invited PLWH to provide inputs on the design and implementation of a user-involvement service, and included them to serve in the Clinic Board of Directors. The London, UK HIV service sought inputs of service users to develop a user-led HIV service, while the Canadian rural clinic involved service users as volunteers and later elevated them into true user-involvement services.

Middle income countries implement user-involvement through non-governmental organisations (NGOs) and community based organisations (CBO). This was a finding by Cornu and Attawell (2003), who examined HIV infected people's involvement in four countries, namely Burkina Faso, Ecuador, India and Zambia. The diagnostic study found that service users typically only accessed services as beneficiaries, or occasionally volunteered within these organisations. The findings revealed four types of models and their main features. These models are access, inclusion, participation and greater involvement models. The same models are practised in South Africa through the PHC in partnership with NGOs and CBO. It was confirmed by PRIMASYS (2017) that the nongovernmental organisation-based community care sector emerged in response to HIV and TB epidemics and is being reorganised into a system of ward-based outreach teams as part of PHC.

8.4 TYPES OF USER-INVOLVEMENT MODELS

As shown by Hickey (1998) and Braye (2000), user-involvement may take many forms from simple methods to the advanced, namely from receiving information, HIV care service, consultation, partnership and control between users and professionals. These forms of interactions are located within the four user-involvement models, namely

access, inclusion, participation and greater involvement. The four models are presented against the study findings to introduce the place of the recommended psychosocial user-led intervention model within the PHC framework. The four models are discussed below against the study findings.

8.4.1 Access

The standard feature of this model is that PWLH are involved as service users. They receive preventive, counselling and medical treatment care support. They are assisted to accept the diagnosis and learn to cope living with HIV so that they can even help others. Similarly, in the study site, it was found that PLWH are involved through accessing services. The service is provided by healthcare professionals. All study participants received HCT, medical treatment care and support from health facilities. It was found that the weakness in this model is that in the post-HIV diagnosis, many participants received minimal post-traumatic interventions as PLWH relied mainly on nurses for almost all their needs. Participants had no access to allied healthcare professionals. Consequently, many experienced posttraumatic reactions deteriorated into poor health outcomes. Many participants experienced better health outcomes after they got information, care and support by other PLWH. It was found that some PLWH who assisted the study participants are pastors, spouses and neighbours cum friends who are also PLWH. Therefore, a user-led psychosocial care and support structure at clinic level is required for better access to comprehensive HIV care services.

8.4.2 Inclusion

The inclusive model provides a platform for PLWH to be involved in the NGO or CBO as staff or volunteers. As pointed out by Patersona et al. (2014), they provide HIV or other services which are not HIV related, namely administrative staff, cooks and horticultural personnel, among others. They may participate occasionally in the activities of NGOs such as home visits, hospital visits and community outreach work, which happen occasionally when they are requested by the NGO to do so, which they carry out as

planned by others. They are less likely to receive formal training to carry out these tasks. The reward material for the activities is minimal and is mainly in the form of being in company with other PLWH or receiving more information about HIV and AIDS.

It was found that a few participants are volunteers in NGOs in which they perform HIV related work occasionally. It was found that they experience being part of the work of NGO as socially and emotionally supportive to them. It was established by Akintola (2011) that service users are motivated to volunteer in Aids Service Organisations as it meets their personal needs, and want to make a difference and to be useful.

It was furthermore found that participants volunteer in providing services to communities, schools and youths in communities. They do campaigns and public speaking on HIV and AIDS. However, they do not receive any remuneration for their services, yet they are unemployed and struggle to meet their bare necessities. The researcher referred some of them to the Department of Social Development (DSD) for social assistance. This type of user-involvement may not be effective when PLWH who provide service are poor and unemployed. It is likely to compromise the quality of service as they have to fend for their families. Consequently, for PLWH to command effective user-led HIV services, they have to be remunerated.

8.4.3 Participation

A common feature for a model identified by Grey and O'Hagan (2015) is consultation, which is formal and regular between service users and non-service users. Service users may be consulted about the services to be rendered, and even participate in planning. They receive remuneration. They are service users who have accepted their diagnosis, and can use their personal experience to shape HIV services.

This model is the least implemented in the study site. However, the study participants may fit into the model in that they possess personal competence; they were able to identify gaps in HIV care services; designed the approach and training content for

community education; possess a reasonable level of education; and are trainable for the field of HIV care.

8.4.4 Greater Involvement

Greater involvement manifests itself in two ways namely when PLHA are employed by organisations and hold management positions, and when they are volunteers and belong to strategic decision-making bodies, such as boards of trustees (Simpson & House, 2003; Patterson, Weaver, Agath, Rutter, Albert & Crawford, 2009). This is an advance model of user-involvement wherein PLWH participate in programme development, implementation and policy making. PLWH may even represent their NGOs externally, which can subject them to stigma and discrimination. But they are mainly PLWH who cope better with living with HIV because they personally have high levels of acceptance and support. Usually, these are people who have been living with HIV for a long time, and have high school qualifications. This type is implemented by NGOs, which are rights-based.

Many study participants had been living with HIV for a long time. It was found that the duration of living with HIV and AIDS ranges from 1 to 19 years. Some participants are in possession of Grade 12, while a few have post-grade 12 qualifications. Involvement with them during the study revealed that they are able to articulate significant issues, such as human rights and PLWH, design, content and implementation of strategies to fight poor health, especially stigma and discrimination. Consequently, a space should be created in the health facilities to accommodate true user-involvement even in the management levels of the HIV care system.

Several authors Cornu & Attawell, 2003; Simpson & House, 2003; Patterson et al., 2003)concurred that there are different forms of models but the common feature for a sustainable user-involvement is that services users should be empowered to have control and power at the operations level so that they can contribute in programme

design, development and implementation . It is on this basis that the psychosocial user-led intervention model was developed for Vhembe District.

8.5 USER-LED INTERVENTION MODEL IN HIV CARE IN VHEMBE DISTRICT

People living with HIV and AIDS in Vhembe receive HIV care through the PHC system in collaboration with NGOs. However, PLWH fall within the system due to the fragmented service delivery. The efficacy of NGOs in the study in providing psychosocial care and support could not be established, while clinic nurses are overburdened by high work volume. Consequently, PLWH do not receive timeous and adequate psychosocial support. It was found that many participants started to experience better health outcomes after receiving information and support by other PLWH, their families, neighbours, friends and church leaders living with HIV and AIDS. Therefore, it is recommended that a psychosocial user-led intervention model be implemented in healthcare facilities with a clear infrastructure.

The user-led intervention model developed for Vhembe District has three organisational levels: operations, management and planning. The user-led service unit is established on a horizontal level with other operational units at the health centre level. The unit is led by people with lived experiences of living with HIV and AIDS whose role is to create, design and implement services or projects for individual service users, families, groups and communities. The unit carries out its intervention in collaboration with other operational units in the centre. Service users for the unit may enter into care directly into the user-led unit or through the other units. The unit shall also refer their service users to other units when a need is identified. They work directly with PLWH who are either entering or are in HIV care. The three units shall report to the management level which consists of different managers in the health centre. Then, the HIV care reports, plans and proposals about HIV care shall be reported at Vhembe District Office. This forms part of Vhembe District Health Strategic Plans. Through this route, the user-led unit

shall be able to influence service design, development, plans and implementation of HIV care in Vhembe District. The proposed organisational structure is presented below:
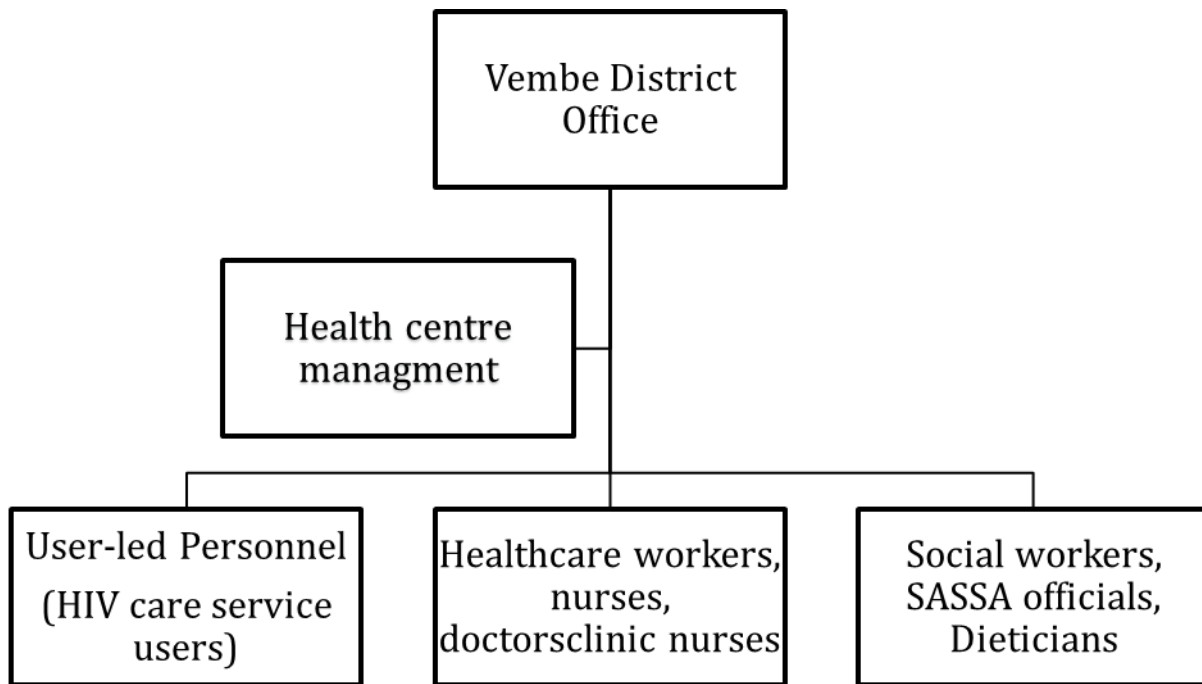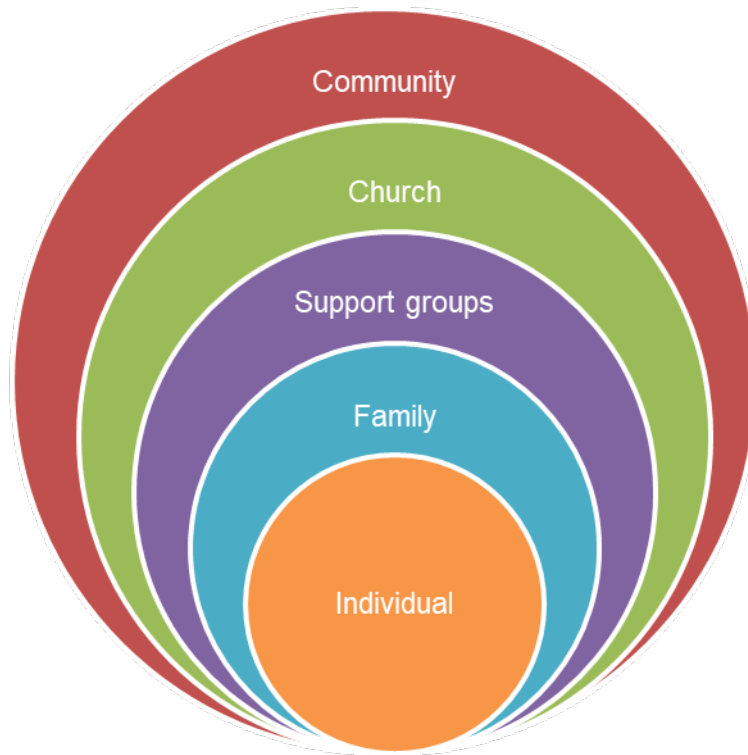

Figure 4: The proposed user-led model organisational structure

The user-led unit should be on a horizontal level with the other two professionally manned units (healthcare and social services). The user-led personnel are members of the staff establishment who receive remuneration either on a contractual or permanent basis, but their services should carry equivalent weight like other units in the health centre. They share resources for their programme interventions with other units in the institution. Their route of communication is bidirectional with the other units as well as vertical into the management of the centre. They shall refer and receive HIV care service user requests from both units for interventions. The upward reporting shall be to the health centre management level. Consequently, there should a coordinator from the unit to liaise directly with management. They shall be represented in the centre management unit during reporting and planning and other operational activities. This shall require that efforts be made by professionals to accommodate user-led service

providers so that they are not intimidated by the professional environment to ensure that their involvement is beyond tokenism.

Based on the findings of individual interviews and focus group discussions, it was established that PLWH need psychosocial care and support from different dimensions. Hence, the model is designed to provide services to individuals, family members, support groups, churches and the larger community in order to activate comprehensive, coordinated and collaborated user-led interventions. Their interventions shall be executed through different levels with each striving to achieve specific aims. As defined by the WHO (2010), intervention is a package of activities that will help to achieve the objectives, and produce a set of outputs which contribute to the desired outcomes and ultimately the impact. User-led activities are informed by the study findings presented in chapter six. They thus meet the requirements of the WHO (2010:6), which require that sustainable intervention activities need to be locally appropriate, feasible and equitable, based on evidence and good practice, synergistic with other health interventions, and take into consideration the cost-effectiveness and sustainability both financially and pragmatically. The user-led interventions consist of seven levels. Each level consists of concrete activities to be carried out. These levels are presented below.

The findings as presented in chapters 6 and 7 provided a blueprint of PLWH needs, wants, challenges as well as concrete intervention activities which should be carried out for better health outcomes. The blueprint provided guidance on the design and implementation of user-led HIV care services in the healthcare system. These activities are to be carried out in collaboration with healthcare professionals and social services personnel who are involved in HIV care. The user-led services targeted the entire service user system. It starts from individuals, families, support groups, churches to larger communities.

Figure 5: The proposed user-led model intervention levels

8.5.1 The Individual Level – Level 1

The aim of Level 1 is to provide timeous access to debriefing services in order to minimise the impact of emotions evoked by the HIV diagnosis and to diffuse conditions which fuel stigma and discrimination, especially self-stigma. Self-stigma precedes external stigma and is the onset of poor health outcomes. Timeous, adequate and relevant individual user-led service averts potential poor coping.

As confirmed by findings, PLWH have unique needs, yet the little available psychosocial services are generic in nature. It is vital that at point of entry into care, they should have access to specialist psychosocial services provided by the user-led unit which includes, but not limited to, pregnancy and Living with HIV, discordant couple, the elderly living with HIV and AIDS, PLWH who acquired HIV while caring for sick family members,

young people who perinatally acquired HIV, grief related to HIV and AIDS, among others. These services may be for those entering care and those in care.

8.5.1.1 Individuals PLWH entering care

It was established that PLWH received pre-test counselling which was mainly medically based by healthcare workers. The user-led pre-test counselling shall augment it by emphasising the psychosocial pre-test support which addresses the psychosocial issues which were confirmed to be problematic in the experiences of living with HIV. The contents of the pre-test counselling shall be informed by individual interviews and the FGS findings. In particular, it shall address fears related to the HIV diagnosis, sources of self–stigma, activate personal strengths, identify and establish support networks empower them with life skills, among others.

The next step which involves actual testing requires further support by PLWH service providers to people entering HIV care. Possible HIV care community members are afraid of going to clinics for HIV testing. Where feasible user-led service providers may accompany community members to the clinic. The model needs to have community-based user-led service providers (known or anonymous) so that community members who made a decision to test may consult them for escort. Being accompanied by another PLWH may reduce anxieties associated with HIV testing and its outcome. Then they shall wait for them to test, and be immediately accessible for support post-diagnosis.

Many PLWH service users passed grade 10 as the highest qualification. They are trainable to work alongside professional healthcare workers in carrying out the actual HIV testing. With the rapport that shall have been established during the pre-test care and support, they are best positioned to provide post-testing care and support on bio-psychosocial needs.

8.5.1.2 Individual PLWH in care

Poor health outcomes among PLWH is a persistent concern. It was confirmed in the study that PLWH have self-defeating conversation about Living with HIV and AIDS, poor treatment adherence, stigma and discrimination by one PLWH to another PLWH. These are poor coping strategies which undermine their being in care. They reflect in their conversations that they are living with fears, shame, sadness, isolation, self-devaluation and self-exclusion, among others. The intervention by service user service providers shall focus on those in care. Specific activities include educating them on how their body works, helping them appreciate that their bodies have change post-HIV infection, and referring them to nurses to help them understand the meaning of the test results. Then the PLWH service provider shall recruit them into meetings one at a time. This shall lead to the next level of the user-led intervention model which is the family level.

8.5.2 The family level – Level 2

The aim of Level 2 is to provide family-focussed care, support, empowerment and psycho education on HIV and AIDS so that they are able to deal with their own emotional reactions about their family members' diagnosis, and thereafter they can effectively support their loved ones living with HIV and AIDS.

Families of PLWH are expected to care and support their diagnosed loved ones in the face of fear of possible stigma and discrimination by their communities. Consequently, they need support for a variety of reasons. Firstly, when one family member gets diagnosed, family members experience many losses, uncertainties and anxieties. Often families must be helped to develop new rituals to draw together those who need support, particularly in the terminal phase of the illness. Specific activities for families shall be to support them to talk about fears and anxieties about their loved ones who had been diagnosed, especially treatment supporters. Secondly, the dawn of HIV and AIDS changed the family structure, roles and responsibilities. Many children are forced into foster homes, some are parentified while others live in child headed households.

Families should be supported to adjust to living with a condition which is accompanied by new and unique needs. Specific intervention activities at this level include but is not limited to:

- Facilitate the medico religious discussions on the concept of an illness, with special attention on the meaning of the HIV diagnosis. This should be done guided by the family's religious affiliation.
- Educate them on palliative care and infection control.
- Link families with or coordinate material resources to improve their living conditions.
- Provide assisted disclosure of the diagnosis to children about parents' HIV diagnosis.
- Support children post-disclosure of parents' diagnosis.
- Support children's treatment supporters individually or in groups.
- Educate the family with guidelines on diagnosis disclosure for children who perinatally acquired HIV.
- Establish peer or inter-family support. Nurture and encourage linkage between families of PLWH (either openly or anonymously) so that families can support one another to share coping strategies to reduce stigma meted against them by community members.

When PLWH and their families feel empowered, it may be time for them to connect with other PLWH in organisations or support groups. A sense of belonging with others is a human need which is a cornerstone for social and emotional health and wellness.

8.5.3 Mutual Aid Support groups – Level 3

The aim of Level 2 is to assist PLWH to enter into mutual aid support groups so that they learn to cope by learning from those who lived the experience. The mutual aids support group approach is premised on the principle that people who experience similar health conditions are able to help one another until they attain better mental health. It is a level of the model which intends to help PLWH to work at new challenges, needs and

concerns which are a consequence of the HIV diagnosis. The long term goal is to reduce manifestations of self-stigma, isolation and alienation and to improve self-efficacy.

In order to further improve on personal and social empowerment, networking, self-esteem and self-efficacy, a support group shall be facilitated to provide for general and special needs. Some of the issues which they shall attend are, but not limited to, disentangling issues related to living with HIV, such as discovering the new identity/self-awareness, stigma and discrimination, diagnosis disclosure, antiretroviral treatment, relationships enrichment, partner reactions to diagnosis, communication skills, alcohol and substance abuse, religion, nutrition, post-diagnosis relationship difficulties, separation/ divorce and child custody matters, among others. Due to the complexities of some issues, they may seek specialist resources for further intervention.

While belonging in support groups is for PLWH in care, this can be a resource for working in the next two levels. It can also be a resource for the healthcare centre as on completion of support group attendance, PLWH may feel empowered to provide voluntary services alongside healthcare workers. They may be empowered to do outreach work with the community, which is the next level of the service model.

8.5.4 The Church Level – Level 4

The aim of Level 4 is to mainstream HIV and AIDS education into churches in communities in order to introduce HIV and AIDS narratives which are favourable to PLWH who are in communities. Intervention activities for this level shall be to:

- Identify local governance structures of churches for buy-in.
- Motivate religious leaders to illuminate theological themes in their teachings, which fight stigma and discrimination.
- Sensitise them on appropriate terminology to refer to HIV and AIDS to change the negative narratives about HIV and AIDS.
- Focus on the medico religious concept of a disease, in particular HIV and AIDS.

- Acknowledge religious leaders' fears and anxieties about HIV and AIDS.
- Encourage religious leaders living with HIV and AIDS to work with the three operations units (user-led, healthcare workers and social service professionals) at the health centres.
- Provide HIV counselling and testing to congregants.
- Provide guidance to churches to work with PLWH organisations which are in their communities.
- Encourage churches to observe International AIDS day within their churches to fight stigma and discrimination.

When subsystems such as the individual, family and the church in communities are supported and have reached active functioning on HIV and AIDS, it shall have possibly reached half the community. Then the larger community can then be mobilised for participation in health promotion, especially caring for PLWH in their community.

8.5.5 The Community Level – Level 5

The main aim of Level 5 is to mobilise the larger community to participate in health promotion matters, in particular, HIV and AIDS education in order to eradicate stigma and discrimination, and alienation experienced by PLWH in communities.

Working with PLWH in care and those entering care, families and churches in communities, shall systematically nurture communities' interest in health matters in general, and fight outdated and wrong perceptions about HIV and AIDS held by communities. This is intended to create a social environment for better health outcomes. Getting larger communities into dialogues on HIV and AIDS matters is developmental and transformative for community members. Activities of this level shall include but not limited to:
- Identify structures of authority in the community.
- Talk to its leaders individually to get a buy-in into HIV and AIDS education.

- Mobilise community leaders to a meeting for them to connect and develop interest in HIV and AIDS matters.
- Together with religious leaders of different churches, coordinate a focus group education on HIV and AIDS.
- Together with community leaders, motivate community members to participate in community health matters.
- Community members should be provided with non-threatening multidisciplinary dialogues. Core facilitators of dialogues should include but not limited to trained pastors, prophets, traditional health practitioners, healthcare workers,PLWH and social service professionals.
- Work with the focus group mentioned above to mobilise the larger community to meetings.
- With a team of multidisciplinary healthcare partners, provide the larger community with health promotion matters, in particular sensitise the community on HIV and AIDS-related stigma and discrimination.
- Identify interest community groups and continuously work with them.

Working in the four levels activate security poles for PLWH which may have collapsed post-HIV diagnosis. The next level of the model tracks the social functioning of PLWH and the entire social system. This is achieved through monitoring and evaluation of the interventions. Indicators of the effectiveness of user-led interventions is evident by the functioning of the four subsystems which are individuals, families, mutual aid support groups, churches and the larger community, especially with regard to their stance on the meaning of living with HIV and AIDS.

8.5.6 Monitoring and Evaluating the User-Led Interventions – Level 6

The aim of Level 6 is to track the effectiveness of user-led interventions. This shall be confirmed by reports from the user-led unit and the other two units on HIV care. Such reports shall highlight on:
- Changes in community narratives on HIV and AIDS matters.

- ▪ Improved health outcomes among PLWH.
- ▪ Individual reports of PLWH who utilised user-led service in the health centre.
- ▪ Improved social functioning of PLWH and their families.
- ▪ Efficacy of community outreach programmes.
- ▪ Non-discriminatory talks by leaders, especially in community gatherings.
- ▪ Inclusion of health promotion talks by communities during their general meetings.
- ▪ Indicators of reduced self-stigma among PLWH.
- ▪ Mutual aid support groups established and functional.

8.5.7 Reports and Review – Level 7

The aim of Level 7 is to share feedback with other operations units who provide HIV care and the clinic management on the impact of the user-led interventions. The nature and format of reports may be provided by the clinic or district management as they are vital to the redesigning and development of user-led programmes in the district. The user-led unit shall provide reports on:

- ▪ Individual service user records.
- ▪ Family focussed care services.
- ▪ Functional support groups.
- ▪ Partnerships with different stakeholders.
- ▪ Outreach projects in communities.

The user-led reports may provide a source of best practice in HIV care, and where necessary, they may improve, redesign, develop and implement new programmes.

8.5 CONCLUSION

Since the discovery of HIV and AIDS three decades ago, there had been many development to improve health outcomes among PLWH. Such developments included the provision of ARV, protection of their rights as PLWH, and the introduction of the

GIPA. The next step is to ensure that user-involvement in HIV care does not remain stuck at a tokenistic level as it currently appears. True implementation of user-involvement through the correct infrastructure is an ethical requisite for HIV care. The user-led intervention model to service delivery transforms service users from consumerism to empowerment. User-involvement in their own care contributes to personal, social and organisational empowerment, which is a cornerstone to human dignity.

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APPENDICES SECTION

Appendix 1: Participants' Consent Form

I.. confirm that I understand the aim of your research and voluntarily consent to participate. I understand that my private information and identity will not be divulged to any person or institution, and my right to privacy will be respected at all times. In instances where my rights are contravened, I have a redress.

My contact details are the following:

Cell no:

Tell no:

Contact time during the day is between …………… and……………..

Email address:

My signature below confirms my informed consent to participate in the study.

…………………………………..   ……………………….

PARTICIPANT'S SIGNATURE   DATE

Appendix 2: Individual Interview Guide

1. Participant no:
2. Date of interview:
3. Venue of the interview:
4. Gender:
5. Age:
6. Occupation:
7. How long have you known that you were living with HIV?
8. What does your community say about HIV and AIDS?
   - Prompt: When they talk about it, what do they say it is?
9. What did living with HIV mean to you before you were diagnosed?
   - Prompt: Describe your thoughts/ experience of living with HIV.
10. What do you think living with HIV mean to you now that you are diagnosed?
    - Prompt: How do you feel about it? What does it mean to you?
11. What made you to think like this?
    - Prompt: What changed how you use to think about living with HIV?
12. What kind of support do you have as a PLWH?
    - Prompt: Day-to-day support?
13. In your day-to-day life, what are the challenges you experience as a PLWH?
    - Prompt: challenges of any kind.
14. How do you deal with these challenges?
    - Prompt: How do you solve them?
15. As a PLWH, what do you think your future looks like?
    - Prompt: What are your plans for your life?
16. How was it like talking to me about your experience of living with HIV?
    - Prompt: Do you have questions or concerns?

Appendix 3: Focus Group Discussion Interview Guide

1. If you were to teach your community about HIV and AIDS, what would you say to them?

2. If someone in your community comes to you and say he/she has decided to take an HIV test, what would you say to that person?

3. When that person comes out of the testing room and tell you that he/she is diagnosed with HIV, what would you say before that person leaves the clinic?

4. What is your experience of participating in the FGD?

Appendix 4: Provincial department of health approval letter

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stols M.L (015 293 6169)   Ref:4/2/2

Mabogo MG
113 Biccardstreet
Polokwane
Limpopo

Greetings,

RE: A phenomenological study on experiences of people living with HIV and AIDS: Towards the development of a user- led intervention model in the Vhembe District, Limpopo.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.

2. Kindly be informed that:-

   • Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.

   • Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.

   • In the course of your study there should be no action that disrupts the services.

   • After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.

   • The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.

   • The above approval is valid for a 3 year period.

   • If the proposal has been amended, a new approval should be sought from the Department of Health.

   • Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

_____   19/07/2017
Head of Department   Date

Appendix 5: Vhembe District Department of Health Approval Letter

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA
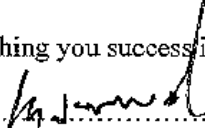
DEPARTMENT OF HEALTH
VHEMBE DISTRICT

Ref: S5/6
Enq: Muvari MME
Date: 02. August 2017

Dear Mabogo M.G

PERMISSION TO CONDUCT A PHENOMENOLOGICAL STUDY ON EXPERIENCES ON PEOPLE LIVING WITH HIV and AIDS

1. The above matter bears reference

2. Your letter received on the 02/08/2017 requesting for Permission to conduct a research in the Vhembe District is hereby acknowledged.

3. The District has no objection to your request .

4. Permission is therefore granted for the study to be conducted within Vhembe District.

5. You are however advised to make the necessary arrangements with the employees concerned.

Wishing you success in your studies

....
..DISTRICT CHIEF DIRECTOR

7/8/2017
DATE

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240

Appendix 6: Ethics Committee Clearance Certificate

University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2306, Email:noko.monene@ul.ac.za

> **TURFLOOP RESEARCH ETHICS**
> **COMMITTEE CLEARANCE CERTIFICATE**

MEETING:	26 May 2017
PROJECT NUMBER:	TREC/61/2017: PG

PROJECT:

Title:	A phenomenological study on experiences of people living with HIV and AIDS: Towards the development of a user – led Intervention model in the Vhembe District, Limpopo Province
Researcher:	Ms MG Mabogo
Supervisor:	Prof JC Makhubele
Co-Supervisor:	N/A
School:	Social Sciences
Degree:	PhD in Social Work

PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

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

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Appendix 7: Briefing Notes for Health Centre Managers

Date

Present

Municipal managers (Social Work supervisors)

First contact was done with the Thulamela Municipal Social Work managers. They were briefed in September 2017 during their monthly meeting. This was followed by a briefing held with the Makhado Health Centre managers in January 2018. Both briefings contained the following information

A summary of the research proposal, with special emphasis on:

AIM AND OBJECTIVES

The aim

The aim of this study is to explore and describe the lived experiences of PLWH in order to develop a user-led intervention model in Vhembe District, Limpopo Province.

Objectives of the study are:

- ▪ To assess a variety of stressors (intrapersonal) from within PLWH.
- ▪ To appraise various stressors from their social environment (interpersonal).
- ▪ To determine the type of social system that they have.
- ▪ To establish coping challenges.
- ▪ To establish coping strategies.
- ▪ To develop a user-led intervention model for PLWH.

Criteria for inclusion in the study:

- ▪ Voluntarily chose to participate.
- ▪ Signed consent forms.
- ▪ Received counselling after the diagnosis.
- ▪ Adheres to treatment.
- ▪ Disclosed their diagnosis.
- ▪ Aged from 18 and over.
- ▪ Speaks or is conversant with Tshivenda.