THE LIVED EXPERIENCES OF WOMEN WITH HUMAN IMMUNODEFICIENCY VIRUS (HIV) IN MALAWI: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

by

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DEDICATION

I dedicate this thesis to my dearest son, Zuriel Pax Matambo.

DECLARATION

This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration, except where specifically indicated in the text. It has not been previously submitted, in part or whole, to any university or institution for any degree, diploma, or other qualification.

Signed:____

Date:____

ABSTRACT

Research on African women and HIV, particularly research that investigates their experiences of living with the virus, has been relatively peripheral. As a response to the apparent knowledge and research gaps, this project is a qualitative study involving women living with human immunodeficiency virus (WLHIV) and attending an anti-retroviral treatment (ART) clinic at Zomba Central Hospital in Southern Malawi.

The study utilised an interpretative phenomenological analysis (IPA) approach, which informed all aspects of the data-collection and data-analysis processes. Using purposive sampling, 12 women were recruited and interviewed on three occasions over a period of six months. The interviews were conducted in Chichewa and audio recorded and later transcribed into English.

Fourteen superordinate themes emerged from the analysis representing the women's prominent life experiences, how they received their diagnosis, and how they contained the trauma of their diagnosis. The analysis also developed themes regarding how they coped with the challenges of living with the human immunodeficiency virus (HIV) and made sense of their experiences. The results showed that the women struggled with multiple challenges experienced through their various identities as WLHIV. The findings also pointed to interlocking disadvantages that put the women at risk of infection, and which were present from childhood. This has implications for more structural and multidisciplinary interventions for WLHIV.

Keywords: Women living with HIV; Malawi; antiretroviral treatment; poverty

ABSTRACT: CHICHEWA VERSION

Kafukufuku wa azimayi amene ali ndi kachilombo koyambitsa matenda a Edzi mu Africa muno, makamaka kafukufuku ofufuza zomwe amakumananazo mmoyo mwawo kaamba kopezeka ndi kachilombo koyambitsa matenda a Edzi, samapangidwa mokwanira. Kafukuku uyu akufufuza za azimayi amene amalandira mankwala a ma ARV, ku chipatala cha Zomba Central ku chigawo cha mwera ku Malawi. Kafukufukuyi wapangidwa powona kuti pali zambiri zomwe sitidziwa zokhudza azimayi amene ali ndi kachilombo koyambitsa matenda a Edzi.

Kafukukukuyi akugwiritsa ntchito njira ya interpretative phenomenological analysis (IPA), imene inalondolera kutolera nfundo ndi kumasulira zomwe azimayiwa amakamba. Chiganizo chotchedwa Intersectionality, ndi chimene chathandiza kutanthawuzira nfundo zomwe azimayi amakamba. Azimayi khumi ndi awiri anasankhidwa ndipo ndinacheza nawo kwa miyezi isanu ndi umodzi, kwa maulendo atatu ndi mzimayi aliyense. Azimayiwo ndinacheza nawo mu chilankhulo cha Chichewa kuti amasuke.

Mukucheza ndi azimayiwa, panatuluka mitu ya nkhani khumi ndi inayi yomwe ikuyimira zomwe akumananazo kamba kopezedwa ndi kachilombo koyambitsa matenda a Edzi, komanso mmene amadzisamalira akasokonezedwa mmaganizo kwa nthawi yayitali chifukwa cha zokhumudwitsa. Kafukufukuyi wasonyezanso kuti azimayiwa amakumana ndi zokhoma zambiri chifukwa chopezeka ndi kachilomboka. Zikuwonetsanso kuti pali zinthu zambiri zimene zimasoweka pa miyoyo ya azimayiwa, zomwe zimayika miyoyo yawo pa chiswe kuyambira ku ubwana. Zotsatirazi zikusonyeza kuti azimayiwa akuyenera kuthandizidwa munjira zosiyana siyana kuti miyoyo yawo ikhale yathanzi.

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This research would not have been possible without the 12 Malawian women who so generously agreed to be interviewed, and I would like to express my sincerest thanks for their contribution.

Thank you to the *Beit Trust* for funding my studies for the second time; first in 2005 to complete my master’s degree at Bangor University in the United Kingdom (UK), and then for this PhD. I would like to express my sincere appreciation to Tim and Jo Johnson in Zimbabwe for their encouragement and belief in my capabilities. I would also like to thank Major General Angus Ramsay for his support. Thanks to Wicks in the UK and John Gillam at Rhodes for ensuring the smooth running of my studies and for their moral support. Many thanks to Secretary to the Beit Trustees Sir Andrew Pocock and Sarah for keeping me focused and motivated in this long journey.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired immune deficiency syndrome
ART	Anti-retroviral treatment
ARV	Anti-retroviral
BPS	British Psychological Society
BTI	Bertelsmann Stiftung's Transformation Index
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
DHS	Demographic and Health Survey
FAO	Food and Agricultural Organization
FGM	Female genital mutilation
GBV	Gender-based violence
GDP	Gross domestic product
GHQ-12	General Health Questionnaire
GT	Grounded theory
HBTC	Home-based testing and counselling
HDI	Human Development Index
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council
HTC	HIV testing and counselling
IPA	Interpretative phenomenological analysis
IPV	Intimate partner violence
MANET+	Malawi Network for People Living with HIV
MDHS	Malawi Demographic and Health Survey
MPHIA	Malawi Population-based HIV Impact Assessment
MS	Multiple sclerosis
MTCT	Mother-to-child transmission

NAC	National AIDS Commission
NACP	National AIDS Control Programme
NCRSH	National Committee on Research in the Social Sciences and Humanities
NHA	National Health Accounts
NSO	National Statistical Office (of Malawi)
NSP	National Strategic Plan
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
RSA	Republic of South Africa
SCTP	Social Cash Transfer Programme
SIGI	Social Institutions and Gender Index
SMEs	Small and medium enterprises
SRH	Sexual and reproductive health
STD	Sexually transmitted disease
UK	United Kingdom
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UN-Habitat	United Nations Human Settlements Programme
USA	United States of America
VCT	Voluntary counselling and testing
VMMC	Voluntary medical male circumcision
WHO	World Health Organization
WLHIV	Women living with human immunodeficiency virus

CHAPTER ONE:

INTRODUCTION AND BACKGROUND

The fight against HIV/AIDS requires leadership from all parts of government – and it needs to go right to the top. AIDS is far more than a health crisis.
It is a threat to development itself.
- Kofi Annan, former UN Secretary General -

1.1 INTRODUCTION

While important strides have been made in Southern Africa to mitigate the devastation caused by the human immunodeficiency virus (HIV), with Malawi as a good example of the benefits that can be achieved by implementing a national antiretroviral (ARV) programme, HIV remains a public health crisis, and the many oppressive socio-cultural factors that gave rise to the pandemic in the first place remain largely intact. To understand those socio-cultural factors that contribute to HIV, the study aims to document the experiences of women living with HIV (WLHIV), the meaning they attach to those experiences, the multiple challenges they face, and the strategies they employ to cope with the challenges and live with the illness. The study also aims to capture the context in which the women experience the illness and their prominent life experiences. The central research question of this thesis is: *What are the lived experiences of being diagnosed and living with HIV for women attending Tisungane Clinic in Southern Malawi*? This is a qualitative study that utilised semi-structured interviews conducted in three phases over a period of six months to capture the experiences of 12 WLHIV. The data were analysed using interpretative phenomenological analysis (IPA) to reveal the women’s experiences and meaning attached to those experiences. The current chapter serves to introduce and orient the reader to the study by defining in broad strokes the disciplinary and socio-cultural context that underpins the research. This involves a description of the socio-economic impact of the HIV pandemic on Malawi’s development. This is followed by a rationale of why the study was conducted using qualitative methods and why it focused on women.

1.2 BACKGROUND

1.2.1 Global estimates

Human Immunodeficiency Virus (HIV) is a virus that weakens the immune system by destroying important cells that fight disease and infection and that reproduces itself by taking over certain white blood cells essential to the body's immune functioning (World Health Organization (WHO), 2007). AIDS stands for acquired immunodeficiency syndrome; a pattern of devastating infections that are the result of a depleted immune system (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2000). The main methods of transmission of HIV are through unprotected sexual intercourse; contaminated blood; contaminated blood products, tissues, and organs; contaminated needles and syringes; and vertical transmission, also known as mother-to-child transmission (MTCT) (UNAIDS, 2000).

In 2015, 2.1 million (1.8 million to 2.4 million) new HIV infections were documented worldwide, culminating in 36.7 million (34.0 million to 39.8 million) people living with HIV (PLHIV) (UNAIDS, 2016a). An estimated 35.3 million people were living with HIV in 2012 in sub-Saharan Africa and women account for 57% of all PLHIV in the region (UNAIDS, 2013). HIV treatment has proved to be successful in preventing the fatal course of the infection, and over the past 25 years, HIV/AIDS has gradually shifted from a fatal, incurable disease to a chronic condition that can be managed through the use of multiple antiretroviral (ARV) drugs that have life-saving and life-prolonging properties (Baranov, Bennett, & Kohler, 2015). Global coverage of ARV therapy reached 46% (43% to 50%) at the end of 2015, with the greatest gains recorded in the world's most affected regions, namely Eastern and Southern Africa (UNAIDS, 2016b). The past 15 years have seen a steady increase in access to life-saving ARV medications in low- and middle-income countries, from just 300 000 people who were receiving treatment in 2002 to 9.7 million in 2012 (WHO, 2013). In Africa alone, with the highest prevalence rates, more than 7.5 million people were receiving treatment compared to 50 000 people a decade earlier (WHO, 2013).

1.2.2 Malawi's HIV pandemic

Currently, Malawi has an estimated population of 17 million (Government of Malawi, 2019) and as of 2011, an estimated 966 000 people were living with HIV (Government of Malawi, 2011). Malawi exhibits significant geographical differences in HIV prevalence. For example, in the Southern Region, where roughly half of the Malawian population resides, HIV prevalence rates are higher compared to other regions (see Figure 1.1). The Malawi Demographic and Health Survey (MDHS) of 2015-2016 estimates that one in ten HIV-positive adults has never been tested for HIV. Amongst those adults, HIV-positive men are more likely to have never been tested, compared to HIV-positive women (15% versus 6%) (National Statistics Office (NSO) of Malawi, 2015a).

According to the 2011 Malawi National Strategic Plan for HIV and AIDS, the first response to the HIV and AIDS pandemic started with the establishment of the National AIDS Control Programme (NACP) in the Ministry of Health. The NACP was replaced by the National AIDS Commission (NAC) in 2001, which currently coordinates and spearheads the national response to HIV and AIDS and contributes to the regional and global response (Government of Malawi, 2011). To strengthen this structure, the government of Malawi went on to establish a Department of Nutrition, HIV and AIDS within the Office of the President and Cabinet in 2006 to better coordinate public policy development and implementation (Government of Malawi, 2011). Central to the NAC's interventions in Malawi have been the prevention of mother-to-child transmission (PMTCT), voluntary medical male circumcision (VMMC), HIV testing and counselling (HTC), and the ART programme, which have significantly reduced new transmissions (Government of Malawi, 2011).

Malawi's HIV story is one of much success when one considers the rapid scaling up of ART and a resulting decline in incidence of HIV infections (Ford, 2013). For example, Malawi has registered a 75% decline in incidence and there has been a decline in annual deaths from 99 000 in 2004 to 48 000 in 2013 (UNAIDS, 2016b). Early initiation of ARV therapy has been shown to reduce AIDS-related deaths and the progression of the illness (Zolopa et al., 2009), improve survival rates, and reduce infection rates in discordant couples (Cohen et al., 2011).

On the rights front, the Constitution of the Republic of Malawi indirectly guarantees the human rights of persons infected and affected by HIV. There is an all-encompassing clause stipulated in the Constitution of the Republic of Malawi (1994) that prohibits all forms of discrimination, including of those living with HIV:

> Discrimination of persons in any form is prohibited and all persons are, under any law, guaranteed equal and effective protection against discrimination on grounds of

> race, colour, sex, language, and religion, political or other opinion, nationality. (Constitution of the Republic of Malawi, 1994, Section 20.1)

Yet, despite this constitutional imperative, the country-wide burden of the impact of HIV and associated discrimination rests largely on poor, rural women.

1.2.3 Socio-economic impact of HIV in Malawi

From the day of independence until present, Malawi seems to have cemented its position in the top ten poorest countries in the world (Mojica, 2016); currently at number one according to its gross domestic product (GDP) per capita estimated at US$820 (Gregson, 2017). The poverty rate in Malawi is high among people in female-headed households (about 57%), compared to 49% among people in male-headed households (Gregson, 2017). Gender disparities also exist in literacy rates, with female literacy estimated at 57% compared to 74% in men (Bertelsmann Stiftung's Transformation Index (BTI), 2016). In Zomba District, where the study was conducted, there are high poverty levels due to a high unemployment rate with rapid population growth and an economy largely dependent on small and medium enterprises (SMEs) (United Nations Human Settlements Programme (UN-Habitat), 2011). Interestingly, only 23% of these SMEs are owned and run by women. The unequal status of women in Malawi is sustained by discriminatory treatment within the family (Branisa et al., 2014). Matrilineal and patrilineal family systems operate in Malawi's ethnic groups and both disadvantage women in terms of land resources, which are the main resources for sustaining livelihood in the country's agriculture-based economy (Berge, Kambewa, Munthali, & Wiig, 2013; Government of Malawi, 2010).

According to the 2016 United Nations Development Programme (UNDP) Malawi Human Development Index (HDI) report, the snail pace in growth or stagnation in Malawi's development is attributed to various factors, one of which is the impact of the HIV pandemic which limits people's participation in economic activities that would be instrumental in improving people's lives, and, therefore, inclusive economic growth (UNDP, 2016). There are many direct and indirect costs of HIV on households. The first are medical costs, which have been found to consume a substantial amount of a household's income that could have been utilised for other needs such as food and education. According to the National Health Accounts (Ministry of Health of Malawi, 2014), a report that generates pertinent information on financing for general health as well as specific diseases and services, including HIV and

AIDS in Malawi, the estimated average health expenditure for an individual is at about US$26. Owing to the long-term nature of the illness, as well as the fact that HIV infections tend to cluster substantially in affected households, the expenditure is greater for households that have family members that are HIV positive (Ministry of Health, 2014).

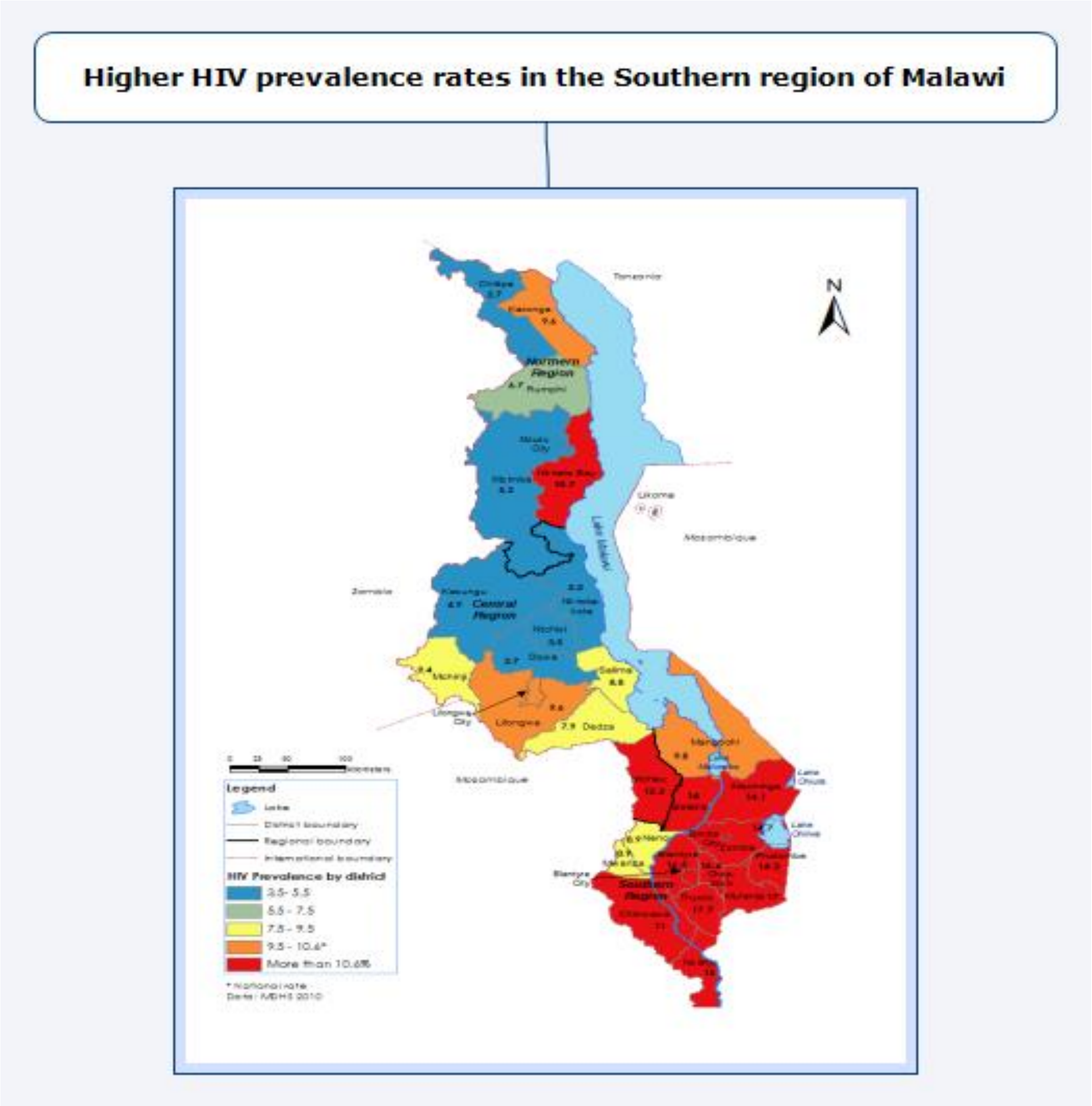

Figure 1.1: Map of Malawi showing HIV prevalence rates by district

Source: NSO (2015b)

Another direct cost for households of the HIV pandemic are funeral costs. Funeral expenses represent a heavy burden for the majority of low-income households (Arrehag, De Vylder, Durevall, & Sjöblom, 2006). This cost is largely borne by rural communities, since it is common for HIV-infected urban dwellers of rural origin to return to their communities when they fall ill. Specifically, direct funeral costs that arise from the deaths of HIV/AIDS patients are the cost of coffins, morgues, and funeral ceremonies. Indirect costs of the disease include diminished labour supply and productivity. HIV/AIDS has been associated with high levels of absenteeism from work and shortages of labour supply (Arrehag et al., 2006).

In addition, even when HIV-positive people continue to work, unless they have achieved a full recovery, their performance may be significantly impaired. According to a Malawian labour survey conducted in 2013, this aspect is highly pertinent to a country such as Malawi owing to its developing status, as most labourers are employed in the agricultural sector (64.4% of the workforce) (NSO, 2013). This indirect cost is not only borne by those who are ill, but also by those who take care of them. In Malawi, owing to its very traditional status and low levels of gender equality, this burden of care usually falls on the women of the household, often already overburdened by domestic chores (NSO, 2013).

Ngwira, Kamchedzera, and Semu (2003) show that since women in the rural areas in Malawi are usually responsible for both cultivating food crops and household tasks, they typically work between 15 to 17 hours per day – substantially more than the eight hours that men are assumed to work.

According to Afrobarometer (2004), 43% of Malawians spend more than five hours a day tending to sick people, a significant portion of this care being provided by women. These demands impact on the labour needed for subsistence farming in a country where a large majority of women (90.7% according to one report) survive by subsistence farming (Food and Agricultural Organization (FAO), 2011).

A third direct impact is due to the increasing number of AIDS orphans who need food, clothing, and school fees, which often fall on non-immediate family members (Munthali, 1998). This, of course, adds to the costs incurred by families, often already struggling to feed and care for themselves and their own children, which increases of the risk of the depletion of resources in households (Munthali, 1998).

HIV also has a direct impact on the economy in Malawi. Economic growth is defined as the increase in real GDP (national income) (Mankiw, 2002). The relationship between this and a country's HIV prevalence is a negative one; an increase in the prevalence of HIV is associated with an adverse impact on economic growth. According to Cuddington and Hancock (1994), the impact of the HIV pandemic on growth is threefold. Firstly, it reduces the size of the labour force because of sickness and premature death. Secondly, workers' efficiency declines because of poor health and loss of cumulative work experience. Thirdly, savings decline because of increased health expenditure.

The higher allocation of government resources and spending on healthcare adversely affects other sectors of the economy. By spending on healthcare, the government diverts funds that could have been allocated to education, and building new infrastructures such as roads, schools, and better transportation systems (Topouzis, 1998). The direct and indirect costs of HIV/AIDS lead to lower government revenues and reduced private savings (because of greater healthcare expenditure and a loss of worker income) and loss of income from tax (Bollinger, Stover, & Palamuleni, 2000). Indeed, the negative impact that HIV has on the development of a small country like Malawi, and the subsequent reduction in the standard of living of those affected, is likely to be very significant.

Poverty itself has been associated with increased HIV risk (Masanjala, 2007). The AIDS pandemic depletes livelihood assets, household resources, and normal livelihood strategies, and renders households vulnerable to collapse and as a result creates a cycle of poverty. In this situation, economically dependent relationships arise that foster marginalisation and create economically dependent relationships in which women are subordinated (Masanjala, 2007). Poor, young, rural women, particularly those who have no access to sufficient food, are at an increased risk of HIV infection because the immediate need for survival detracts from sexual empowerment and increases the risk of unsafe sexual practices (Pascoe et al., 2015).

To address the problem of poverty and HIV, Malawi responded by implementing the Social Cash Transfer Programme (SCTP) to enhance social protection for PLHIV, as suggested by the UNAIDS outcome framework 2009-2011 (UNAIDS, 2010). Structural approaches such as the SCTP have shown promising results as a possible strategy to reduce vulnerability to HIV by mitigating the impact of poverty that might lead to risky sexual behaviours (Baird, Garfein, McIntosh, & Özler, 2012; Heise, Lutz, Ranganathan, & Watts, 2013). The SCTP provides monthly incomes and grants to the poorest 10% of households that are labour constrained, as identified by community social protection committees.

Findings have shown significant improvements in the lives of PLHIV after social cash transfers (Miller & Tsoka, 2012). PLHIV report better health because of better nutrition from food diversity and food security and the availability of resources that enable them to access treatment services (Miller & Tsoka, 2012). Studies also point to a reduction of risky sexual behaviours in women and adolescents who receive cash transfers that provide them with an income, thus reducing the likelihood of being infected (Baird et al., 2012; Pettifor, MacPhail, Nguyen, & Rosenberg, 2012). This demonstrates that interventions that target structural factors such as poverty are a very necessary component of population-based HIV interventions. Throughout the thesis, it will emerge more clearly that, in the case of WLHIV, it is not just about provision of medical interventions such as ART therapy that improves their wellbeing. It also involves uplifting them economically, addressing social inequalities that disadvantage them, and providing support to enable them to become more independent and less vulnerable.

1.3 PRIORITIES OF HIV RESEARCH IN MALAWI

The established research literature of HIV in Malawi has long focused on understanding the socio-demographic and economic aspects of HIV such as migration and infection (e.g., Anglewicz, 2012; Anglewicz, Van Landingham, Manda-Taylor, & Kohler, 2016) and the distribution of HIV (e.g., Poulin & Muula, 2011). Furthermore, the direction of HIV research is driven by Malawi government health plans which tend to lean towards investigating the biomedical aspects of the illness and clinical trials. For instance, the launch of the National Plan for the Elimination of Mother-to-Child Transmissions (MTCT) programme (Ministry of Health Malawi, 2012) saw burgeoning research in the area of Prevention of Mother- to- Child Transmission (PMTCT) programmes, focusing on the impact of the intervention (e.g., Kim et al., 2013) and the reduction of paediatric infections (e.g., Price et al., 2014).

Voluntary counselling and testing (VCT) is another prioritised research area with focus seen on evaluating programmes on access to home-based testing and counselling (HBTC) across socio-economic strata (e.g., Weinreb & Stecklov, 2009) and timing of HBTC in anti-retroviral treatment (ART) programmes (e.g., Helleringer, Mkandawire, Reniers, Kalilani-Phiri, & Kohler, 2013). While this biomedical focus is very important and necessary, there appears to be a lack of qualitative research on the lived experiences of those people who are the subjects of such biomedical interventions. A relationship exists between individuals and their environment, and their experiences are influenced by that environment (Bronfenbrenner, 1979). It is therefore important to understand the developmental and historical contexts that influence the experiences of people living with an illness such as HIV. Furthermore, evidence exists that chronic illness progression is usually mitigated by factors other than biological ones only. The biopsychosocial model of illness, for example, states that biological, psychological, and social factors interact to influence the prevention, causes, presentation, management, and outcome of the illness (see Engel, 1977). Hence, the current study focuses on investigating the lived experiences of people with HIV in order to unravel the socio-cultural context and psychosocial aspects of the illness.

Methodically, there are few studies that utilise qualitative methods in HIV research (Power, 1998). Unlike quantitative methods, in studies using qualitative methodology, the participants are known personally and the researcher experiences what the participants experience by looking at the setting and people holistically (Taylor & Bogdan, 1998). This approach maintains the human aspect of social life that is often lost when groups of people are necessarily reduced to variables or statistical equations in quantitative research endeavours (Taylor & Bogdan, 1998). In HIV research, quantitative methods fail to capture some critical matters of concern, such as the psychological manifestations of the illness, reducing the research conducted to a matter of statistics at the expense of other important personal issues (Bezuidenhoudt et al., 2006). Researching lived experiences typically involves studying reality, as perceived by participants, with the goal of uncovering the meaning that events and occurrences have for the participants (De Casterlé et al., 2011). I use this study to capture how WLHIV frame their lives after the diagnosis. On these grounds, this research aims to fill the gap of limited qualitative studies in HIV research.

Furthermore, I chose to focus on women because in Africa, young women and adolescent girls are especially vulnerable to HIV (UNAIDS, 2015). Physiologically, women are more susceptible to contracting HIV because they have a larger surface area in terms of the vagina and tears during sexual intercourse are more frequent (Fuller, 2008). Cultural practices also put women at higher risk; for example, dry sex, vaginal douching, and when women practise anal sex to satisfy their boyfriends while retaining virginity, as well as a host of other practices (Cameron, Rohleder, Swartz, Kalichman, & Simbayi, 2009). Perhaps most significantly, evidence also suggests that gender power dynamics trap women in relationships that further increase their risk (Ramjee & Daniels, 2013).

This is certainly true of women in Malawi. The MDHS of 2010 indicates that 11% of adults aged 15 to 49 in Malawi are living with HIV, with more women infected than men. Among women aged 15 and 49, the HIV prevalence rate is 13%, while among men aged between 15 and 49, the HIV prevalence rate is 8% (NSO, 2010). HIV prevalence is highest among women and men with no education (12.8% and 11.0%, respectively) (NSO, 2015a). A number of factors put women at a higher risk of HIV infection in Malawi. According to the Malawi National HIV strategic plan 2015-2020, HIV disproportionately impacts women in Malawi due to physiological vulnerabilities, gender inequalities, and low socio-economic status that increase their vulnerability to HIV (Government of Malawi [GOM], 2015a). Young girls who drop out of school are pressured into early sex and marriage but also lack proper knowledge of HIV prevention services because there are no youth friendly HIV services to freely seek counselling on sexual and reproductive health (SRH) issues (GOM, 2015b). Considering the abovementioned factors, research that focuses on women with HIV in Malawi, which complements existing qualitative and quantitative research on HIV, is highly relevant.

1.4 THE PURPOSE OF THE STUDY

In the study, I aimed to gain an in-depth understanding of the lived experiences of WLHIV in the context of their personal stories. This goal was achieved by interviewing 12 women visiting an ARV clinic in Southern Malawi, Zomba District (see Figure 1.2), over a period of six months on three separate occasions.

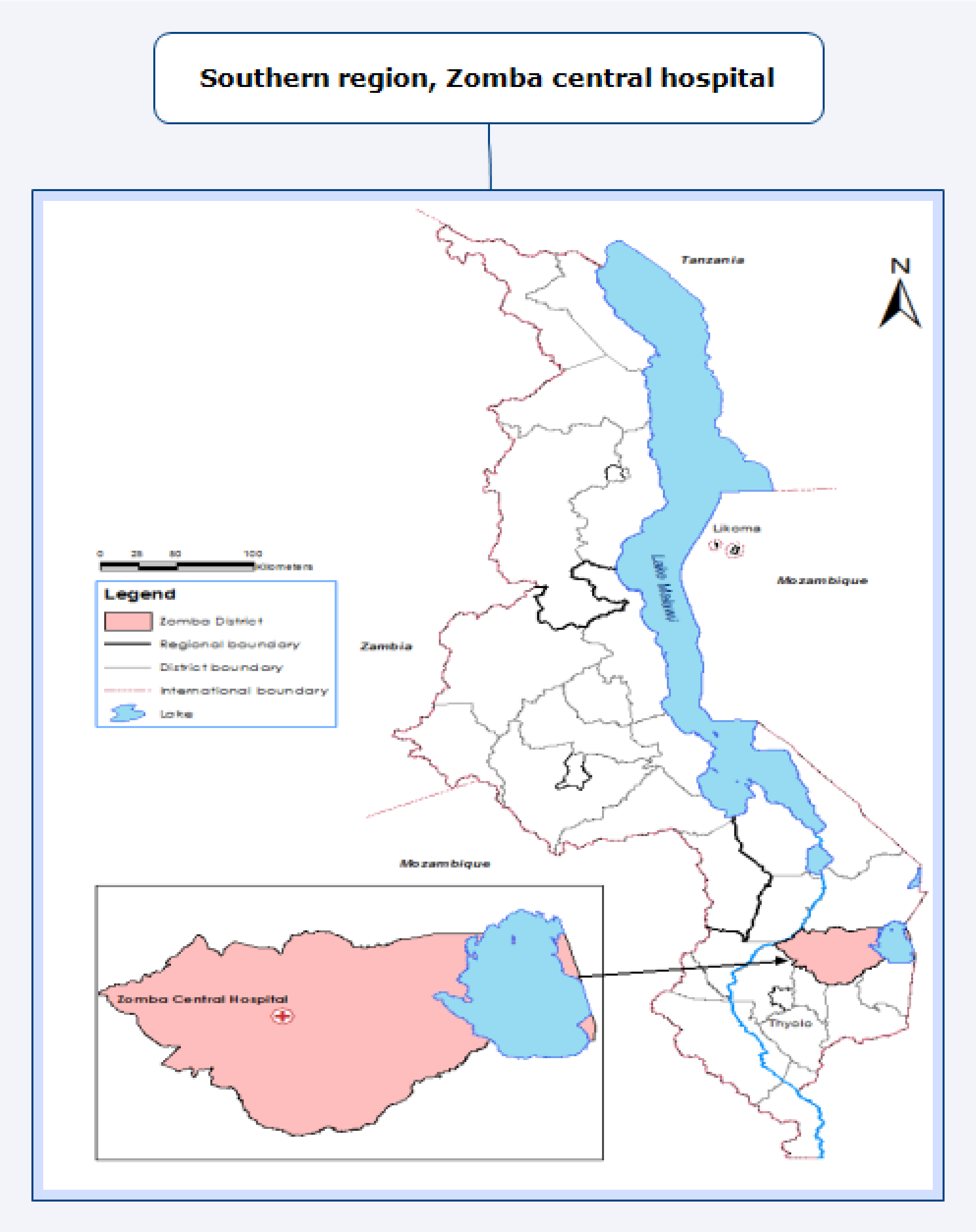

Figure 1.2: Map of Malawi showing study site

Source: NSO (2015a)

While the 12 women interviewed in the study had distinct biographies, they shared the social, cultural, and economic context explicated in this chapter.

Semi-structured interviews captured the experiences of living with HIV using theoretical and analytical procedures of IPA, a qualitative approach in psychology most comprehensively described by Smith, Flowers, and Larkin (2009). IPA, which is described in more detail in the methodology chapter, is an approach that offers an epistimeological stance, provides guidance in conducting research and describes a corpus of studies (Smith, 2004). I utilised

IPA because it is concerned with lived experiences. The end goal was to access the experiential-based accounts of the women's prominent life experiences, the women's challenges of living with HIV, how they coped with the challenges, and how they made sense of their experiences.

1.4.1 Rationale for the current study

In order to understand fully how living with HIV affects women's life, it is important to base the research about women, on them telling their own stories about their backgrounds, personal histories and conditions that have shaped their lives. It is not enough to know, for example, that WLHIV experience violence in their relationships; but it is also important to know the context in which their relationship decision-making took place. This study uses a qualitative approach because much research on WLHIV has been written from the perspective of the medical discipline, by medical scholars, and hence there is a gap in the literature on the lives of women living with the virus, and how they interpret their own lives (Aulette-Root, Boonzaier, & Aulette, 2014). Given the various issues that complicate women's lives, such as the social construction of the illness, medical issues, interpersonal relationships, and gender dynamics, it is more beneficial to solicit the information from the women themselves, by using a qualitative approach (Aulette-Root et al., 2014). The mentioned scarcity of adequate research on experiences of WLHIV explained in their own voice supports the appropriateness of this in-depth qualitative study on lived experiences of WLHIV in Malawi.

Notwithstanding, the extensive research on WLHIV, conducted with women from multiple contexts with different backgrounds, the current empirical study is original in that it seeks to understand experiences of living with HIV within the context of Malawi. Geographically, most of the recent literature on lived experiences of WLHIV originates from Western countries (e.g., Edwards, Irving, & Hawkins, 2011; Lingen-Stallard, Furber & Lavender, 2016; Ndirangu & Evans, 2009; Peterson, 2010; Sanders, 2008), Latin America (e.g., Ailinger, Cortes, & Molloy, 2016), East African countries (e.g., Gona & DeMarco, 2015; Kako, Stevens, Karani, Mkandawire-Valhmu, & Banda, 2012; Wekesa & Coast, 2013), and more from South Africa and less from Malawi. The lack of Malawian-based research in this area may result in Malawian women being assumed to share the same characteristics with their Western, Middle Eastern, and West African counterparts. This is one of the first studies to investigate the lived experiences of WLHIV in the Malawian context. The 12 women in this study may not represent the experiences of every Malawian woman living with HIV and, of course, WLHIV do not always share the same story. Their lives are complex and diverse and the voices of the 12 women will reflect this. However, it is true that they have in common with other women in similar disadvantaged positions, an ongoing struggle to create and occupy spaces where their views and voices are heard and acknowledged. Hence, the need to encourage them to speak for themselves and research is one of the best ways to facilitate women speaking freely about their experiences when other avenues are unreachable to them.

As will be illustrated in detail in Chapter Three, studies using IPA to investigate the lived experiences of HIV are only recently emerging (e.g., Yang, Lewis, & Wojnar, 2015). A search of existing literature indicates that there are as yet no published studies in Malawi applying the IPA approach to the exploration of the experiences of WLHIV. To address this gap, the current study involved three-part semi-structured interviews with 12 women and used IPA both as a theory and as an analytic framework to illuminate the lived experiences of HIV. With this in mind, the key research question was: *What is the lived experience of being diagnosed and living with HIV for Malawian women?* The secondary research questions that guided the inquiry were:

a) What is the social context in which women in Malawi experience HIV?
b) What are their prominent life experiences?
c) What are their actual experiences of receiving an HIV diagnosis?
d) What are their actual experiences of living with HIV?
e) What meaning do they attach to their experiences of living with HIV?

1.5 THE SIGNIFICANCE OF THE STUDY

This thesis argues that the adverse experiences faced by WLHIV are not generated by an HIV seropositive status alone, but rather by multiple forms of oppression and disadvantages in their lives; that these themselves are conditions of vulnerability to HIV infection. The study demonstrates that the women experience intersecting oppressions from early in their lives (e.g., gender inequalities, patriarchy, cultural norms, and lack of access to education) that create and sustain vulnerability to HIV. After undergoing the initial trauma of their diagnosis, their multiple identities as WLHIV (e.g., mother, wife, single, divorced, pregnant, sex worker) are impacted differently by the diagnosis and create double stigma when coupled with their HIV status. Furthermore, their experiences of living with HIV produce compounded challenges such as stigma, discrimination, lack of support, and economic challenges, which the women have to cope with alongside managing their illness. Their lives are not affected by an HIV status alone, but by multiple social challenges, cultural forces and oppressions that criss-cross each other and negatively impact their lives.

Thus, medical interventions such as provision of ARVs, PMTCT programmes, and SRH services are necessary but not sufficient in supporting and changing the quality of lives of women with HIV. This is particularly true when seen in the light of the milieu in which these interventions are delivered, where psychosocial support is lacking. This has implications for more structural and multifaceted interventions for WLHIV in Malawi.

The analysis developed 14 superordinate themes regarding the women's experiences. The themes encompassed the women's socio-cultural context, characterised by childhood poverty, lack of educational opportunities, early marriages, and subordination to their domineering, and abusive partners. The women exhibit initial intense reactions to their diagnosis, such as shock and anger, but later adapt to and manage their illness. In the interviews, the women also reflected on the psychosocial and economic challenges of living with HIV and the mechanisms they use to cope with those challenges and how they make sense of their experiences.

The study provides in-depth insight into the lived experiences of the women while providing them an opportunity to speak about living with HIV in their own words and from their own perspectives. Disadvantaged groups, such as the women in the current study, face significant barriers in health research participation (George, Duran, & Norris, 2014). One of the barriers particular to qualitative research is language, which limits the voice of eligible participants (Harris & Roberts, 2003; Squires, 2009); for example, in African contexts, those who are unable to speak English are under-represented (Newington & Metcalfe, 2014). The use of IPA and a three-part semi-structured approach to interviewing conducted in the local language allowed the life stories of the women to be accessible in order to understand the illness of HIV in the socio-cultural context in which it occurs and the psychosocial struggles that accompany the diagnosis.

Evidence also demonstrates that participating in research has direct benefits on mental health for women in stigmatised positions such as those living with HIV, because the research space gives them an opportunity to vent out their experiences without feeling judged (Felsher, Wiehe, Gunn, & Roth, 2018). In this study, the trusting relationship that developed between the 12 women and myself as the researcher may have facilitated the women’s feelings of catharsis from expressing their personal stories.

In addition, this will be the first in-depth qualitative study on lived experiences of HIV undertaken by a psychologist in Malawi. The emphasis on the psychosocial aspects of HIV, specifically, how PLHIV cope with the illness, is consistent with the Malawi National HIV/AIDS Strategic Plan (2011-2016), which lists psychosocial support as one of the priority areas in HIV care (GOM, 2011). The study’s findings are therefore valuable for informing the country’s psychosocial support strategies, clinic practice, and policy development.

This thesis constitutes an original contribution to knowledge as no work has previously sought to document the lived experiences of WLHIV in Malawi using IPA methodology. Listening to the women, it became clear that they do not choose to be silent and complicit about their plight; rather they lack spaces in which what they have to say about their experiences is empathised with, not minimised, questioned, or judged. The study provided the women a safe space and an opportunity to speak about living with HIV from their perspective while also, perhaps, releasing some of their psychological trauma.

1.6 ORGANISATION OF THE THESIS

The overall structure of the study takes the form of eight chapters, including this introductory chapter. Chapter Two presents a narrative literature review, which highlights the areas of focus of existing studies on women and HIV. The chapter also attempts to clarify what has been addressed in the area of women and HIV and reveals the gaps in the existing literature that this study attempts to fill. Because the literature highlights many overlapping and interconnected adversities that WLWHIV face, the chapter concludes with a brief discussion of intersectionality (Crenshaw, 1991). The topics that are covered in the literature review are necessarily presented in a sequence and so the inclusion of a brief discussion of intersectionality is, therefore, a useful tool to emphasise that living with HIV may be much more than the sum of multiple adversities. However, this is not a theoretical framework for the thesis. IPA provides its own theoretical stance and methods to do a fine-grained analysis of the interview data, while avoiding, as far as is possible, the contamination of the themes and the curtailment of unanticipated themes that might result from the imposition of any pre-determined hypotheses or theoretical frames (Smith, 2004). It is not that the study renounces other theoretical understandings of the participants’ experiences, but rather that in the process of analysing the data, I must remain true to the text and open to any psychological interpretations that makes sense of the data.

Chapter Three provides a description of the methodology and methods employed to answer the research questions. It includes the rationale for choosing the particular qualitative approach and offers an account of the philosophical foundations of IPA and the epistemological and ontological stance of the research. The chapter includes a discussion of the ethical risks associated this type of inquiry and how these have been mitigated.

Chapters Four, Five, and Six present the results of the anaylsis. Consitent with IPA’s inductive approach, these three chapters present the results with minimal refernce to to the extant psychological literature. Each chapter addresses each of the broad research questions. The fourth chapter details the cultural and social background of the women’s lives to expose the factors that have shaped their experiences of living with HIV. Chapter Five presents the themes regarding the trauma of receiving their diagnosis, the impact of the diagnosis on their decision-making on several aspects of their lives, and the meaning they attached to those experiences. Lastly, Chapter Six discusses the themes, which reveal the challenges the women faced and how they coped with these challenges.

Chapter Seven features the discussion of the key findings presented in the previous three chanpters and how they relate to or contest the current literature on the topic.

Finally, the conclusion includes a reflection on the methodology, a consideration of the strengths and the limitations of the study, followed by recommendations and suggestions for future related research in Malawi.

1.7 CONCLUSION

This chapter presented an overview of the study, particularly regarding the context of HIV in Malawi and the rationale for utilising a qualitative approach. The next chapter critically analyses existing literature on women and HIV in order to delineate what has been done in the research area and to establish the gaps that the current study intends to address.

CHAPTER TWO:

LITERATURE REVIEW

One of the best ways to fight stigma and empower HIV-positive people is by speaking out openly and honestly about who we are and what we experience.
- Alex Garner, HIV activist -

2.1 INTRODUCTION

The purpose of this chapter is to report on research that is relevant to the experiences of WLHIV and to highlight the gap that the current empirical study aims to address. In other words, the chapter also aims to contextualise the study by discussing pertinent literature. Because the literature review documents multiple and intersecting adversities and forms of discrimination that many HIV-positive African women face, the chapter includes a description of intersectionality (Crenshaw, 1989) towards the end of the review. The description of intersectionality has been incorporated to help highlight the multiple issues women face and illustrate the complexities of the experiences of WLHIV.

As pointed out in the introduction, the broad aim of the study was to gain understanding of the lived experiences of women diagnosed with HIV and attending an ARV clinic in Southern Malawi.

This is a narrative literature review, which, according to Bryman (2012), is less focused and wider ranging than a systematic review. Systematic reviews are normally well suited for clinical studies and usually require two or more reviewers (Schlesselman & Collins, 2003). They involve explicit methods for the search procedures used to find eligible studies to answer a very specific research question. Narrative reviews, on the other hand, aim to cover a wide range of issues within a given topic but do not necessarily follow the rules regarding the search for evidence (Collins & Fauser, 2005). I chose a narrative review because it suits the exploratory aims of the study.

Various online databases and search engines were used to identify relevant research articles. Although not exhaustive, the review materials included peer-reviewed published journal articles, reviews, and empirical studies, as well as government and international reports. The researcher conducted literature searches periodically throughout the process of proposing the study, collecting and analysing data, and writing up the thesis.

Important to note is that while there is little literature about HIV and women in Malawi, there is much more literature that is relevant when the scope of the search is expanded to include studies from other, similar, African countries and also in other developing countries in the Global South. While one must be careful of assuming that these findings apply equally to Malawi, it is both useful and necessary to include studies from other countries to attempt to understand the experiences of women who are living with HIV in Malawi. Sometimes, when necessary and relevant, research conducted in developed contexts is also described. While there are likely to be experiences unique to Malawian women, there are also likely to be experiences regarding living with HIV that are common to women in sub-saharan African countries, and common to women around the world. Therefore, though this review draws from literature from around the world, local and near-local studies, where these exist, are prioritised.

Before presenting the review, two points should be made about the dominant literature on HIV and women. Firstly, research with WLHIV is largely on the biomedical aspects of the illness, while the subjects are rarely given a voice to narrate their experiences. This observation is not made without regard for the very significant contribution biomedical research has made to medical interventions that have improved the lives of WLHIV. However, listening to their voices puts the women at the centre of research and captures the psychological aspects of living with the illness and the socio-cultural context in which the illness occurs, as well as aspects that biomedical research may not access.

Secondly, the existing studies are predominantly quantitative in nature, which inevitably omits the women’s experiential accounts. The existing qualitative studies investigate lived experiences as a secondary aim, and, thus far, there has been no research to investigate the lived experiences of WLHIV in Malawi using the IPA approach with an intersectional framework.

In the literature review, I attempt to demonstrate and focus on how WLHIV might be experiencing a host of overlapping challenges associated with their HIV diagnosis. Literature was drawn from different disciplines and was reviewed under four main themes, which categorise the overlapping challenges WLHIV face namely:

a) Stigma and discrimination;
b) Violence and HIV;
c) HIV and mental health; and
d) Sexual reproductive health (SRH) needs of WLHIV.

2.2 STIGMA AND DISCRIMINATION

Perhaps the major challenge of living with HIV is the stigma surrounding the illness. This is particularly true for WLHIV, because of their socially disadvantaged position in society and their lack of power to challenge or resist stigma and discrimination (Campbell, Nair, Maimane, Sibiya, 2005). Stigma is defined as an ideology that identifies and links the presence of a biological disease to negatively defined behaviours or groups in society (Deacon, 2005). Discrimination, on the other hand is the actions that result from these negative beliefs which may discourage people at the receiving end of the stigma to access services and resources related to their condition (Deacon, 2005).

Stigma surrounding HIV comes in many forms and I will highlight what the different types are. According to Deacon (2005), stigma not only affects the person living with HIV, but also the people around the person and anything associated with them; what she called courtesy or secondary stigma. The people affected can be health workers, carers, or relatives. Layered stigma is when one experiences stigma because there is an already existing stigmatised condition, which makes an individual more vulnerable to stigma (Deacon, 2005). For example, individuals who have Tuberculosis may also be targeted with HIV stigma. Later in the thesis, I demonstrate that WLHIV are burdened with other identities which carry a stigma on their own, and an HIV status adds yet another layer to this.

Deacon (2005) further explains that there are different consequences of stigma amongst different classes of people. Individuals who are wealthy and can access adequate healthcare suffer less from stigma than an individual who is poor and has poor access to healthcare. It is also clear how one’s position in the society can expose one to experience intersecting stigma. For a woman who is not empowered, poverty may drive them into sex work, and if they are also HIV positive they will experience stigma as a sex worker and as a WLHIV (Deacon, 2005). Existing forms of disadvantage and stigma are interlinked and tend to occur where there are stigmatising conditions (Deacon, 2005). In Malawi, WLHIV assume multiple roles, such as being carers for relatives or their own children who are HIV positive. They thus experience secondary stigma and the fact that they are already marginalised and experience many disadvantages, also makes their stigma intersect with other forms of social exclusion.

Over time, stigmatised people tend to internalise the stigma, that is they start believing the social perception of themselves as blameworthy for having a disease and they start devaluing themselves (Deacon, 2005). Brown, Macintyre, and Trujillo (2003) define internalised stigma as the real or imagined fear of societal attitudes and potential discrimination borne out of a particular characteristic or disease (e.g., HIV), or association with a particular group or behaviour (drug user, commercial sex worker).

The stigmatised individuals typically react by isolating themselves and shunning social services because they fear being stigmatised and labelled further (Deacon, 2005). They may also avoid social encounters because they fear the inadvertent disclosure of their HIV status and discrimination (Deacon & Stephey, 2007). Fear of stigma also influences the decision to disclose one’s status because an HIV-positive status is central to one’s identity (Wekesa & Coast, 2013). Receiving a diagnosis of HIV infection disrupts the personal biographies of men and women with HIV and they have to redefine their biographies to accommodate the revelation of their diagnosis and deal with the stigma (Wekesa & Coast, 2013).

A description of HIV stigma is explained candidly in a moving memoir titled *Witness to AIDS* by one of the prominent AIDS activists in South Africa, Edwin Cameron (Cameron, 2005). As a person living with HIV since 1989, Cameron (2005) explains that the stigma of living with the virus is a greater fear to many than perhaps the fear of succumbing to an agonising death caused by the disease. Cameron (2005) further explains that the powerful and destructive effects of stigma are borne out of a combination of two forces, one from within (the person living with HIV) and one from external forces (society). Externally, stigma springs from the prejudiced, bigoted, fearful reactions others have to AIDS. Internally, it lies in the fears, the self-loathing, self-undermining, and ultimately self-destroying inner sense of self-blame that people with AIDS or HIV experience (Cameron, 2005).

In a survey with PLHIV in Cape Town, South Africa, it was found that PLHIV experienced internalised stigma which manifested itself as feelings of being dirty, shame, or guilt because of their status (Simbayi et al., 2007). Studies show that PLHIV who internalise HIV stigma experience greater depressive symptoms (Earnshaw, Smith, Cunningham, & Copenhaver, 2015). The shame and self-blame that they feel results in their remaining silent about their diagnosis and this challenges healthcare promotion because the individuals do not seek treatment and care (Duffy, 2005). Other impacts of stigma on the individual include loss of identity, isolation, loneliness, and loss of self-esteem, and may reduce health-seeking behaviours (Duffy, 2005).

Externalised stigma refers to the negative attitudes that others hold against stigmatised subjects, while enacted stigma is the actual experience of prejudice and discrimination (Jacoby, 1994). Some researchers make a further distinction between enacted and felt stigma. Enacted stigma refers to actual events of discrimination while felt stigma, similar to internalised stigma, refers to the shame associated with enacted stigma and the fear of encountering further enacted stigma (Scambler, 2004). A study with serodiscordant couples in three countries (Tanzania, South Africa, and Ukraine), for example, found that couples were subjected to stigmatising experiences such as name calling, gossip, and labelling (Rispel, Cloete, & Metcalf, 2015). Such stigmatising experiences present a dilemma whether to disclose one's status or experience stigma, although disclosure encourages others to reveal their HIV status.

Similarly, in Malawi, PLHIV fear stigma, and dread others knowing their HIV status. According to a 2012 study conducted by the HIV Leadership Through Accountability Programme and the Malawi Network of PLHIV (MANET+), HIV-related stigma is ongoing and acts as a barrier for PLHIV to access HIV treatment and healthcare services (HIV Leadership through Accountability Programme & MANET+, 2012). The PLHIV who participated in the study explained that they experienced social exclusion from religious gatherings or other activities. They also reported being physically and verbally harassed, losing their jobs, being forced to take HIV tests, and being pressured to disclose their status (HIV Leadership through Accountability Programme & MANET+, 2012).

From the gender dimension, research shows that HIV-related stigma impacts women's lives more than men's and that they experience more internalised and enacted stigma than men (Asiedu & Myers-Bowman, 2014). The fact that HIV is largely a sexually transmitted disease carries the negative connotation that women who are HIV positive are promiscuous. Women are labelled as prostitutes for their positive status, while men are usually spared such labels because society is generally far more tolerant of promiscuity of men than of women (Parker & Aggleton, 2003). Women also experience stigma from health workers, and fear disclosure of their status and discrimination from community and family (Colombini, Mutemwa, Kivunaga, Moore, & Mayhew, 2014). A study conducted with African women living in the

UK revealed that the women were faced with judgemental attitudes and were perceived as immoral in their communities because of their diagnosis (Ndirangu & Evans, 2009). Adding to these findings is a systematic review of 45 qualitative studies on the experiences of WLHIV from Canada, India, Uganda, Australia, and Thailand (Paudel & Baral, 2015). The authors observed that WLHIV who experienced high levels of stigma from friends, family, and the community blamed themselves and hesitated to seek treatment (Paudel & Baral, 2015). Another longitudinal qualitative study with 54 women from Kenya found that women who experienced stigma felt marginalised and unwanted by their communities and families such that they were cut off from community living, and thus felt disempowered (Kako & Dubrosky, 2013).

As mentioned, the ramifications of stigma and discrimination are enduring and potentially harmful especially to women’s health because stigma can pose a barrier to women accessing HIV services. A 2014 Canadian study found that women experienced poor-quality healthcare, such as lack of sufficient counselling connected to stigma which subsequently led to self-imposed isolation from healthcare services (Ion & Elston, 2015). The women experienced fear and shame of revealing their status and avoided support groups offered at hospitals. Women in this study also reported challenges of accessing care in settings outside HIV clinics because they felt stigmatised because of the harsh treatment they received during diagnosis (Ion & Elston, 2015). The findings resonate with a 2011 study conducted in India, which revealed that women who experience stigma in healthcare settings employed isolation as a coping mechanism, which limited their access to care (Lekganyane & Du Plessis, 2012). Specialised services such as family planning and postnatal services also present challenges for WLHIV because of the widespread stigma. Pregnant women may avoid counselling and testing after experiencing discriminating acts from hospitals (Monjok, Smesny, & Essien, 2009). The stigmatising attitudes they experience from healthcare providers negatively influence their reproductive decision making (Saleem, Surkan, Kerrigan, & Kennedy, 2015). Fear of HIV stigma also limits women’s involvement in PMTCT. In a Malawian study, it was found that it is crucial to disclose one’s status to participate in PMTCT, but women were reluctant to disclose their status because they feared stigma, and the loss of economic support from their husbands (Flax, Hamela et al., 2017).

Although this is not an exhaustive account of the extensive literature on stigma and discrimination in PLHIV, the following conclusions can be drawn: HIV is a highly stigmatised condition with WLHIV experiencing more stigma because of their disadvantaged position in society. Stigma is often feared more than the actual diagnosis or course of the illness. Fear of stigma negatively affects women's access to care and HIV services, because gaining access to care requires disclosure of ones' status. Disclosure can increase stigma, but on the other hand, it can also bring social support (Kalichman, 2003).

The current study reveals how the women describe their experiences of HIV stigma and discrimination in particular; the forms of marginalisation WLHIV are subjected to in their communities and the narratives that reinforce the stigmatising attitudes. In the following section, I discuss gender-based violence (GBV) as another pressing challenge that WLHIV face globally.

2.3 VIOLENCE AND HIV

Another challenge facing WLHIV worldwide is gender-based violence (GBV). The United Nations Convention on the Elimination of all Forms of Discrimination against Women (CEDAW, 1979), in Recommendation 19, defines GBV as "violence being directed against a woman because she is a woman or that affects women disproportionately". It has been noted that women who experience violence are more likely to acquire HIV, and WLHIV are more likely to be subjected to GBV (Dunkle et al., 2004). A systematic review of studies from the United States of America (USA), Brazil, East Africa, and India showed that there was a significant association between intimate partner violence (IPV), sexual and psychological violence, and HIV infection (Li et al., 2014). Moon (2007) argued that because women need physical security before they can protect themselves from HIV, a woman who is experiencing violence cannot refuse sex or demand protection, so in this case, the violence directly prevents the woman from preventing HIV and increases her risk. An increase in HIV prevalence in the general population also directly results in the increased risk of violence against women and the risk of spousal violence (Chin, 2013).

A 2012 review of studies on GBV and HIV noted three ways in which GBV and HIV are linked (Dunkle & Decker, 2013). Firstly, sexual assault is associated with higher risk of transmission because there is higher likelihood of broken skin with a violent assault than with consensual intercourse (Draughon, 2012; Dunkle & Decker, 2013). Secondly, women who are exposed to violence are at high risk of HIV because men who are violent usually engage in high-risk sexual behaviours themselves and are often HIV positive (Dunkle & Decker, 2013). Thirdly, violence disempowers women, diminishing their ability to negotiate when sex happens and the circumstances surrounding it (Dunkle & Decker, 2013).

In South Africa, assault, violence, and coercive sex are common occurrences in relationships (Wood & Jewkes, 1997; Wood, Maforah, & Jewkes, 1998). Males use violence as a form of control and women stay in the relationships because they fear more violence. Girls who experience sexual abuse have an increased likelihood of risky sexual behaviours in adulthood because of the psychological trauma from the experience (Van Roode, Dickson, Herbison, & Paul, 2009). Sexual violence in early childhood has also been associated with an increased life-time risk of Sexually Transmitted Diseases (STDs) (Reza et al., 2009).

IPV has also been associated with a decrease in adherence to ART medication during and after pregnancy (Yee et al., 2018). In a Zambian study, women who experienced violence showed suboptimal adherence to ART drugs and PMTCT protocols during pregnancy (Hampanda, 2016). Similarly, a South African study conducted in antenatal clinics found that IPV was associated with poor access to PMTCT and secondary HIV-prevention measures (Hatcher et al., 2014). Taking medication and accessing HIV services sometimes alerted the women's spouses to their diagnosis and this could trigger violence because some men believed that the woman was bringing the disease into the relationship. Thus, many women shunned HIV services altogether (Hatcher et al., 2014). Even with access to treatment, some women were inclined to discard their medications because they feared that if their husbands discovered that they were on medication, they would accuse them of infidelity and become violent (Zunner et al., 2015).

Indeed, such abuse affects women's emotional, psychological, physical, and spiritual wellbeing (Mazonde & Thurston, 2013). Current research seems to suggest that the emotional abuse that WLHIV suffer from because of exposure to IPV is associated with a faster rate of decline of cellular immunity and accelerates the deterioration of health (Jewkes, Dunkle, Jama-Shai, & Gray, 2015). In other words, stressful events, in this case IPV, negatively affect the health of WLHIV. A Malawian study interviewed 12 women from clinics and the women reported experiencing emotional abuse from their partners because of their HIV status. (Chilemba, Van Wyk, & Leech, 2014). The authors found that men abandoned women and blamed them for the infection and the women were psychologically damaged because of the humiliation they suffered from having their status revealed and being labelled immoral (Chilemba et al., 2014). For the women in this study, the interviews were the only outlet to describe their experiences of emotional abuse because, unlike physical violence, emotional abuse is not visible.

One of the reasons why WLHIV experience violence from their partners is due to their disclosure of their status. Shamu, Zarowsky, Shefer, Temmerman, and Abrahams (2014) investigated the link between the disclosure of HIV status of pregnant WLHIV and the link with IPV. The study found that there was a high risk of physical, sexual, and emotional IPV before disclosure and a high rate of negative reactions from partners immediately after disclosure. Because of fear of violence, WLHIV may be hesitant to disclose their status, seek HIV services, and subsequently not receive treatment (Shamu et al., 2014)

Cultural beliefs about the status of women in society also seem to contribute to tolerance of GBV. For instance, in Malawi, violence against women is very common and appears to have increased in recent years despite intensified campaigns and legislation against it (NSO, 2010). This is the case because violence is considered acceptable according to Malawi customary law, which allows men to exercise their authority within the household (Mkandawire, 2009). The Malawi National Gender Policy (2012-2013) indicates that incidents of violence in Malawi are usually perpetrated by the women’s husbands, boyfriends, or intimate partners (Ministry of Gender, Children and Community Development of Malawi, 2011).

The common perception of GBV in Malawi is that it is essentially a domestic issue, which should be resolved within the family or community, a view which contributes to the serious gap in public policy making and the resultant responses at community level of stiff legal punishment for its perpetrators (Mkandawire, 2009). Deep rooted patriarchal beliefs position women in an inferior position to men such that events in the home, such as talking back to the man, not having food ready on time, failing to care adequately for the children or home, refusing sex, questioning the man about financial issues, and expressing suspicion of his infidelity can trigger GBV (Mkandawire, 2009). The women themselves buy into this oppression by holding cultural beliefs that endorse violence against women (Small & Nikolova, 2015). For example, many women believe it is acceptable for a man to beat a woman if she does not obey her husband, refuses sex, or burns food. This violence, as already noted, renders many women powerless and puts them at a greater risk of HIV exposure (Small & Nikolova, 2015). Women also fear the social stigma that comes with being “the wife who did something wrong”, yet they also fear incriminating their husbands, who are usually the bread winners, while leaving the abusive home may mean loss of financial support and opportunities to rebuild their lives (Mkandawire, 2009).

Gender inequalities also play a role in this toxic interaction between violence and HIV risk. Relationship power inequity and IPV co-occur in relationships and increase the incidence of HIV infection (Jewkes, Levin, & Penn-Kekana, 2003). A study conducted in the USA exploring the psychological, personal, and cognitive factors that contribute to IPV among WLHIV found that abuse was a result of power dynamics in the relationship (Njie-Carr, 2014). The men in the study reported that they physically abused their wives because they had to assert their power as decision makers in the relationship when they were confronted with challenges to their status. On the other hand, increased power in the relationship has been found to be protective against forced sex and transactional relationships and lessens incidents of violence (Conroy et al., 2016). Considering the low socio-economic status of women in Malawi, as described in the introductory chapter, it is likely that gender inequality puts them at risk of violence because it limits their agency and power in relationships. In the current study the women narrate in their own words their lived experiences of how the power dynamics in their relationships, their subordinate position in the communities and their HIV status work together to create this vulnerability to violence.

Despite the high vulnerability of women to sexual violence, the socio-legal, political, and economic forces in Malawi are not conducive to the protection of women against sexual violence (Kathewera-Banda et al., 2005). There are few safe spaces or settings where abused women can support each other, nor research groups which provide them with the fora to talk about their experiences. For example, Mkandawire-Valhmu and Stevens (2009) conducted focus group discussions with women in Southern Malawi and found that the focus groups acted as a forum for encouraging dialogue and supported the collective agency of women who had experienced abuse, an opportunity to speak about their experiences that had not been available to them before.

Little has been done to successfully curb GBV and manage HIV transmission. A report by Gibbs, Mushinga, Crone, Willan, and Mannell (2012) concluded that HIV-prevention programmes do little to integrate measures to prevent GBV. The authors reviewed the National Strategic Plans (NSPs) of 20 countries in Southern and East Africa and found that very few included primary prevention and reduction strategies for GBV. The NSPs of the 20 countries lacked relevant research outputs to inform their responses to GBV, with most research leaning towards the biomedical aspects of the illness.

It seems that there are a number of factors, namely cultural norms, patriarchy, gender inequalities, and lack of support, that interact and sustain the existence of GBV. Given that women in Malawi live with multiple gender inequalities and oppressive cultural norms, it was deemed important to understand how WLHIV in particular experience GBV, the context in which the GBV occurs and how they attempt to exercise agency against these constraints. So far, no study exists that collates the lived experiences of GBV for WLHIV in Malawi. One notable study which investigated experiences of violence in WLHIV only highlighted the broad categories of the types of abuses the women experience and factors that contributed to the women's vulnerabilities to GBV (e.g., Kathewera-Banda et al., 2005), but the life stories of the women and the contexts in which the violence occur were not captured.

I now move on to discuss the mental health impact of HIV infection on PLHIV, and specifically, how WLHIV suffer the burden of disability due to the stresses of living with HIV.

2.4 HIV AND MENTAL HEALTH

In relation to the current study, it is important to examine the relationship between mental health and HIV infection in order to appreciate the women's psychological experiences after the diagnosis, how they cope with the trauma of their diagnosis, and other psychosocial challenges associated with their status. And also, to establish that HIV is not only a physical medical condition, but like any other chronic illness, affects mental health, hence the need to ensure appropriate psychosocial interventions for those living with the virus.

According to the WHO Constitution, health is defined as “complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity” (WHO, 1948). Mental health in relation to PLHIV is used, in its broad sense, as not merely the absence of mental illness, but a state of wellbeing, free from psychological distress, where the individual can cope with the normal stresses of life, can work productively and fruitfully, and be able to make a contribution to his or her community (WHO, 2013a). There is a dearth of research on the bidirectional effects mental illness and HIV have on each other, with much less known in sub-Saharan Africa, although significant research has been conducted in developed countries (Breuer, Myer, Struthers, & Joska, 2011).

It has been established that people with HIV have a higher chance of developing mental health disorders compared with those suffering from other chronic conditions (Abiodun, Lawal & Omokanye, 2018). Published research shows that the most common mental disorders in PLHIV are depression, alcohol use disorders, and neurological disorders (Chibanda, Benjamin, Weiss, & Abas, 2014). The prevalence of depression and anxiety is high in HIV patients (Mello, Segurado, & Malbergier, 2010; Adeoti, Dada, Fadare, 2018). In a sample of mothers who were attending a child health clinic in a rural district hospital in Malawi, common mental problems such as depression were found to be associated with mothers with HIV (Stewart et al., 2010). Higher levels of depression were also reported among rural Ugandan HIV-infected women (Hatcher et al., 2012). Similar results were found in a study conducted in India (Unnikrishnan, Jagannath, Ramapuram, Achappa, & Madi, 2012). Suicidal ideation and suicide attempts have also been reported in WLHIV (Cooperman & Simoni, 2005). If left unattended, mental health problems have the potential to negatively affect clinical outcomes, wellbeing and quality of life (Kapetanovic, Dass-Brailsford, Nora, & Talisman, 2014). Other psychological issues that PLHIV face while coping with the illness include denial, loss, grief, guilt, anger, low self-esteem and suicidal behaviour (Bezuidenhoudt et al., 2006). In the following sections, I describe the different ways in which HIV as a chronic condition negatively impacts mental health.

2.4.1 Stresses of living with HIV

PLHIV are more likely to suffer from mental illness because of the challenges of adjusting to the stress brought about by the illness (WHO, 2008). According to Lazarus and Folkman (1984, p. 19), stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources, which endangers their wellbeing. Mental health problems can arise at the point where the person receives a diagnosis and when the physical symptoms from opportunistic infections start to develop, which cause their health to deteriorate and increase stress (Catalan et al., 2011). The anticipation of being tested for HIV to know one's status also triggers feelings of anxiety and fear, marked by uncertainty and ambivalence (Kaler & Watkins, 2010). Perceived risk of HIV infection brings about fear and uncertainty about health, worries about economic conditions, social support, and HIV-related stigma (Hsieh, 2013). Given the demanding nature of the ARV drug regimen and lifestyle changes one needs to adapt to, the decision to begin treatment itself may cause much pressure and distress to an individual (Kalichman & Ramachandran, 2002).

The self-monitoring of one’s health needed for ARV adherence can also increase health anxiety (Boulind, 2014). PLHIV with families worry about their children’s future if they should become critically ill and die, and the economic challenges of taking care of their children (Gombachika, Sundby, Chirwa, & Malata, 2014). The stress from the human rights violations which PLHIV experience also has a negative psychological impact on them. The findings of a study conducted in Malawi revealed that PLHIV felt depressed, lived with anxiety, were frustrated, and felt sorry for themselves when their right to privacy was violated by the way their positive statuses were disclosed (Malera, 2012). Diminished social support from family, friends, and community and the stigma that follows also cause significant distress to the individual with HIV (WHO, 2008). Indeed, the effects of HIV stigma on people’s mental health are very significant. A Nigerian study by Adewuya et al. (2009) showed that a little over a quarter of their sample met the then diagnostic criteria for PTSD following intense experiences of HIV stigma.

One way to fully capture the mental health effects of HIV infection is to assess the broad impact on people’s quality of life. The concept of quality of life encompasses multidimensional subcategories, which include life satisfaction, wellbeing, happiness, economic indices, and meaning (Bagwell, 2016). In relation to measuring health quality of life, questionnaires often measure various subcategories related to general health and wellbeing such as limitations in physical and social activities, limitations in usual role activities because of physical health problems, bodily pain, poor mental health, and emotional problems (Bagwell, 2016). Research shows that PLHIV have significantly lower quality of life and lower physical and mental health and social functioning, which further deteriorate as the disease progresses (Fan, Kuo, Kao, Morisky, & Chen, 2011). Quality of life is usually impaired after an HIV diagnosis due to feelings of uncertainty of longevity, fears about the illness, and fear of suffering from stigma and discrimination (Wig et al., 2006). An earlier study in Angola by Bernatsky, Souza, and De Jong (2007) found that HIV-positive pregnant women scored significantly higher on the General Health Questionnaire (GHQ-12) than the controls, indicating lower quality of life and poorer mental health. Delineating the reasons for low quality of life and poor mental health in WLHIV is a review of studies regarding mental health services of poor HIV-infected women in sub-Saharan Africa (Brandt, 2009). The findings revealed that women experienced multiple roles in relation to the HIV epidemic - for example, caring for the sick - and they also experienced social implications of living with the illness, such as stigma. This puts them at high risk of mental health problems, particularly depression (Brandt, 2009). Quality of life is also diminished in WLHIV who experience abuse and violence. WLHIV who experience GBV exhibit mental health problems such as anxiety, post-traumatic stress symptoms, suicidal thoughts, low self-worth, guilt, concentration difficulties, and emotional distress (Zunner et al., 2015; Glémaud et al., 2014). Other forms of abuse which diminish quality of life and pose a threat to mental health, that WLHIV experience include forced and coerced treatments, judgemental attitudes from health workers, and lack of SRH choices (Orza, Chung et al., 2015).

Quality of life and better mental functioning in PLHIV can be improved with better management of the illness and thus improved coping. It is helpful to start by describing the self-management of chronic illness before considering the specific challenges of living with HIV. According to Lorig (1994), self-management of chronic illness means having the skills to deal with the illness, skills to continue with normal everyday life, and skills to deal with emotions. Self-management entails using skills to manage the work of dealing with an illness while managing to continue with one’s daily life activities and managing the emotions brought about by chronic illness (Lorig, 1994, p. 13).

A qualitative meta-synthesis analysed studies that described processes of self-management in chronic illness (Schulman-Green et al., 2012). The results developed three categories of self-management, namely (a) focusing on the illness, (b) activating resources, and (c) living with chronic illness. The process of focusing on the illness involves individuals learning about the needs of their illness, taking ownership of their health needs, and performing health-promoting activities. The resources needed for optimal self-management include family members, health providers, and friends to assist individuals to manage financially, psychologically, and spiritually (Schulman-Green et al., 2012). The self-management process of living with chronic illness also involves tasks and skills related to coping with the illness and growing as a person. This involves the processes of expressing and exploring various emotions, adjusting and coming to terms with the illness, and meaning-making, which involves efforts to determine the meaning of the illness by revaluating one’s life (Schulman-Green et al., 2012). Swendeman, Ingram, and Rotheram-Borus (2009) developed an integrative framework of HIV self-management. The authors identified 14 elements in chronic disease self-management, which were categorised in three broad activities, namely (a) physical health, (b) psychological functioning, and (c) social relationships. Physical health elements were health-promotion behaviours, treatment and adherence, self- monitoring of physical states, prevention of transmission, and accessing proper treatment and services. Psychological functioning elements included self-efficacy and empowerment, cognitive skills, reducing negative emotional states, and managing identity shifts. Social relationship elements included collaborative efforts with healthcare providers, social support, disclosure and stigma management, and positive social and family relationships (Swendeman et al., 2009).

When one considers the complexity of managing HIV as an illness, the challenges WLHIV face, such as stigma and violence, may render it difficult for them to manage the illness well. Components of managing the illness, which, for example, require support, show that successfully managing HIV as an illness does not depend solely on individual effort, but also largely depends on the environment. One may be physically well and functioning psychologically, but if social relationships are hostile and unwelcoming, as in the case of WLHIV who are stigmatised and subjected to violence, this may prevent successful management of the illness. The current study brings to light the social context in which women experience HIV and how the women compensate for the unavailable resources needed to manage their health effectively.

Next, I describe the types of coping strategies, namely problem-focused coping and emotion-focused coping that may be employed to enhance one’s quality of life when living with chronic illness. Problem-focused coping strategies aim to define the problem, find a number of solutions, weigh the options in terms of the most effective, choose among the options, and act on them (Lazarus & Folkman, 1984). Emotion-focused coping strategies involve cognitive processes directed towards the reduction of psychological distress. An Iranian study explored the coping strategies of HIV-infected patients and found that they employed both emotion- and problem-focused coping strategies (Mahmoudi, Dehdari, Shojaeezadeh, & Abbasian, 2015). In the study, in the problem-focused category, the strategies used were adherence to medication in order to stay healthy, participating in education sessions, and trying to impose condom use on their husbands. To deal with economic challenges, some started small businesses. Emotion-based strategies that were employed include isolation and avoidance of the sources of stigma (Mahmoudi et al., 2015).

Research indicates that receiving support is one of the main coping strategies for PLHIV as those who had been part of a support group were less likely to have a mental disorder than those who had not been part of any support group (Freeman et al., 2007). Support groups are beneficial in mitigating the impact of stigma and discrimination and provide opportunities for the safe disclosure of one’s HIV status (Paudel & Baral, 2015). Support groups are also a coping strategy because when PLHIV congregate in these groups, they feel less isolated and decrease feelings of shame as they share similar experiences (Paudel & Baral, 2015). As an intervention, support groups are expected to have a high impact on morbidity and retention in HIV care and a moderate impact on mortality and quality of life of PLHIV (Bateganya, Amanyeiwe, Roxo, & Dong, 2015).

Peterson (2010) noted that although social support is key to coping with HIV, women lacked the resources needed to receive the support. In the qualitative study with 45 women living in the USA, the author identified that the women experienced depression, anxiety, and low mental functioning but could not receive support because they feared stigma and interference from their relatives. The lack of support is exacerbated by the burden of HIV care that women take on in the communities. For example, HIV-positive married women find themselves taking care of their sick husbands, often supporting their physical needs at the expense of their own health (Edwards et al., 2011). Women also lack informational support in the form of provision of guidance about HIV. An exploratory study with women in a South African clinic reported that the women lacked information about the basic pathology of HIV, how it impacts their health, the modes of transmission, and how they could protect themselves, including the use of ARVs (Thompson, Havenga, & Naudé, 2015).

Where there is lack of support, evidence suggests that women rely on individual coping strategies. A study in Uganda revealed the emotion-focused coping strategies that women employed after an HIV diagnosis (Medley, Kennedy, Lunyolo, & Sweat, 2009). To cope with stigma, the women in the study reported avoiding those who made unpleasant remarks about their status and chose to isolate themselves from the community. This is similar to findings of a South African study conducted in a work setting with ten employees living with HIV, where the participants reported that they isolated themselves and withdrew socially to avoid comments about their status (Judgeo & Moalusi, 2014). Isolation may be employed as a coping mechanism in PLHIW who do not receive sufficient support – which, paradoxically, is likely to put people at greater risk of depression and further erode remaining social support (Cacioppo, Hawkley & Thisted, 2010).

A focus on individual coping strategies is unlikely to be helpful if a country does also not provide a safe and secure legal, social and health context. For instance, Malawi offers little by way of mental health support to individuals because of financial constraints, with the bulk of resources poured into research and interventions in physical health conditions such as Malaria and Tuberculosis (Udedi, 2016).

This discussion of coping and support highlights that HIV is not only a medical problem and, while provision of ARV's has proven benefits, psychosocial interventions which strengthen the coping mechanisms of individuals are deemed to contribute significantly to the success of fighting HIV and mitigating the mental health impact of the illness.

As explained in the introduction, the study focuses on women for a variety of reasons: they are generally poorer than, being less empowered economically and therefore at risk of marginalisation. Women also are likely to experience GBV, while an HIV infection carries a visible stigma for them. Thus, the burden of mental disability is more significantly experienced by women because they have more risk factors for developing mental health issues. Surveys such as those conducted by Orza, Logie et al. (2015) show that, for women, receiving an HIV diagnosis precipitates mental health problems such as depression, sleep problems, shame, and self-blame in women. Women experience psychological and emotional suffering after diagnosis and the challenges of living with the HIV stigma also bring about feelings of anxiety, loneliness, isolation, and, subsequently, depression and suicidality (Peltzer, Ogawa, Tusher, Farnan, & Gerkovich, 2016). A number of studies have examined the experiences of women upon receiving an HIV diagnosis which reveal the psychological impact of the revelation (e.g., Alomepe, Buseh, Awasom, & Snethen, 2016; Kako et al., 2011; Lingen-Stallard et al., 2016; Ransom, Siler, Peters, & Maurer, 2005). Women report that receiving the diagnosis is a traumatic experience for them as they struggle with limited resources while experiencing stigma (Alomepe et al., 2016). In another study, women reported experiences of shock, anger, and fear, as well as suicidal thoughts on receiving their diagnosis, which occured mostly due to the illness of a husband or child (Ransom et al., 2005). For these women, HIV testing caused much anxiety as they worried about confidentiality and stigma, in addition to what the future held for them (Ransom et al., 2005). A UK-based study using in-depth interviews found that to cope with the diagnosis, women participants commonly reported that they initiated self-imposed isolation while keeping the diagnosis secret and focusing on their children (Lingen-Stallard et al., 2016). A Kenyan study by Kako et al. (2011) reported that women particularly struggle to accept that the source of infection is their husband. Thus, accepting the diagnosis comes much later and they eventually disclose their status. It is important to note that if these reactions to diagnosis are true for a well-resourced context where counselling support is available (e.g., Lingen-Stallard et al., 2016), the implications might even be greater for women living in developing contexts, like Malawi.

What is clear thus far is that receiving an HIV diagnosis involves dealing with an array of emotional struggles that can pose a threat to ones' quality of life. There is a need to have the skills to manage the illness and this requires employing coping strategies and receiving psychological support. With WLHIV in Malawi, no research has yet documented what WLHIV experience during their diagnosis, how they process the trauma of their diagnosis, and how they eventually find meaning in living with HIV.

Issues of motherhood and childbearing also bring about stress for WLHIV. In many African societies, a woman's feminine identity is bound to her capacity to bear children; hence, reproduction and motherhood are celebrated and considered a social passport (Nguessan, 2010). Evidence suggests that, for WLHIV, childbearing decisions, fertility choices, pregnancy, and motherhood experiences present psychological challenges as they struggle to reconcile their HIV status and motherhood. Sanders (2008) conducted a phenomenological study with nine HIV-positive women living in the USA to investigate the meaning of pregnancy and motherhood. The women reported feelings of emotional distress after diagnosis, stigma, and emotions related to pregnancy and childbirth. The experience of being pregnant and HIV positive left them feeling isolated and anxious about what motherhood might bring. The women also felt ambivalent about the pregnancy because they were engulfed with fear, not only for their own health but also for that of their unborn children who may too become infected (Sanders, 2008). In addition, they felt stigma because of the way health workers managed them. In the same vein, a study on pregnant WLHIV in Thailand found that after child birth, the women experienced stigmatisation, depressive symptoms, and suicidal ideation (Ross, 2013). Similar findings were reported by Kelly, Alderdice, Lohan, and Spence (2013) in a study with ten women receiving maternity care in Ireland. The study focused on women's interactions with midwives and found that the women felt anxious, not because of being HIV positive and pregnant, but because of negative interactions with the staff (Kelly et al., 2013).

Pregnancy and childbirth has also been found to cause trauma and guilt in WLHIV, especially during the ongoing testing of the infant to ascertain whether they are free of the infection (Shannon, 2015). In Shannon's descriptive study with 45 HIV-positive mothers, the author reported that the women in the study found the experience of living with HIV and being pregnant challenging; in particular, the women found watching their child being tested psychologically distressing (Shannon, 2015). Motherhood concerns of WLHIV also revolve around disclosure of their status to their children. McDonald (2013) conducted interviews with 34 Australian mothers with HIV who were diagnosed during their childbearing years. The experience of disclosing their status was a complex decision because, on the one hand, they felt the children had to know, and on the other, they did not want to burden the children with anxieties and worries about their health. Some mothers disclosed their status partially, by mentioning that they had a chronic illness, while some chose not to discuss the diagnosis at all to protect the children from worry and stigma (McDonald, 2013).

Because of these negative emotional experiences, WLHIV often decide against having children because of other anxieties which include fear of their own death (Gogna, Fernández, Di Corrado, & Obiols, 2013; Lazarus, Struthers, & Violari, 2013; Yeatman & Trinitapoli, 2013). Oftentimes WLHIV who already had children express no desire to have more children mainly because they fear infecting the child in the case where prophylaxis may not work (Lazurus et al., 2013). In a study with Argentinian WLHIV, Gogna et al. (2013) found that the women feared leaving orphaned children should they die and planned to be sterilised in order to prevent pregnancy so that they did not have more children. Another study conducted in rural Malawi uncovered the reasoning behind the fertility desires of WLHIV (Yeatman & Trinitapoli, 2013); those who did not have any children did wish to have a child, while those who already had one or more children decided not to become pregnant again.

It appears that for WLHIV, normal life experiences such as pregnancy bring about worries and anxieties about their own health, and the health of their unborn child, adding to the stresses of living with HIV. The diagnosis influences their reproductive decisions due to fears of infecting the unborn, and they dread the task of having to disclose their status to their children in the future. The current study captures, in nuanced detail, such deeply personal experiences about how their perceptions about themselves change as they learn to manage conflicting emotions about being a WLHIV and motherhood. It is only through allowing the women to narrate their personal stories that these experiences can be acknowledged as real.

2.4.2 HIV infection increases risk of mental illness

In addition to the stress of living with HIV, as a medical condition, HIV directly affects the central nervous system, which causes neuropsychiatric complications such as HIV encephalopathy, depression, mania, cognitive disorders, and dementia (WHO, 2008). In a study conducted in Malawi, symptomatic neurocognitive impairment, mild neurocognitive disorder, and HIV-associated dementia were detected in a sample of adults with HIV (Kelly et al., 2014). Immunosuppression, ART, and neurological aspects of the illness have also been found to cause depression (Valente, 2003). Evidence also suggests that HIV/AIDS symptomatology and psychosocial stress pose a threat to behavioural and mental health (McIntosh & Rosselli, 2012). Continuous use of ARVs has also been found to cause significant side effects such as pain, anxiety, and fatigue (Doerfler & Goodfellow, 2016). The ART drugs themselves can cause neuropsychiatric symptoms. A Malawian study concluded that 60% of those put on Efavirenz, a medication commonly used as part of combination therapy for HIV treatment, may experience some form of neuropsychiatric side effects, which include anxiety, mood changes, nightmares, psychosis, and suicidal ideation (Drury, Gleadow-Ware, Gilfillan, & Ahrens, 2018).

2.4.3 Mental disorders increase HIV risk

According to the WHO (2008), mental health problems, including substance abuse disorders, are associated with a high risk of HIV infection and, later, poor adherence to medication. When mental, neurological, and substance abuse disorders are present in PLHIV, they affect treatment outcomes negatively by reducing adherence to ARV medication (Kaaya et al., 2013). Poor adherence may mean not taking the medication at all, or taking the medication at the wrong time and not attending clinic appointments (Kagee, 2012). Thus, a healthy level of psychiatric functioning is necessary to ensure treatment adherence.

Inconsistent engagement with HIV care is especially prevalent among vulnerable populations with mental health and substance abuse disorders (Michlig et al., 2018). Poor adherence is worrying because it impacts directly on physical health and causes declining health, which in turn causes more psychosocial distress. For instance, individuals with substance abuse disorders have difficulties adhering to treatment but also compromise their immunity because alcohol has a direct effect on the body (Hinkin et al., 2004). Psychosocial factors affecting compliance to drugs include the inability to cope with the stress of being diagnosed, experiences of stigma, poor interpersonal relationships with family, care settings, and the community at large, and medical regimens that are complicated and difficult to follow (Crespo-Fierro, 1997).

Psychopathology, including substance abuse and depression, increases the chances of risky sexual behaviour because of compromised judgement, which increases the probability of spreading the disease or becoming infected (Schadé, Van Grootheest, & Smit, 2013). A study in Malawi examined HIV prevalence, HIV service uptake, and HIV-related risk behaviours among patients with neuropsychiatric disorders attending a mental health clinic in Malawi (Lommerse, Stewart, Chilimba, Van den Akker, & Lund, 2013). The findings point to low uptake of both HIV services and preventive measures and ART compliance among the patients. Literature on the high risk of HIV infection for injection drug users has only recently been emerging (Reid, 2009). Injection substance abusers are at a high risk of infection because they not only share injection needles, but are more likely to engage in risky sexual behaviours (WHO, 2008).

A South African investigation into the attitudes of PLHIV towards psychiatric disorders showed that PLHIV hold negative views towards people with mental illness (Sorsdahl, Mall, Stein, & Joska, 2010). PLHIV not only showed low levels of awareness of mental health issues such as substance abuse and schizophrenia, but also had little understanding of the psychological nature of psychiatric disorders and existing treatments, and hence were less likely to seek treatment and care. In terms of health workers, there is often a lack of confidence and support from mental health professionals in caring for people with HIV/AIDS who have mental health problems (Chorwe-Sungani, Shangase, & Chilinda, 2014).

Perhaps the necessary focus on one’s physical health when HIV-positive means that attention to one’s emotional health is neglected. Additionally, the demands of coping with the stigma of being HIV-positive might mean that a person is less inclined to risk further stigma by acknowledging mental health challenges. So individuals might suffer poor mental health which in turn affects their ability to manage the illness. As yet, there exists no research documenting the mental health issues that may accompany living with HIV infection in women in Malawi. In this study, the women shared their stories before diagnosis and how their lives changed after the diagnosis, revealing the psychological challenges that living with HIV brings. This information, I hope, may bring to attention the need for prioritising psychosocial interventions in HIV care, especially for women. The next section discusses the challenges women encounter in the area of SRH.

2.5 SEXUAL REPRODUCTIVE HEALTH (SRH) NEEDS OF WOMEN LIVING WITH HIV (WLHIV)

Increasingly, HIV/AIDS has been recognised as an SRH issue, with several European governments revising their international policies to that end (Germain, Dixon-Mueller, & Sen, 2009). With the success of potent ARVs, many WLHIV enjoy a quality life and still desire to have children despite their diagnosis because medical technology makes it possible to prevent mother-to-child transmission (MTCT) of the virus (Abbawa, Awoke, & Alemu, 2015; Stanwood, Cohn, Heiser, & Pugliese, 2007). PLHIV have the right to form families but are sometimes discouraged from doing so (Bell, Mthembu, O'Sullivan, & Moody, 2007), with HIV-positive women in particular being more vulnerable to rights violations (Wilcher & Cates, 2009). One of the most significant threats to SRH rights of WLHIV is forced sterilisation. Forced or coerced sterilisation of WLHIV is still taking place despite existing human rights provisions (Zampas & Lamačková, 2011). A study conducted in four Latin American countries found that WLHIV experienced coerced and forced sterilisation from health workers (Kendall & Albert, 2015). The women in the study reported that they received pressure from health workers to be sterilised after receiving an HIV-positive diagnosis by being misinformed about the consequences of subsequent pregnancies and children's future health. Sterilisation was used as leverage for WLHIV to receive medical care and breast milk substitution for their infants (Kendal & Albert, 2015).

Coercive sterilisation of WLHIV has also been reported in African countries. In 2008, Namibia documented 13 legal complaints from HIV-positive women of coerced sterilisation in public hospitals (Patel, 2008). A study in South Africa revealed the experiences of 22 HIV-positive women who reported the physical, social, and emotional impact of forced and coerced sterilisation they experienced (Essack & Strode, 2012).

When seen in the light of the other challenges described in the previous sections, coercive sterilisation reflects the stigma that surrounds being HIV positive and motherhood. Coercive sterilisation is an invasion of women's bodies without their consent, inflicted because of their HIV status. The connotation of this permanent violation is that there are individuals who are considered unfit to conceive; a false notion when one considers that ARV medication and efforts to prevent vertical transmission do exist. Being considered unfit to be a mother and having one's body tampered with has the potential of impacting negatively on ones' psychological wellbeing. In this example, we can see how the challenges reproduce one another. HIV stigma results in human rights violations and human rights violations threaten mental health, which in turn may diminish quality of life of WLHIV more than living with the virus in their body.

Interventions that might improve the SRH rights of women with HIV include the provision and promotion of contraceptives as part of family planning and counselling during routine HIV services, ensuring early post-partum visits, and supporting HIV disclosure (Gay, Hardee, Croce-Galis, & Hall, 2011). However, it seems that WLHIV experience another challenge related to delivery of the service itself in accordance with their needs. Church and Lewin (2010) highlight that there is a need to address the needs of HIV patients, strengthen the link between SRH and HIV services and have health workers who understand the broad health needs of WLHIV. Research, however, shows that there is a lack of awareness of the sexual reproductive desires of WLHIV in HIV care services. The sexual reproductive needs and desires of WLHIV are not adequately addressed in healthcare because healthcare workers hold negative attitudes towards WLHIV, which deters the women from discussing their sexual reproductive intentions (Sofolahan & Airhihenbuwa, 2013). Health workers also discourage WLHIV from having children when they seek contraceptives to prevent pregnancy (Sofolahan & Airhihenbuwa, 2013).

Understanding healthcare needs and providing SRH information is important because it offers an opportunity for WLHIV, who do not wish to have a child, to have ready access to family planning services, and if they are already pregnant and do not wish to continue with their pregnancy, to be offered safe abortions (Wilcher, Cates, & Gregson, 2009). For women who wish to have children, lack of proper information can lead to anxieties over HIV transmission to their unborn children because of the conflicting health advice on safe contraceptive methods (Nduna & Farlane, 2009). WLHIV worry about how being on ARV drugs while pregnant might affect their child, childbirth, and postpartum recovery (Nduna & Farlane, 2009). Providing high-quality services is necessary to enable women to make an informed choice about whether to have children and to reduce HIV transmission by preventing unintended pregnancies and reducing the number of infants born with HIV (Mazzeo, Flanagan, Bobrow, Pitter, & Marlink, 2012). Routine counselling would also support WLHIV to plan their pregnancies, obtain information, and make informed choices about pregnancy planning and transmission prevention (McCall & Vicol, 2011).

A lack of empowerment, mentioned in the introduction section, may be a factor that makes it more challenging for the women to speak for themselves, or to ask for the information they need regarding their SRH. Noting this, one of the goals this research aimed to achieve was to allow women participants to re-count their SRH and experiences.

In the following sections, I consider the two issues concerning SRH affecting WLHIV in detail, namely: unmet family planning needs, and concerns about the safety of contraceptive use.

2.5.1 Unmet needs for family planning

I begin by describing the various types of contraceptive methods before discussing the family planning needs of WLHIV and the safety concerns of contraceptives for WLHIV. The contraceptive methods available for WLHIV are male and female condoms, hormonal contraceptives, intrauterine devices (IUDs), and diaphragms (McCall & Vicol, 2011). Male condoms are the most effective in reducing HIV transmission but have a high failure rate in terms of preventing pregnancy (McCall & Vicol, 2011). Hence, many women prefer other methods of pregnancy prevention. Consistent use of condoms is often a challenge for long-term or married partners because they carry the connotation of infidelity (Chimbiri, 2007). The female condom, on the other hand, is prone to errors of usage and is generally not freely available because it is costly (McCall & Vicol, 2011). Using contraceptives such as condoms not only helps in the prevention of HIV but also transmission of other STIs (WHO, 2017). Hormonal contraceptives include the oral contraceptive pill, contraceptive patches, progestogen-only pills, and implants, and are effective but they offer no protection against HIV transmission (McCall & Vicol, 2011). The most highly effective methods of contraception in preventing pregnancies are copper- and Levonorgestrel-releasing IUDs (McCall & Vicoll, 2011).

With regard to the efficacy, choice, and patterns of contraceptive use in WLHIV, Blanchard et al. (2011) reported a lack of availability of long-acting methods of contraception in sub-Saharan Africa, with the preferred methods being condoms and injectable methods. Condoms have been found to be effective in protection against HIV transmission, as already mentioned;

although the utilisation rate is considered low, while dual methods were found to be more effective in ensuring pregnancy prevention and other sexually transmitted diseases (STDs) (Enyndah & Enaohwo, 2012; WHO, 2017).

Despite this availability of contraceptives, evidence suggests that there is a high rate of unmet family planning needs. Unmet family planning needs refers to the lack of contraceptive use in women who want to postpone their next childbirth (WHO, 2017). According to WHO (2017), in the developing world alone, 214 million women who want to avoid pregnancy are not using any contraceptives for multiple reasons. One of them is the lack of a range of choice of methods, poor quality services, and limited access to contraception, particularly among young people. Women also fear side effects from using contraceptives, experience gender-based barriers and cultural and religious opposition (WHO, 2017). A Nigerian study found that 85% of the 400 women in their study who did not desire to conceive and have children did not use contraceptives because of misconceptions and fear of adverse effects (Ezugwu, Nkwo, Agu, Ugwu, & Asogwa, 2014). WLHIV tend to have a high need for family planning because they tend to alter their fertility wishes after diagnosis (MacQuarrie, 2015). Family planning for WLHIV helps in the reduction of unwanted pregnancies, which might result in HIV infected babies (WHO, 2017).

Malawi records one of the highest fertility rates in sub-Saharan Africa, with 26% of women of reproductive age not using family planning methods and having an average of five children per woman (Irani, Pappa, & Dindi, 2015). For women in rural Malawi, 45% of their pregnancies are unplanned (NSO, 2015a) mostly because they have difficulties accessing contraceptives (GOM, 2015). The 2012 Malawi Plan for the Elimination of MTCT (Ministry of Health Malawi, 2012) states that WLHIV in particular face challenges. This is because family planning services are provided within the normal service delivery setting, which may or may not be close to HIV clinic delivery points and are usually different from these entities due to infrastructure challenges (Ministry of Health Malawi, 2012). This is problematic because women shift from one department to the other, and as a result, they are forced to queue several times and many women give up in the process. There are also limited choices of contraceptive methods for women; as such the uptake of long-term contraceptive methods is low (Ministry of Health Malawi, 2012).

To address these challenges, current literature proposes integrating family planning into routine HIV services to ensure that HIV-positive women and HIV-positive men have better access to family planning services, and to involve men in the family planning decision-making process (Newmann et al., 2013). It is particularly important for men to be involved in reproductive health programming because the use of contraceptives such as condoms require male support in order for them to work (Nieves et al., 2015).

The other issues which contribute to WLHIV's unmet family planning needs is a lack of counselling or support for women who desire to have children and a lack of information about reversible contraception methods (Stanwood et al., 2007). A Ugandan study revealed that WLHIV experience challenges in obtaining information about counselling and about their reproductive rights, intentions, and desires (Ddumba-Nyanzi, Kaawa-Mafigiri, & Johannessen, 2016). The women in the study reported negative experiences with the healthcare workers and hence sought advice about contraceptives from their peers. The women also had difficulties understanding the information because the language used to deliver the counselling was too technical. They thus avoided discussing their childbearing decisions because it conflicted with the medical information that they received from the healthcare workers (Ddumba-Nyanzi et al., 2016). Even when there is high contraceptive use amongst WLHIV, there is usually a lack of family planning services offering variety of contraceptive choices tailored to women's individual needs (Kancheva et al., 2013). This might inadvertently exclude other women whose needs are not being addressed, such as WLHIV.

The proposed solution it seems is more counselling, as the evidence shows that WLHIV who receive quality information about contraceptive methods show a significant increase in the use of contraceptives from not using any at all (Magalhães, Amaral, Giraldo, & Simoes, 2002). A study in Malawi investigating the eligibility, preferences, and acceptance of IUDs with women attending an integrated HIV/ART clinic in Lilongwe, Malawi, found that women preferred IUDs after appropriate counselling, which substantiates the claim that promotion of specific contraceptives in WLHIV require education (Haddad et al., 2014). Similar findings were documented in a cross-sectional survey investigating levels of awareness of IUD contraceptive devices among WLHIV in South Africa. Initially, levels of awareness about the method were low, but the women were receptive to the use of IUDs after receiving explanations about the method (Todd et al., 2012; Credé et al., 2012). In Zambia, an intervention study with 18 407 women who were counselled about contraceptive use reported that 61% of the women successfully accessed contraceptives after the counselling (Chibwesha et al., 2011).

The omission of the personal stories of these women in research renders it difficult to fully discern the root causes of the reasons for unmet family planning needs. For instance, we do not know the nature of the relationships WLHIV have, which may be a deciding factor for whether one uses long acting contraceptive methods or short-term contraceptive methods or none at all. The nature of the relationship may also be oppressive and disempowering for the woman to assert and establish consistent contraceptive use with their partners. From what is evident from the literature so far about the lives of WLHIV, they live with multiple challenges such as stigma, violence in their relationships and disability. These interlinked challenges may be responsible for creating an environment of uncertainty about their future, and this lack of control over their own lives may result in a lack of control over fertility choices.

2.5.2 Safety of contraceptive methods among WLHIV

As mentioned earlier, the fear of side effects deters some WLHIV from using contraceptives. There is inconclusive evidence on the issue of contraceptive use safety; in particular fears that hormonal contraception might increase the risk of HIV infection and accelerate the disease progression have not been put to rest (Jacobstein & Polis, 2014). Concurrently, inconsistent evidence on the safety of contraception emerged from studies, with some studies backing the safety of contraceptives and others highlighting the dangers. For example, a Zambian randomised control study with a sample of 559 women found IUDs to be safe and effective but that hormonal contraception was associated with more rapid HIV disease progression (Stringer et al., 2007), while a review conducted by Castaño (2007) reported that IUDs were safe and reversible, had no drug interactions with ARVs, and did not appear to increase the transmission of HIV infection. Similarly, an analysis of the Demographic and Health Surveys (DHS) conducted between 2003 and 2006 in four African countries (Malawi, Kenya, Lesotho, and Zimbabwe), which found that using hormonal methods and the risk of higher HIV progression remained as low as 6% (Leclerc, Dubois-Colas, & Garenne, 2008). In a review paper on the interactions between HIV and hormonal and IUD contraceptives in WLHIV in sub-Saharan Africa, no concrete evidence was established regarding the risks of transmitting or acquiring HIV attributable to using contraceptive methods (Stuart, 2009).

After a 2012 technical consultation team of the WHO examined different research studies on the safety of contraceptive use and HIV risk, the evidence was deemed insufficient to justify changing the guidelines on the use of hormonal contraception by WLHIV. It was agreed that there should be a realistic balance between the theoretical risks of contraception associated with transmission of HIV, disease progression, and unwanted pregnancy (WHO, 2012). Since that time, more studies have emerged that support the safe use of hormonal contraceptives for WLHIV. One study concluded that although drug interactions are possible with some hormonal methods and ARVs, hormonal contraception is recommended for use by WLHIV without restrictions (Noguchi et al., 2015). A review of 22 studies on contraception and HIV risk found that the evidence did not support the association between the use of oral contraceptives and increased risk of HIV acquisition (Polis et al., 2014). In concurrence with this evidence are results from a recent longitudinal Zambian study with discordant couples that investigated the impact of hormonal contraceptive methods on HIV acquisition among HIV-negative women cohabiting with HIV-positive men (Wall et al., 2015). The results from follow-ups with the couples from 1994 to 2012 show that there was no association between hormonal contraceptive methods and HIV acquisition (Wall et al., 2015).

The use of qualitative interviews, such as those employed in the current study, allow the women to speak about these experiences in their own words and thus provide a more comprehensive understanding of how the use of contraceptives affects their bodies. For example, in a Ugandan study on lived experiences of using hormonal contraception, women described experiencing discomforts in using hormonal methods and eventually discontinued using them and lived with the uncertainty of unwanted pregnancy (Mwizerwa & Rozzano, 2011). Such experiential accounts with WLHIV may give insights into how they make decisions about contraceptive use based on their experiences and how they assess the risks of contraceptives in relation to their health status. Hence, the current study also includes in the interviews accounts of their experiences with contraceptive use as WLHIV.

The next section examines various challenges faced in the area of prevention of vertical transmission among WLHIV.

2.6 PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (PMTCT)

Sub-Saharan Africa is the region with the highest number of pregnant WLHIV in the world, and women are eight times more likely to be HIV positive than men (UNAIDS, 2014).

The efficacy of PMTCT which has greatly reduced MTCT has been well documented. New infections among children have been eliminated in the 22 priority countries that are home to about 90% of pregnant women with HIV globally (UNAIDS, 2013). Globally, 64% of pregnant WLHIV had received ARV medicines for PMTCT in 2012, compared with 59% in 2011 and 49% in 2009 (UNAIDS, 2013). In Malawi, an evaluation study on the impact of ARV regimens and maternal CD4 count on HIV reported that when PMTCT is administered properly, it significantly decreases the rate of vertical transmission (Kim et al., 2013). Facilitators of PMTCT include excellent quality of support services provided by clinics; for example, follow-ups by doctors on whether the women have a good understanding of the purpose of taking the ARVs throughout their pregnancy (Iroezi et al., 2013). The major challenge, however, for PMTCT in Malawi has been a lack of capacity to retain patients and reducing lack of follow-up (Ministry of Health Malawi, 2012). These findings emerged from a study conducted by Chinkonde, Sundby, and Martinson (2009), where in-depth interviews were conducted with 14 women who dropped out of PMTCT and 14 women who completed the programme. Women reported difficulties accessing treatment because of poor staffing in the clinics and lack of male support (Chinkonde et al., 2009). The other reason cited for dropping of out of PMTCT was fear of inadvertent disclosure from their frequent visits to the clinic and cessation of breastfeeding to start the child on formula. PMTCT drop-outs also had poor access to the services due to lack of transport (Iroezi et al., 2013).

While PMTCT is clinically effective, various socio-economic and socio-cultural barriers interfere with the delivery and adherence to the intervention. A critical review of 12 primary studies in Malawi and Nigeria identified that socio-economic factors, such as poor accessibility to PMTCT programmes, poor literacy, and poor awareness, impacted the ability to adhere to proper replacement feeding therapy necessary for the success of PMTCT (Okoli & Lansdown, 2014). In Malawi, guidelines for PMTCT are not suitable for women who are too poor to afford alternative infant formula after weaning their babies (Muheriwa, Chimwaza, Maluwa, Nyasulu, & Pindani, 2013). The main socio-cultural factors included stigma, discrimination, and cultural norms that put women in a position where they could not make their own decisions about their own health but relied on their husbands and extended family members (Okoli & Lansdown, 2014).

Another socio-cultural challenge to PMTCT is pressure from family members who seem to have a big influence on women’s health decisions. A Malawian study found that women faced challenges in deciding how to feed their infants because they were in a conflicted position to choose between what health experts recommend and their mother-in-laws who have influence over their lives (Ostergaard & Bula, 2010). The women were aware that exclusive breastfeeding is recommended in the first six months of a child’s life, but it was difficult for them to practise this because their mother-in-laws and their husbands often had more power over them. Incidentally, the same study also identified the poor nature of counselling the women received, with most participants citing inappropriate timing of counselling, which took place right after the HIV test and in a group setting when they were still confused about their diagnosis (Ostergaard & Bula, 2010).

Beliefs and practices that women hold also compound the challenges in the utilisation of PMTCT services in Malawi. Muheriwa et al.’s (2013) in-depth study found that the women held positive beliefs about the benefits of testing so that they knew their status in order to protect their babies; and that breastfeeding and taking Nevirapine protected the baby from the virus. In actual practice, the beliefs did not necessarily translate into better engagement with PMTCT services. Some religious beliefs also bar people from going to a hospital to access PMTCT services (Okoli & Lansdown, 2014). A recent qualitative study conducted in-depth interviews with 32 women attending an option B+ and PMTCT programme and 32 others who dropped out of the programme to follow up to ascertain their breastfeeding practices, specifically how participation in the programme influenced breastfeeding duration (Flax, Yourkavitch et al., 2017). The results from the thematic analysis found that the women who dropped out of the programme feared disclosure, stigma, and lack of social support. Their decision to wean their babies was influenced by worries about transmitting HIV to the child, while some women continued to breastfeed despite stopping taking ARVs (Flax, Yourkavitch et al., 2017).

The main issue working against WLHIV to utilize PMTCT services properly it seems are the already identified interrelated issues namely stigma, poverty, and lack of empowerment. Social cultural barriers such as cultural norms that subordinate women and render it difficult for them to make their own health decisions provide a glimpse into the context in which they experience the illness. The current study shifts the focus from looking at medical interventions like PMTCT as a stand-alone panacea for improving the lives of WLHIV, to appreciating the personal and contextual factors that make it difficult to advance the women’s quality of life. Specifically, how for WLHIV, their female status in their communities, define their health experiences and makes their lives more difficult than the medical condition itself. Compounding these existing challenges with PMTCT, are gender related factors, which I detail in the next section.

2.6.1 Male involvement in PMTCT services

It is long recognised that involving men is important for the success of PMTCT (Ramirez-Ferrero & Lusti-Narasimhan, 2012). Male partner involvement in family planning influences reproductive decision making and facilitates contraceptive use (Nieves et al., 2015). In PMTCT interventions, male partner involvement has been shown to increase uptake in women who previously shunned the service (Kalembo, Zgambo, Mulaga, Yukai, & Ahmed, 2013).

A number of studies have focused on understanding the barriers to male involvement in PMTCT. Nyasulu and Nyasulu (2011) conducted in-depth interviews and focus group discussions with 52 participants, which included 20 mothers receiving PMTCT services. The study reported that women experienced opposition from their male partners, with most men refusing to allow the women to join PMTCT to avoid stigma and discrimination in the community. The women felt that they had to seek permission from their husbands to attend PMTCT (Nyasulu & Nyasulu, 2011).

Nyondo, Chimwaza, and Muula (2014) noted that men were not knowledgeable about PMTCT services and the benefits of accompanying the women. This is coupled with a reluctance of being seen at the clinic on what was not considered to be a male issue. The men believed that the clinic was the women's domain and childbearing issues were for women only. It also happens that most men who are not aware of their status fear that once their spouse has started the PMTCT programme, it is inevitable that they will be tested and their status will be revealed. They fear too that once the women start taking their medication to prevent vertical transmission, they would also be required to start their own treatment, something that they report they are not prepared for (Nyondo et al., 2014).

Factors promoting male involvement in PMTCT include involving the community and specifically influential people from the community to promote the benefits of male involvement. Private rooms for couples counselling and other interventions that increased privacy were also found to increase male involvement (Nyondo et al., 2014). An earlier study by the same authors identified several strategies that increased male involvement (Nyondo, Muula, & Chimwaza, 2013). These were extending invitations to the men and utilising education and communication channels such as radio, adverts, and motivational talks. The invitation was a direct notification to the men, which was perceived as respectful because it was a card with a stamp from the hospital, formally inviting them to the antenatal clinic

(Nyondo et al., 2013). The invitation card method has since been confirmed to be a feasible strategy for increasing male involvement in PMTCT services (Nyondo, Choko, Chimwaza, & Muula, 2015).

Interventions to improve male involvement seem to be beneficial to the delivery of PMTCT services, but it is not clear whether these benefits might extend to other domains of the couples’ lives. The challenge to involve men in PMTCT services is clearly a reflection of the subordinate status assigned to women in these patriarchal family structures, which put women in a position where they are unable to make decisions about their own health. Indeed, much literature seems to point to one stark conclusion: if the effectiveness and reach of these biomedical interventions are to be improved, then a range of socio-economic interventions are required to dismantle the structures that subordinate women in the first place. Ultimately men should involve themselves, not by special invitation but rather because they take joint responsibility for ensuring the wellbeing of their partners and their children

To sum up, conclusions from the studies on SRH and PMTCT reviewed thus far suggest there is much focus on the biomedical aspects of HIV and that these studies were confined to the clinic setting (e.g., Haddad et al., 2014; Todd et al., 2012; Wall et al., 2015). Because of this biomedical focus, the favoured methodologies tend to be quantitative in nature, such as surveys and randomised controlled studies. In contrast, there have been relatively few studies utilising qualitative methods to investigate these biomedical aspects of HIV and SRH or PMTCT (e.g. Muheriwa et al., 2013; Chinkonde et al., 2009; Iroezi et al., 2013). While these qualitative studies provide useful information on SRH and PMTCT in WLHIV, methodically they are usually conducted with larger samples (e.g., Chibwesha et al., 2011), which may compromise the depth of the information collected. The use of a sample of 12 and IPA methodology was, on my part, to ensure that there is an intimate understanding of the women’s experiences and the context in which the experiences occur.

SRH services present multiple overlapping challenges to WLHIV such as rights violations, lack of counselling and safety concerns about health with certain types of contraceptives. With PMTCT, they experience socio-cultural challenges, which hinder their full participation in the programme. Beneath the challenges with SRH and PMTCT services, are multiple oppressions, and constraints in their personal life stories that sustain these obstacles and render them unable to fully control their reproductive health.

So far, I have been highlighting the importance of capturing the context within which the women experiences living with HIV in order to get to the root causes of their challenges and to thus propose more structural interventions. In the literature review, I have attempted to highlight that women experience multiple stigma and oppression as WLHIV which can co-occur, and which interacts with their lower social status.

As explained in the introduction chapter, WLHIV are disadvantaged and oppressed in various ways; they experience low socio-economic status and gender inequalities, which place them in vulnerable positions in relation to HIV infection. Living with HIV also brings about a myriad of challenges related to their diagnosis, most of which are related to inequalities, which start earlier in their lives. For example, a Kenyan phenomenological study with WLHIV found that women face multi-layered challenges and different levels of discrimination based on their serostatus (Kagotho, 2014). WLHIV faced challenges in the wealth transfer process because of gender inequalities, patriarchal social structure, poverty, and lack of participation in the socio-economic situation (Kagotho, 2014). For this reason, I use the theory of intersectionality to further the understanding of how the experiences of WLHIV are shaped.

2.7. THE CONCEPT OF INTERSECTIONALITY

Given that the review documents multiple interrelated adversities, it is useful to conclude the discussion of the literature with a very brief mention of intersectionality to emphasise the ways in which these adversities interact to lock WLWHIV into marginalised positions. The concept of intersectionality was first introduced by Kimberly Crenshaw as a critique of the one-dimensional approach to issues of race and gender as they applied to Black women who experienced, instead, what she describes as an intersection of discriminations. Crenshaw argued that when categories of race and gender are treated as isolated dimensions of discrimination, this limits their explanatory capacity (Crenshaw, 1989). Such a one-axis conceptualisation of race and gender is not useful to understand the specific situation of Black women, whose experiences are shaped by the intersection between two dimensions of inequality (Crenshaw, 1989). For example, in an essay, “Mapping margins: Intersectionality politics and violence against women of colour”, Crenshaw (1991) examined how racism and patriarchy intersect in the lives of Black women living in shelters for abused women. The women in the shelters had low socio-economic status because of the oppression they experienced as Black women and were subjected to violence in their relationships because of patriarchy (Crenshaw, 1991).

While there are a variety of definitions of the term, Brah and Phoenix (2013, p. 76) offer a useful one that captures all the multiple dimensions of the challenges that WLHIV face as identified in the previous sections.

> We regard the concept of 'intersectionality' as signifying the complex, irreducible, varied, and variable effects which ensue when multiple axis of differentiation – economic, political, cultural, psychic, subjective, and experiential – intersect in historically specific contexts. The concept emphasises that different dimensions of social life cannot be separated out into discrete and pure strands.

For the purpose of this literature review, therefore, intersectionality provides for a fuller appreciation of the multidimensional experiences of oppression and discrimination (Lutz, Vivar, & Supik, 2011). To understand intersectionality, one must look at the social context, the institutions, and structures that play a role in the exclusion of some people and not others, the policies, and the kinds of discrimination taking place (Crenshaw, 2016). This aspect was deemed most relevant for this research because it provided the lens from which to understand how Malawian women experience various disadvantages borne from the cultural, social, and patriarchal structures that subordinate them and render them vulnerable to HIV. Intersectionality implies that there is a need to stop addressing these issues in isolation but instead look at the multiple forces at play that render difficult any tenable notion of agency that the WLHIV want to exercise over their lives.

2.8 SUMMARY

In conclusion, the review demonstrates that WLHIV experience varied major life challenges. It seems that before and after receiving the diagnosis, WLHIV are confronted with a host of challenges that threaten their wellbeing, perhaps more so than the HIV infection itself. Because of their HIV status, they experience stigma and live with the threat of violence and also experience actual violence, both which bring about stress and may contribute to poor mental health. Where this becomes a complex problem is that the challenges create a symbiotic relationship. For example, mental illness is a stigmatised condition, so it may be that WLHIV who experience mental health issues avoid seeking treatment because they fear the stigma of being labelled mentally ill. The mental health issues may be brought about by the violence they experience as a WLHIV and their low socio-economic status; and lack of empowerment constrains them from leaving abusive relationships and getting the right support for the mental health issues. Women experiencing sexual violence have their SRH rights infringed and this places them in a vulnerable position to the risk of HIV infection (Kathewera-Banda et al., 2005). This implies that being HIV positive puts women in the way of multiple adversities, which have a synergetic relationship, and because of this, it may compound the experience of living with HIV.

In accessing HIV related services such as SRH and PMTCT the women face stigma, cultural and economic barriers that impede them from benefiting fully from these efforts that have the potential of improving their quality of life. What this means is that, although the women may be physically well and able to access medical treatment, pre-existing conditions and secondary issues related to their diagnosis impact on their quality of life, sometimes more than having the virus in their body. It is also important to note that all these challenges largely occur in an environment where the women have no formal support systems, particularly in the case of underdeveloped countries like Malawi. Being poor, economically disempowered and lacking in education limits access to information. The current study brings to light these contextual factors, describing in the women’s own words what makes the lives of Malawian WLHIV so challenging.

In addition to these challenges, it appears that other underlying contextual factors, which I touched on in the introduction section, such as economic status, also play a role in how PLHIV experience the illness (Metaweh, Ironson, & Barroso, 2016). In general, PLHIV struggle with lack of finances for basic needs, impoverished living conditions, and lack of proper nutrition (Metaweh et al., 2016). Studies of lived experiences also point to gender-based obstacles and economic hardships (Kako et al., 2012). Men have extramarital affairs, abuse substances, refuse to use condoms, and force women to have sex with them. But because of economic desperation, WLHIV involve themselves in transactional relationships to be helped materially in their communities (Kako et al., 2012). In the narratives of two Indian women, they explained the gender inequalities that drove their experiences of living with HIV (De Souza, 2010). The women described lacking control and power over their lives because of living under patriarchal oppression, which dictated their decision to marry and have children while young (De Souza, 2010). The current study builds on such findings, to detail the gender-based obstacles and living conditions of Malawian women, and how these shape their experiences of living with HIV.

In documenting these challenges, I do not intend to advocate that WLHIV are always passive victims and that they should only be identified with their struggles and adversities alone. WLHIV are not always people who need to be saved or have decisions made for them, but need to be heard in order to learn from them what it is they require to make their lives better. I hope that soliciting the lived experiences of Malawian women will unravel the underlying oppressions they endure, and root causes of their disadvantages, which seem to sustain the challenges they encounter, particularly stigma towards WLHIV. Indeed, we know about these challenges but they do not reflect the entirety nor the core of the women's experiences of living with HIV and the meaning they attribute to those experiences, hence the need to conduct research that investigates the lived experiences of these women.

The study addresses two gaps in the literature. Firstly, it has been noted that the majority of the research on HIV topics seems to be quantitative in nature while focusing on biomedical aspects of the illness, and there are even fewer qualitative studies on the lived experiences of WLHIV, and they do exist, the lived experiences are too often investigated secondary to other aims (e.g., Cloete et al., 2010; Pretorius, Greeff, Freeks, & Kruger, 2016). The present study makes lived experiences the focus of the investigation and provides rich, detailed accounts of what it is to live with HIV. By focusing on lived experiences, I aimed to capture the aspect of HIV as an illness that the commonly employed quantitative methods fail to fully capture, such as the context in which these challenges occur which encompass their cultural norms, their personal life stories, psychological experiences and how they cope and manage their illness.

Secondly, in the qualitative studies investigating WLHIV, the methods employed may not be the most suitable for investigating lived experiences hence they may not capture the core causes of the challenges facing WLHIV. For example, with Mkandawire-Valhmu and Stevens' (2009) study, the authors used a postcolonial feminist perspective, their aim being to demonstrate the usefulness of focus groups as a qualitative method in researching marginalised groups such as WLHIV, and their lived experiences were secondary to that aim. Unlike IPA, postcolonial feminist methods focus on power relations and the larger society structures of a phenomenon, as opposed to individual experiences. Similarly, Kako et al. (2012) and De Souza (2010) used postcolonial feminism as the method of inquiry in their studies with WLHIV, and thus may have focused solely on the gender aspects of the women's experiences and missed the psychosocial aspects of living with HIV; for example, how the women cope and found support. Having noted that there is no Malawian based study that has used the IPA in researching lived experiences of WLHIV, using the method to investigate these experiences breaks new ground in terms of analysis in that it leads to generating richer data and gaining a deeper meaning of women's experiences. Furthermore, the present study chose to use three-part semi-structured interviews, which include a life story interview, in order to create a comprehensive picture of the women's journey of living with HIV.

Within this understanding, I mention intersectionality, which suggests that key to understanding such experiences are to appreciate the overlapping of the multiple factors affecting disadvantaged women's lives and multiple identities they assume. In this regard, a discussion of women separate from their multiple issues downplays the complexity of living with HIV.

2.9 CONCLUSION

This chapter analysed selected literature and highlighted the multiple issues that WLHIV face. Bear in mind too that all of these co-occurring psychosocial challenges are in addition to the considerable demands of coping with a deeply stigmatised and life-threatening illness. Most significantly, WLHIV in Malawi (and other developing countries) are likely to experience multiple forms of intersecting adversity and oppression. The literature is not exhaustive of all the literature in the area of HIV and women; rather, the material has been presented according to its relevance in informing the reader about the background, aims and purpose of the study. One of the aims of the study is to ensure that the women are at the centre of the research and the voices of the women are heard in order to gain first-hand accounts of their experiences. Overall, the literature review identified that no study exists which specifically investigates the lived experiences of WLHIV in Malawi using IPA. In the next chapter, I describe the procedures and methods used in this investigation, and in particular, why the study adopted IPA as its methodology.

CHAPTER THREE:

METHODOLOGY

3.1 INTRODUCTION

This chapter is devoted to setting forth how the research was conducted. The aim of the current study was to understand the lived experiences of being diagnosed and living with HIV. The question guiding the study is: *What is the lived experience of being diagnosed and living with HIV for Malawian women attending an anti-retroviral treatment (ART) clinic at Zomba Central Hospital in Southern Malawi?* The overarching paradigm adopted for the study is presented, including the explanation as to why qualitative methods have been adopted as a method of investigating the experiences of living with HIV. The methodology and analytical strategy, IPA, are also explained in detail. Later in the chapter, the methods used to conduct the study and the criteria for ensuring quality and ethical issues in the study are addressed.

3.2 RESEARCH PARADIGMS

In this section, I elucidate the paradigm or the lens through which the research question is understood. Thomas Kuhn (1922-1996) first used the term "paradigm" in his classic book, *The structure of scientific revolutions* (1962), where he put forward propositions on how he conceived the development and history of science. In the book he argues that science does not progress as a linear accumulation of knowledge; instead it undergoes periodic revolutions, or changes, called "paradigm shifts" (Kuhn, 1962). To explain his ideas on scientific progress, Kuhn (1962) used the term "paradigm shifts" in two senses: as a shared idea and a shared solution:

> On the one hand, it stands for the entire constellation of beliefs, values, techniques and so on shared by members of a given community. On the other hand, it denotes a sort of element that constellation, the concrete puzzle solutions which employed as models or examples, can replace explicit rules as a basis for the solution of the remaining puzzle. (Kuhn, 1962, p. 175)

Likewise, researchers have different beliefs that they share about ways of generating knowledge and finding solutions for their research questions and research problems. A research tradition or paradigm thus means an established group of scholars with shared and related assumptions about the nature of reality and knowledge (Jacob, 1989).

The standpoint of the various research paradigms is reflected in how they answer the ontological, epistemological, and methodological questions when employed in an inquiry. Ontological questions grapple with the form of the nature of reality and what can be known about it (Guba & Lincoln, 1998). Epistemological questions deal with knowledge questions, in terms of what can be known, and the relationship between the knower and the known. Methodological questions respond to inquiries about the process of finding out whatever one believes can be known (Guba & Lincoln, 1998). Gray (2013) explains that the chosen research methodology is influenced by a theoretical perspective, and a theoretical perspective is influenced by the researcher's epistemological stance. He thus defines ontology as the study of *being*; that is, the study of nature and it embodies *"what is"*. Epistemology, on the other hand, provides a philosophical background for deciding what kinds of knowledge are legitimate to know and it embodies *"what it means to know"* (Gray, 2013, p. 19).

The main paradigms in research are positivist and non-positivist paradigms. Central to positivism are two forms of knowledge recognised as having legitimacy and authority. Empirical knowledge is represented by the natural sciences, and logical knowledge is represented by logic and mathematics (Hughes & Sharrock, 1980). The research approaches associated with the positivism paradigm are quantitative inquiries, which include methods such as surveys and experiments and use statistical techniques to interpret research findings (Bryman, 2012). Positivist approaches were deemed unsuitable for investigating lived experiences, thus the current study uses the non-positivist interpretivist paradigm, which is concerned with everyday lived experiences.

3.2.1 Qualitative inquiry

This is a qualitative study. Strauss and Corbin (1998, p. 11) define qualitative research as "any type of research that produces findings not arrived at by statistical procedures or other means of quantification". The goal of qualitative research is to develop rounded and contextual understandings on the basis of rich, nuanced, and detailed data. Qualitative inquiry is systematic research conducted with demanding procedures and employs checks on the data recording to ensure the credibility of the results (Taylor & Bogdan, 1998).

Qualitative research is both interpretivist and constructionist. It is interpretivist because its epistemological position emphasises the understanding of the social world through an examination of the interpretation of that world by its participants (Bryman, 2012). It is constructivist because its ontological stance implies that social properties are outcomes of the interactions between individuals, rather than phenomena “out there”, and separate from those involved in the construction (Bryman, 2012). In the qualitative research paradigm, the current study is located in the interpretivist and socio-constructivist perspectives. Social constructivism, which is combined with interpretivism, views individuals as seeking understanding of the world in which they live or work. Individuals develop subjective, varied, and multiple meanings of their experiences of the world around them (Creswell, 2012). Table 3.1 is a summarised representation of this study’s research method and methodology.

Table 3.1: Research methodology

Paradigm	Research question	Theoretical roots	Methodology
Qualitative (Interpretivist and socio-constructivism)	What is the lived experience of being diagnosed and living with HIV for women attending an ART clinic in Southern Malawi?	Phenomenology Hermeneutics Idiography	IPA

One reason qualitative research was favoured for this study is due to its flexibility; there are no rules, only guidelines to be followed when conducting the study. “The method serves the researcher; never is the researcher a slave to procedure and technique” (Taylor & Bogdan, 1998, p. 10). This was helpful for the current study because it enabled the participants to freely express issues about their lives, which ensured a natural flow of the research process. Furthermore, the qualitative approach was chosen because qualitative data provide contextual information and refer to meanings and purposes attached to human actors and their activities, and as a result can provide rich insight into human behaviour (Guba & Lincoln, 1998). This is congruent with one of the aims of this study of understanding the context in which the women’s experiences of living with HIV occur.

Qualitative methods have proved to be suitable for examining sensitive HIV-related issues (Power, 1998), such as what the current study investigates, namely the experiences of women with HIV. In recent years, there have been a growing number of qualitative studies that have been successfully conducted regarding living with HIV (e.g., Abrahams & Jewkes, 2012; French, Greeff, & Watson, 2014; Nattabi, Li, Thompson, Orach, & Earnest, 2012), HIV post-diagnosis experiences in relation to identity and sexual behaviour (e.g., Wekesa & Coast, 2013), the process and impact of HIV disclosure (e.g., Cusick, 1999; Linda, 2013), barriers to HIV services (e.g., MacPherson et al., 2012; Madiba & Canti-Sigaqa, 2012), and ART adherence support and counselling (e.g., Cocohoba, Comfort, Kianfar, & Johnson, 2013). The current study contributes to the literature on qualitative studies on HIV.

3.3 RESEARCH METHODOLOGY: IPA

3.3.1 What is IPA?

As stated earlier, this research aims to answer the following question: *What is the lived experience of being diagnosed, and living, with HIV for Malawian women?* Because the study is concerned with exploring human experience and meanings attributed to those experiences from a psychological perspective, the Interpretative Phenomenological Analysis was chosen.

IPA is a qualitative research methodology developed by Smith et al. (2009). The approach is concerned with the detailed examination of human lived experience and meanings attributed to those experiences from a psychological perspective (Shinebourne, 2011). The focus of IPA is on participants' accounts of their experiences to obtain an insider's perspective of the phenomenon (Willig, 2013). IPA is concerned with how participants experience a particular situation, but also recognises that the meanings people ascribe to events are a result of interactions between themselves and the social world. In making meaning of the participants' lived experiences, IPA acknowledges the role of the researcher's feelings, thoughts, assumptions, and experiences, and deems these influences necessary for making sense of another person's experiences (Smith et al., 2009), and these do not act as a bias but as a precondition for understanding experience (Willig, 2013). Smith et al. (2009) further stipulate that the meaning-making of participants' experiences takes place through certain kinds of resources (e.g., narratives, discourse, metaphors) and contexts (e.g., interactions such as interviews and settings such as universities and hospitals). Culture also provides a framework for meaning-making and understanding experience as tied to the language and culture of the participants. Hence, to understand the meaning of the experiences and to understand the experiential claims made by the participant, a certain level of cultural competence is required by the investigator (Smith et al., 2009). Cultural competence, as used in research, refers to an awareness of the unique and defining characteristics of the populations for which health professionals provide care and from which they wish to enrol clinical research participants (O'Brien et al., 2006).

Understanding the socio-cultural context in which the participants' experiences are constructed is key for a researcher to be able to interpret their experiences. As an investigator conducting an IPA study in Malawi, I am cognisant of the socio-cultural setting by virtue of being born and raised in the country. Being Malawian facilitated my understanding and interpretation of the women's accounts of their experiences. In addition, it is very significant that the study was conducted in the local language, Chichewa, which both the participants and I speak. IPA requires close engagement with the participants and there is an intimate interaction between the researcher and the participants (Smith et al., 2009). Indeed, Smith (2004) suggests that a shared language is almost a prerequisite for IPA. While translators can be used, this is, of course, far from ideal (Raval & Smith, 2003). Being able to conduct the interviews in the same language as the participants facilitated this participant-researcher connection and allowed me to reach a group of participants who would otherwise be excluded from this sort of research. The next section provides a brief background of the roots of the methodology in order to highlight the features that make the approach most suitable for the current study.

3.3.2 The Theoretical foundations of IPA

3.3.2.1 Phenomenology

IPA has its philosophical origins and epistemological underpinnings in phenomenology, hermeneutics, and ideography (Smith et al., 2009; Pietkiewicz & Smith, 2014). Phenomenology is essentially the study of phenomena or experience (Cerbone, 2014). As Moran (2001, p. 5) put it:

> Phenomenology is best understood as a radical, anti-traditional style of philosophising, which emphasizes the attempt to get to the truth of matters, to describe phenomena, in the broadest sense as whatever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experiencer.

In research inquiry, phenomenological research questions tend to aim at understanding the meaning of an experience; for example, “What does it mean to feel anxious?”, as opposed to investigating the number of times that person has felt anxious at a given time (Kruger, 1979). The context is central to understanding the phenomenon under investigation because a phenomenon takes its meaning from context. “Without reference to the context of a phenomenon, there can be little clarity regarding its inherent psychological meaningfulness” (Kruger, 1979, p. 148). The commitment to the detailed description of the social context in which women experience HIV in the study is based on this proposition, and will be explained in detail in a later section.

Subjects to be used in phenomenological-based studies are selected based on their ability to provide accurate descriptions of the experience under examination (Polkinghorne, 1989). The confidence in the choice of subjects is owed to the fact that the purpose of the research endeavour is to describe the structure of an experience and not the characteristics of the group that has had the experience (Polkinghorne, 1989).

The phenomenological component of IPA is the emphasis on describing the essence of people’s conscious lived experiences. IPA thus favours methods which will enable participants to offer rich, detailed, first-person accounts of their experiences (Smith et al., 2009). Interpretation involves two aspects: the first is the phenomenological commitment to giving voice to the participants, while the second is to contextualise and make sense of these accounts from a psychological perspective (Larkin, Watts, & Clifton, 2006).

3.3.2.2 Hermeneutics

Simply defined, hermeneutics is the study of interpretation (Orange, 2011). As a method, hermeneutics concerns itself with the interpretation of experience. The interpretative aspect of IPA draws from hermeneutics and requires researchers to engage in self-reflection, with the goal of embedding those reflections in the interpretative process (Laverty, 2008). IPA involves a two-stage interpretation process where researchers attempt to make sense of participants’ personal experiences and participants also attempt to make sense of their experiences – referred to as “double hermeneutics” (Pringle, Drummond, McLafferty, & Hendry, 2011). The focus is on the participant’s world and viewpoint and this involves an empathic approach. The interpretation of the data involves both the researcher and participant making sense of their world (Pringle, Drummond, McLafferty, & Hendry, 2011). The essence of IPA is the combination of phenomenology and hermeneutics. The phenomenological aspect attempts to get as close as possible to the personal experiences of the participant, while the hermeneutic aspect recognises that it involves interpretation of the phenomenon by both the participant and the researcher (Smith et al., 2009). Eatough and Smith (2008) emphasise that the participant should be the starting point and should be privileged as the source of interpretive activity which occurs. The analysis chapter explains how the researcher understands the women's experiences whilst reporting on their own understanding of living with HIV.

3.3.2.3 Idiography

IPA is idiographic because it starts with a detailed examination of each case (Shinebourne, 2011). The approach is thus suitable for producing a detailed and contextualised understanding of subjects' experience. The goal is to develop a narrative account of the phenomenon and this goal is attained by employing a rigorous account of cases (Shinebourne, 2011). As such, IPA encourages the use of case studies and small samples, because they offer deep and detailed analyses of a particular lived experience (Smith et al., 2009). Even in the analysis, the process begins with the detailed examination of each case and then proceeds to examine the similarities and differences across cases, and identifying the patterns of shared meaning of experiences across participants (Smith et al., 2009).

Although IPA has its theoretical roots in phenomenology, hermeneutics, and ideography, it is unique in not specifying theoretical assumptions about how the participants' accounts should be interpreted (Larkin et al., 2006). This epistemological flexibility means that researchers can make inferences about cognition while also emphasising a discursive commitment to the role of context and language in shaping people's lived experiences (Smith, 1996). Given the central role of cognition in mediating experience and emotional distress (Beck & Haigh, 2014), this study retained a commitment to cognition by drawing on the recent trend in cognitive science that, although far from a unified theoretical framework, suggests that cognition is embodied, embedded in the natural environment, and extended beyond the boundaries of the organism (Robbins & Aydede, 2009). The idea of embedded cognition includes not only the immediate natural environment, but also the socio-cultural context (Smith & Semin, 2007). Rather than thinking of cognition as confined to representations and processes that happen in the brain and are separated from the external world, much evidence suggests that the social context profoundly shapes, and is shaped by, what are often thought of as inner cognitive processes. Cognition occurs in the context of other people, face-to-face encounters, personal relationships, and social group membership that define who we are (Smith & Conrey, 2009). In that case, cognition is not a modal information process that proceeds independent of a larger context, but an organism involved in intensive moment-to-moment interaction with its environment (Smith & Conrey, 2009, pp. 458–459). It is for this reason that this study, among other aims, is committed to detailing the socio-cultural context in which the women's experiences occurred. The relevance of context is discussed further in the next section.

3.3.3 The role of social context in IPA

IPA is a phenomenological approach that pays attention to the "person in context" or "being in the world"; implying that the individual and the social world cannot be divorced from each other, so one cannot meaningfully take the person out of the context (Braun & Clarke, 2013). IPA utilises the term "being in the world" to denote an intentional, embodied, situated person and the term "lived experiences" is used to capture the interpreted and meaningfully lived aspect of our being in the world (Larkin, Eatough, & Osborn, 2011).

From these views of the situated person and the "person in context" it can be deduced that meaning-making happens in a context and the interpretation of these experiences by the researcher is dependent on knowledge of the context in which they occur in order to make reference to what the participants describe about their lives. For this reason, understanding the social context in which HIV occurs is key in this study because the lives of the women cannot be disconnected from the social conditions that shaped the way they experience and construct their illness.

As mentioned in the introduction, much research on HIV using quantitative methods focuses on the biomedical aspects of the illness and overlooks the context in which the illness occurs. The biomedical focus on illness usually discounts personality and social or societal conditions that impact disease progression and functioning, as if one must only understand a person's biological status (Engel, 1977). The biopsychosocial model, on the other hand, assumes that health and wellness are caused by a complex interaction of biological, psychological, and socio-cultural factors. Different systems are linked together – ecological, social, psychological, biological, and physical systems – and contribute to the outcome of the illness (Engel, 1977). Thus, understanding the social context provides a holistic picture of what it is to live with HIV for these women, with regard to the different factors that contribute to their experiences other than their HIV infection alone. I illustrate this in the figure that follows.

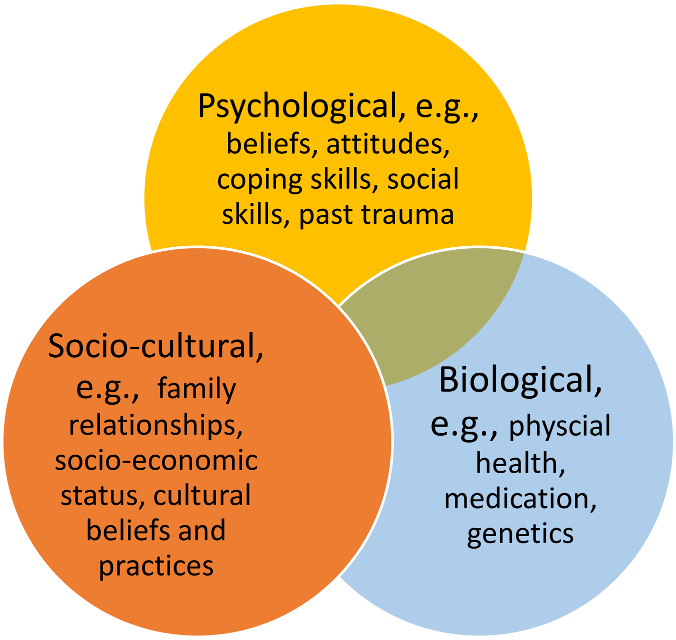

Figure 3.1: Biopsychosocial model of illness

Source: Engel (1977)

Thus, in presenting the results of this study, a whole chapter is dedicated to the social context of the women's experiences in order to understand how they make meaning of their experiences and also guides in interpreting their accounts. As Larkin et al. (2006, p. 117) state:

> IPA's interpretative component contextualizes these claims within their cultural and physical environments, and then attempts to make sense of the mutually constitutive relationship between 'person' and 'world' from within a psychological framework, e.g. 'What does this mean for this person, in this context?'

3.3.4 Rationale for using IPA

As mentioned in the previous chapter, there are no published Malawian studies using the IPA approach to investigate the lived experiences of WLHIV, therefore this will be the first. I chose IPA for the following reasons. Firstly, IPA's phenomenological philosophy is consistent with the research aims and the questions that the study sought to answer, namely understanding the lived experiences of WLHIV through their experiential accounts. IPA is becoming increasingly useful in investigating experiences of living with HIV (Yang et al., 2015; Mavhandu-Mudzusi & Sandy, 2015).

Secondly, its usefulness in research in the discipline of psychology is growing (Brocki & Wearden, 2006). Because IPA is concerned with human experience and how individuals make meaning, it appeals to the discipline of psychology. It is this meaning making that illuminates the embodied, cognitive, affective, and existential domains of psychology (Smith et al., 2009, p. 34). One of the aims of the study is to shift from the biomedical focus of HIV diagnosis to the psychosocial aspects of living with the illness and the context in which it occurs. The psychosocial experiences of the illness can be obtained due to IPA's idiographic nature, which allows in-depth details to be accessed and analysed by first understanding each case one at a time in order to build knowledge.

Thirdly, IPA fits with the epistemological position of the Malawian culture on ideas of generation of knowledge. The Malawian Chewa epistemology and notions of truth define knowledge as an accumulation of experience (Kaphagawani, 1998). Using an analysis of African proverbs, Kaphagawani (1998) concluded that knowledge in the Malawian Chewa tradition is a cumulative experience, whereas wisdom is a product of experience, and by extension, those with experience are viewed as knowledgeable. IPA values experiential accounts of participants to understand the phenomenon under investigation.

Prior to deciding on IPA as the method of choice, other qualitative approaches with similar epistemologies were considered. Mertens (2014) writes that there are seven types of qualitative research strategies: ethnography, case study, phenomenology, grounded theory (GT), participatory research, clinical research, and focus groups.

Ethnographic research is common in anthropology and answers the question, “What is the culture of this group of people?” Ethnographers focus on understanding particular phenomena in their socio-historical contexts for the purpose of discovering socio-cultural laws (Patton, 1990). Ethnography was not suitable for this research because the researcher sought to understand women's experiences of living with HIV as a phenomenon, rather than how the women interacted with one another, as would be the goal of an ethnographic investigation.

GT aims to develop explanatory theories of basic social processes studied in context (Starks & Trinidad, 2007). The theory is developed by examining concepts grounded in the data, with the goal of developing an explanatory theory of basic social processes. The research questions that GT answers focus on understanding how the basic processes of a phenomenon happen in a particular context. In the GT approach, the aim of the research process is to derive theory grounded in systematically gathered and analysed data (Strauss & Corbin, 1998, p. 12). GT is similar to IPA because it is inductive in its approach. The difference lies in their aims of analysis. IPA is interested in explaining the similarities and differences between participants, while GT aims to develop broadly generalised claims (Brocki & Wearden, 2006). GT studies broader social dynamics and provides socially embedded accounts of phenomena. IPA, on the other hand, focuses on the individual and the nature of the phenomenon. Furthermore, GT serves a descriptive and explanatory purpose, which may also be used to predict specific conditions related to the context in which they were generated (Corbin & Strauss, 1990). Another reason I choose IPA is that grounded theory has fragmented and there are competing approaches that have emerged, while IPA remains a relatively coherent qualitative approach (Willig, 2013).

Because the study focuses on women, another approach that was seriously considered was feminist research methodologies, which argue that individuals' daily activities or material and lived experiences structure their understanding of the social world (Hesse-Biber, 2012). Thus, a woman's oppressed position within society provides insight into the society as a whole and captures the social reality. For this study's research question, this standpoint proved less than ideal because it downplays the diversity of women's lives, especially the varied experiences of those who differ in race, class, sexual preference, and other characteristics. In relation to feminist methodologies, the main strength of IPA is its hermeneutic and idiographic epistemology and focus on understanding the phenomenon as lived from the perspective of the person.

As mentioned in the literature review, there is a trend in the existing literature to investigate lived experiences using qualitative methods, which might not be completely suitable for capturing lived experiences of WLHIV to allow sufficient access into the details of the participants' lives. For example, one study in the USA used explanatory models of illness and disease to explore the experience and meanings of living with HIV (Laws, 2016). Another study used GT to understand how WLHIV in Lebanon view their status and make meaning following diagnosis (Kaplan, El Khoury, Field, & Mokhbat, 2016).

Similar studies using the IPA approach are non-existent, with existing studies favouring phenomenological methods. For example, Kohan, Mohammadali Beigi, Fathizadeh, and Malbousizadeh (2009) conducted a phenomenological study with Iranian women to investigate their lived experiences. Gona and DeMarco (2015) also used phenomenological methods in a study with Zimbabwean women to explore their experiences of living with HIV. Liamputtong, Haritavorn, and Kiatying-Angsulee's (2013) phenomenological study generated themes that described how women learned about their diagnosis, their emotional reactions to the diagnosis, and how they coped and managed their illness.

While these studies are closer to what the current study aims to achieve in terms of focusing on the lived experiences of WLHIV, descriptive forms of phenomenology were used and perhaps further layers of meaning would have emerged had an interpretative form of phenomenological analysis such as IPA been utilised. The current study transcends description of experiences by the researcher to solicit the meaning of those experiences from the participants and subject them to interpretation. While other qualitative approaches would certainly have contributed useful knowledge, for the purposes of this study, with its focus on lived experience of a small group of participants, IPA was deemed most appropriate. Having said this, IPA, like all approaches, has its critics.

3.3.5 Evaluation of IPA

Several criticisms have been levelled against the IPA method. The role of language, the suitability of the participant's accounts, and whether IPA is able to provide explanations about phenomena have all been questioned (Willig, 2013). It has been argued that language may not be able to give true expression to experiences because words that are spoken construct reality rather than describe it. Because IPA relies on participants' accounts, questions have also been raised about the ability of participants to communicate their full experiences and use language to capture the delicate details of their physical or emotional experiences. Furthermore, it has been pointed out that IPA describes and documents experiences but does not necessarily explain them (Willig, 2013). Another criticism of the IPA approach is that findings cannot be generalised and are potentially subjective, intuitive, and impressionistic (Pringle et al., 2011).

The debate about the role of language as something that describes or constitutes social reality is a fundamental one. Potter and Wetherell (1987) in an explicit attack on the dominance of social cognition, which assumes that what participants say can be mapped to their underlying cognitions, argue rather that participants assume particular roles demanded by the social occasion of the interview and their responses represent the linguistic resources available to them, drawing on pre-existing discourses. IPA shares with social-cognitive approaches a commitment to the mind, even if approached very differently, while also appreciative of language and context in shaping participants responses, and similarly committed to qualitative psychology, making it, according to Smith (1996), an approach that might mediate these two opposing traditions.

It is certainly true that the quality of the data that is collected is limited to some extent by the participants' abilities to communicate their experiences. The skill of the interviewer would surely mitigate this concern to some extent. Significantly, for this study, the participants are interviewed in their first language. And while the abilities of participants to describe their experiences should be a concern, it is noteworthy that the corpus of IPA studies is large and growing in the areas of health and illness, sex and sexualities, psychological distress, and life transitions and identity (Smith, Flowers and Larkin, 2009). Indeed, this large body of research speaks for itself.

While it is acknowledged that some IPA research may emphasise description at the cost the proper interpretation of the data (e.g., Brocki & Wearden, 2006), Smith (2004) argues that while description is in itself useful, good IPA research would involve a critical engagement with the text, and present readings of this text that the participants would not necessarily see or acknowledge themselves. As Larkin, Watts and Clifton (2006) put it, IPA's commitment is twofold: on the one hand researchers must understand and 'give voice' to the concerns of their participants, while also making sense of these claims from a psychological perspective.

Lastly, the suggestion that findings cannot be generalised and are potentially subjective, intuitive, and impressionistic (Pringle et al., 2011) seems to miss the point of IPA. The very aim of IPA is to gain a deep, nuanced understanding of what it is for individuals to experience an illness or some other significant experience. There are approaches that emphasis generalizability, but this is often at the cost of nuance. IPA is an approach that complements other research methodologies.

While there are criticisms of IPA, as there are of most research methodologies, also much can be said about the suitability of IPA to this research study. Significantly, the IPA approach is commonly applied in research investigating lived experiences of illness, in particular physical and mental health, although its use in other experiences is growing (Smith, 2011). IPA recognises the complexity of the constructed nature of illness and thus, to understand an illness, it focuses on reported accounts of those experiencing the illness, which is a shift from the biomedical model of illness and disease where the key to understanding disease is observable bodily symptoms (Brocki & Wearden, 2006). This means that the IPA approach allows the researcher to go beyond the biological understanding of the illness and delves deep into how the person experiences the illness psychologically. For example, Levy and Cartwright (2016) used IPA to explore how five men with advanced prostate cancer managed their emotions while living with the threat of imminent and certain death from cancer. The interviews detailed personal accounts of the emotional and physical impact of their diagnosis, how they came to terms with the way in which their bodies changed, and the strategies they used to deal with pain, fatigue, and low mood (Levy & Cartwright, 2016). This aspect of IPA was found to be beneficial to this study because one of the study aims is to explore how an HIV diagnosis affects WLHIV emotionally and to unravel the psychological mechanisms they employ to deal with the diagnosis.

Other subjective experiences and conditions that IPA is able to access include; long-term recovery from addiction (e.g., Shinebourne & Smith, 2011; Watson & Parke, 2011), experiences of living with brain injury (e.g., Howes, Benton, & Edwards, 2005), chronic lower-back pain (e.g., Osborn & Smith, 2006; Snelgrove, Edwards, & Liossi, 2013), myocardial infarction (e.g., Hogg, Garratt, Shaw, & Tagney, 2007), and anorexia nervosa (e.g., Sternheim, Konstantellou, Startup, & Schmidt, 2011), to name just a few. The IPA approach has also been flexibly used in investigating sensitive personal topics. For example, Grundy-Bowers, Hardy, and McKeown (2015) used IPA to understand the sexual behaviour of homosexual men. The impact of breast cancer surgery on body image and sexual image and intimacy in couples was also investigated using IPA (e.g., Loaring, Larkin, Shaw, & Flowers, 2015).

Furthermore, in paying attention to the participants' accounts, IPA also captures the social context in which an illness occurs. In a study by De Ceuninck, Van Capelle, Visser, and Vosman (2016), interviews were conducted with patients with multiple sclerosis to determine how they experienced the disease within the family setting. The participants described how it became difficult for them to take care of their families, their family members' reactions, attitudes towards their illness, and difficulties getting support (De Ceuninck et al., 2016).

Thus, while there are many ways in which researchers can investigate topics, IPA was deemed to be very suitable to the aims of this research.

3.4 RESEARCH PROCESS

The research process progressed by following the seven stages of an interview investigation as outlined in Kvale (1996) (see Figure 3.2). The first stage involved the formulation of the research questions and clarifying the rationale of study. At this point of the research, I developed a comprehensive research proposal which was assessed by the Department of Psychology at Rhodes University and the Faculty of Humanities Higher Degrees Committee. In the designing stage, each stage of the research was thought through in relation to the knowledge being sought in the study and the moral or ethical issues that might arise in conducting the study. The third stage involved developing an interview guide with a reflective approach to the knowledge sought and the interpersonal relations of the interview situation.

After the interview stage, interview material was prepared for analysis, which involved a transcription from oral speech to written text. With the purpose of the investigation in mind, the most appropriate method of inquiry and analysis for the research was utilised, in this case IPA, which was chosen for its idiographic focus and emphasis on experiential accounts.

Trustworthiness was established by verifying the findings with the participants' accounts and the use of verbatim quotations. The final stage, which is the goal of the whole research process, was to communicate the findings of the study, the methods applied, and the ethical aspects of the investigation that were taken into consideration.

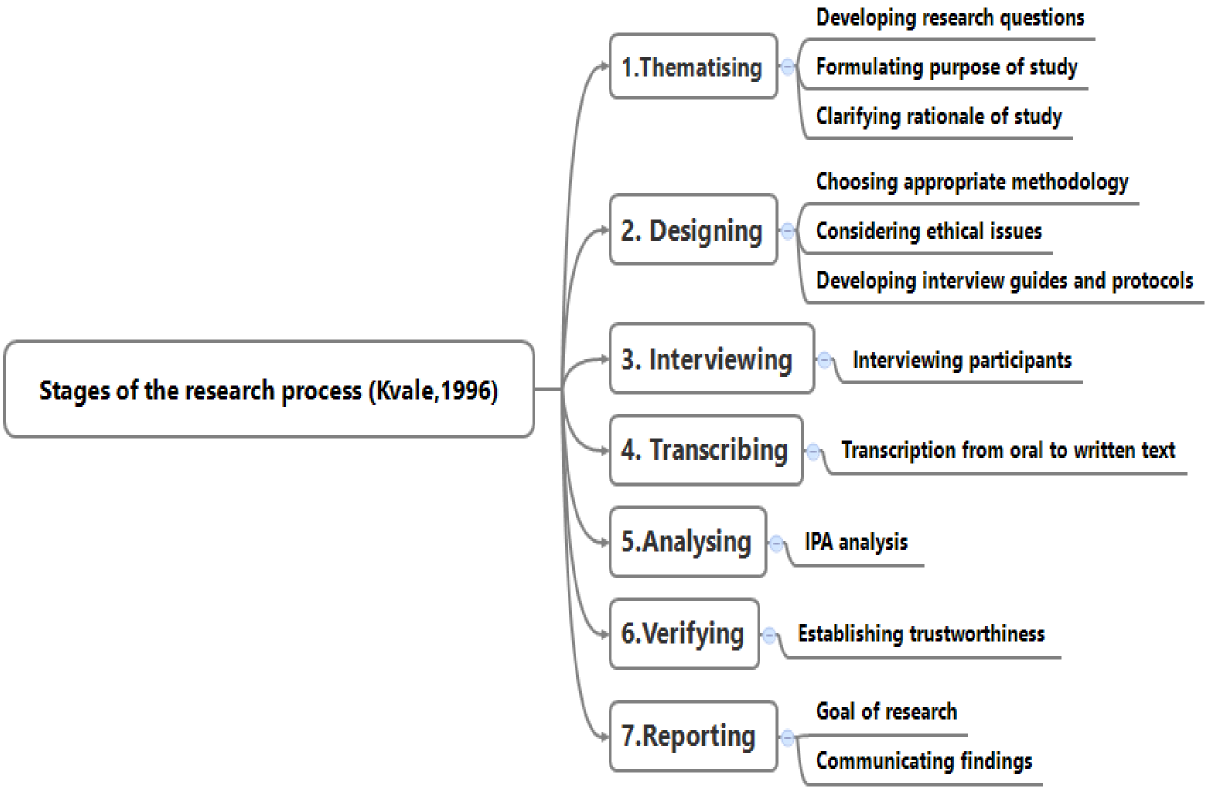

Figure 3.2: Research process of the study

3.5 RESEARCH DESIGN

A research design is the basic structure of a research project; the plan for carrying out the inquiry with focus on a research question that is key to the concerns of a particular epistemic community (Schwartz-Shea & Yanow, 2012).

3.5.1 Sampling

The study is based on interviews with 12 women who were recruited from the Tisungane Clinic, which was opened in 2004 by Dignitas International. The clinic, located at Zomba Central Hospital in Zomba District in Southern Malawi, provides crucial HIV-related services such as VCT, PMTCT, and the delivery of ART to adults and children, as well as services for HIV-positive patients requiring specialised care. The Tisungane Clinic functions as a referral site for patients from the entire South East Health Zone in Malawi, which has a catchment population of 3.1 million people.

Although the term “sampling” is associated with quantitative approaches, Smith et al. (2009) use the term to refer to the way in which participants are selected for an IPA study. In qualitative studies, the sample is not intended to be statistically representative (Ritchie, Lewis, & Elam, 2013) but sufficient to collect deep, rich, contextual data. Purposive sampling was utilised because it allows researchers to choose a case because it illustrates some feature or process in which they are interested (Silverman, 2010). This sampling procedure was suitable because the aim of qualitative research is to purposively select informants that will best answer the research question (Creswell, 1994, p. 148). According to Patton (1990), the logic and power of sampling depend on the selection of rich cases for in-depth study. Patton (1990, p. 184) further makes recommendations on the sample size:

> There are no rules of sample size in qualitative inquiry. Sample size depends on what you want to know, the purpose of the inquiry, what’s at stake and what will be useful, what will have credibility, and what can be done with the available time and resources.

This sampling technique fits well with IPA studies, which normally utilise a purposively selected, small, homogenous sample (Shineborne, 2011). There are no strict rules to the sample size because IPA is primarily concerned with depth and detailed accounts of individuals’ experiences following from the theoretical accounts and epistemology of IPA (Shinebourne & Smith, 2011). As such, single case studies and small samples are suitable for an IPA study (Smith et al., 2009). For example, Charlick, Fielder, Pincombe, and McKellar (2016) conducted a case study to understand the journey of exclusive breastfeeding of one woman. A sample of two was used to understand the clinical experiences of music therapists (e.g., McCaffrey, 2013) and experiences of adult liver donation (e.g., McGregor, Dickson, Flowers, Hayes, & O’Carroll, 2014). Clüver, Elkonin, and Young (2013) interviewed four young women to understand their experiences of sexual relationships in a South African township. A sample of five was used by Conroy and De Visser (2015) to investigate the social experiences of non-drinking students in a college setting. Another study used seven women to investigate their experiences of pregnancy, physical activity, and dietary choices (Atkinson, Shaw, & French, 2016). Wyatt, Murray, Davies, and Jomeen (2015) also used a sample of seven to understand how women and their partners made sense of postpartum psychosis. Similarly, Kirkham, Smith, and Havsteen-Franklin (2015) interviewed seven women to investigate their lived experiences of chronic back pain. Martin, Bonas, Shepherd, and Hedges (2016) used eight participants to investigate the experiences of the management of scars by adults with burn wounds. A sample of 15 was used to investigate the experiences of fatherhood (e.g., Eskandari, Simbar, Vadadhir, & Baghestani, 2016), and 21 participants were used in a study by Smith, Spiers, Simpson, and Nicholls (2016) to understand the psychological challenges of living with ileostomy. As demonstrated by these cited studies, a sample of 12 women is larger than many similar studies and well within the normal range demonstrated by these examples of published IPA research.

3.5.2 Inclusion criteria

In formulating the inclusion and exclusion criteria – that is, who should and who should not be permitted to participate in the study – the investigator must take into consideration the scientific goals of the study (Loue, 2000, p. 76). As suggested by Rubin and Rubin (2011), interviewees are expected to be experienced and knowledgeable in the area the researcher interviews them about. Furthermore, to allow the essential description of the phenomenon without distorting the essential meaning of the data, specific criteria for selecting participants must be observed (Kruger, 1979). The participants must be those who have experienced the phenomenon being researched; they must possess the verbal fluency to communicate feelings, thoughts, and perceptions in relation to the research; must speak the same language as the researcher; and must be willing to be open about their experience to the researcher (Kruger, 1979). To this end, the inclusion criteria utilised in the study required that a participant should:

- be a Malawian woman between the ages of 18 and 45;
- be diagnosed with HIV for one or more years (to allow for detailed experiences);
- be receiving ART treatment at the Tisungane Clinic at Zomba District Hospital;
- be verbally fluent in the national local language, Chichewa;
- be willing to voluntarily participate in the study; and
- be available for all three interviews.

3.5.3 Recruitment procedure

Eligible women who matched the selection criteria were first identified by the medical team of the Tisungane Clinic who gave a health talk to the clients who attend their clinic, where they also explained the details of the research and asked those who were interested to register to participate in the study. The clinic staff then compiled a list of the clients who expressed interest to participate and who would be available for all three interviews. The list was then given to me and clinic staff later arranged and facilitated appointments on the days the participants expressed their availability to be interviewed. A detailed description of the nature of the three-part interviews that were conducted with each participant, and how the interview questions were developed, follows next.

3.6 DATA COLLECTION: IN-DEPTH SEMI-STRUCTURED INTERVIEWS

The current study used a model of in-depth phenomenological interviews which involved conducting a series of three separate interviews with each participant (Seidman, 2012). Follow-up of participants over the course of the three interviews would have been uncomplicated because the Tisungane Clinic has a master card system where participants who are willing to be followed up leave their full details and records of their visits. As it happened, all 12 participants presented themselves for the three interviews on the agreed-upon dates, and follow-up efforts were required.

One-on-one semi-structured interviews were used to collect the data in all three phases of the interviews. Semi-structured interviews are conducted on the basis of loosely structured open-ended questions which define the area to be discussed and probes are made, where appropriate, to pursue an idea in more detail (Britten, Jones, Murphy, & Stacy, 1995). Semi-structured interviews involve asking open-ended questions of people, listening to and recording the answers, and then following up with additional relevant questions (Britten et al., 1995).

The questions were open-ended and non-directive to provide participants with an opportunity to freely share their personal experiences of the phenomenon under investigation without limiting them to specific topics (Willig, 2013). This was most important because each of the women's experiences, although similar, had a unique story and unfolded differently.

As with all methods, interviews have some limitations. Semi-structured interviews are time consuming (Gray, 2013). Due to the conversational style, the interviews can take a long time, especially when the researcher does not want to interrupt the flow of ideas of the participants' narrations. To manage this challenge, the interviews were audio recorded and later transcribed. The use of an audio recorder is essential because it permits an interviewer to concentrate on the process of listening, interpreting, and re-focusing on the interview (Gray, 2013). In the design stage of the study, the objections levelled against qualitative research interviews outlined by Kvale (1994) were taken into account.

3.6.1 The first interview: Focused life story

The first interviews focused on the life history of each participant to establish the context of the participants' experiences. Life story interviewing is a qualitative method for gathering information on the subjective essence of one person's entire life (Atkinson, 2002). A life story is a narrative essence of what has happened in the person's life and covers the time period from birth and beyond and should also include important events, experiences, and feelings of a life-time (Atkinson, 2002). The goal is to allow the people interviewed an opportunity to tell their story in a way they choose to tell it. It is useful in research because it is an effective way of gaining understanding of how the self evolves over time. As a psychological approach, it enables the researcher to gain a subjective perspective and understanding of the broad scope of topics or issues that individuals experience (Atkinson, 2002).

In the book, *The life story interview,* Atkinson (1998) suggests more than 200 questions an interviewer can ask to obtain a life story. In this study, the development of the interview guide was directed by adapting some of those questions which covered the following domains: birth and family origin, cultural setting and traditions, social factors, education, love and work, historical events and periods, inner life and spiritual awareness, major life themes, vision of the future, and closure questions (refer to Appendix 16).

3.6.1.1 Benefits of the life story interview in an IPA study

Firstly, the life story, with its focus on the biography of the women, helped to set the unique socio-cultural and contextual background of the participants that had shaped their experiences of living with HIV; for example, understanding how early adversity played a role in their current situation and how those early experiences and their immediate environment determined how they coped with the illness. Capturing the complete story of the participants also helped to form a psychological understanding and contextual sensitivity of how they interpreted their experiences of living with HIV.

The life story interview was crucial to understand the women's environmental, social, and cultural influences that shaped their experiences of living with HIV. For instance, the first interview asked questions about their cultural background, childhood, social roles, and interpersonal relationships. These questions evoked personal information that assisted in contextualising the lived experiences that were elaborated upon in the follow-up interviews.

Secondly, using the life story interview was an ethical decision on the part of the researcher. Listening to the women's stories showed a sense of humanity and acknowledged the participants as real people by paying respect to their stories and bestowing them the role of telling their own story.

In the analysis phase, the life story interviews provide an empathic understanding necessary to engage with the hermeneutic approach to inquiry, which is the core of IPA. As McLeod (2011, p. 27) states: "Sensitive interpretation requires developing a personal sense of understanding of the emotional and interpersonal worlds, and cultural-historical situation of the person(s) who generated the text."

The life story interview provided the foundation that I later used to make sense and interpret the participants' accounts. Significantly, the inclusion of interviews to gain a detailed understanding of the participants' life histories is an expansion of the usual approach to IPA that is intended to enhance the interpretation of their experiences.

3.6.2 The second interview: Details of their experiences

The second interview concentrated on capturing the details of the women's experiences of living with HIV from the time of diagnosis to the time of the interviews. By this stage of the interviews, the women were more open and relaxed after the rapport established in the first interview. There were ten topical areas to capture these experiences, which were introduced, and then the participant was left to talk, with a few probes where the researcher needed clarity on their stories. The areas of discussion included the details of how they received news of their diagnosis, sexual reproductive health issues, experiences of stigma, the challenges they face, and how they manage their health, relationships, and support systems (refer to Appendix 16).

3.6.3 The third interview: Reflecting on the experiences

In the third interview, the participants were primarily clarifying what they had explained in the first and second interviews. They reflected on the experiences that they described in the two interviews and added more detail to their stories. The participants talked freely about whatever came to their minds, about their feelings, worries, and thoughts about the future (refer to Appendix 16).

3.6.4 Developing interview questions: The interview guide

Rubin and Rubin (2011) describe interviews as structured conversations which are organised by combining main questions, follow-up questions, and probes. Questions serve a descriptive and facilitative purpose, rather than assessing a pre-existing opinion, attitude, or level of knowledge (Pollio & Thompson, 1997). Since this is an IPA study, the research questions focused on understanding the participants' experiences and their orientation towards the world (Smith et al., 2009). The questions in the interview required not only being respectful, but also sensitive, as well as sufficiently probing to provide an opportunity for all aspects of the phenomenon to be captured, yet flexible enough to allow facilitation of expression in as many circumstances as possible. As open-ended as the questions were, I exercised caution to avoid upsetting or irritating the participants. Sensitive topics were introduced in context to avoid introducing the topic abruptly and upsetting the participants.

3.6.5 Interview procedure

The women were invited into a quiet room at the clinic where there were no distractions. Before the interview, I handed the information sheet and read it to the participants and after the participants showed understanding of the research, the consent form was discussed. The participants then signed the consent form after they demonstrated that they understood what it entailed to be a participant in the research and that the interview would be audio recorded. The recorder was then switched on and the interviews lasted for 60 to 90 minutes.

3.7 TRANSCRIPTION AND TRANSLATION

The interviews were conducted in the local language, Chichewa, and all research instruments were translated from English to Chichewa. The translation was carried out to ensure that the participants who spoke only Chichewa understood the contents of the research documents. This study recognised the role of translation in constructing knowledge, and the role of translators as active agents in the research process (Regmi, Naidoo, & Pilkington, 2010). As such, I did the initial translation of all the instruments. To ensure accurate translation, a professional Malawian translator back translated the documents to English.

I transcribed the audio-recorded interviews into English. The interviews were translated into English for purposes of supervision and dissemination of results. I made sure that the transcription and translation was carried out within a few days after the interviews to avoid losing the context in which the stories were narrated. After the translation, I would quickly read the transcripts and listen to the recordings to see if accurate meaning had been retained. I was able to transcribe and translate the research material because of my experience from a previous role as a research supervisor (refer to Appendix 7). Because I was already familiar with the theoretical orientation of the research, as well as its objectives, translation took a meaning-based approach from the local language, Chichewa, into English. As the translator, I attempted to convey the meaning of the source language within the natural grammar of the target language, English.

The audio-recorded semi-structured interviews were transformed into interview transcripts following the guidelines outlined by McLellan, MacQueen, and Neidig (2003) and Mergenthaler and Stinson (1992). I ensured that I transcribed the audio-recorded interviews within a few days of the interview to avoid an accumulation of audio interviews that were not transcribed and, as mentioned earlier, to retain the context while the memories of the interviews were still fresh. Translating the transcripts also helped me to be fully immersed in and become familiar with the data as a prerequisite for good IPA analysis. Transcribing serves as part of the interpretative process, as opposed to being a technical procedure; and unanticipated phenomena can be noticed through the close observation that is involved during transcribing (Bailey, 2008; Brinkman, 2013). The transcription process assisted in hearing and understanding the participants better. Such familiarisation with the data may not have been possible if the transcription process had been completed by an outside agent other than myself. I typed each transcript with double spacing and wide margins to allow for note taking. The discussion that follows describes the steps that were followed in analysing the data.

3.8 DATA ANALYSIS

The analytic process was informed by the guidelines for IPA analysis (Smith et al., 2009) (see Figure 3.1). The analysis process began with active engagement with the data through listening to the interview recordings and re-reading the transcripts line by line several times. The first transcript was read and re-read and this transcript was used to generate the coding template for the remaining transcripts. A detailed line-by-line reading of the data was undertaken to identify the underlying meaning and concepts behind the statements in the interviews (Smith et al., 2009). Each interview transcript was subjected to the same analytic procedure.

The second stage involved initial noting. The transcripts had two margins; one on the left and one on the right. The left margin was used to make notes, paying close attention to the language, phrases, and metaphors used by the participants. Notes were made on descriptive, linguistic, and conceptual comments on the transcripts (Smith et al., 2009) This process was followed with each case to prepare for the next stage of developing emergent themes.

Emergent themes were identified in the third stage. The themes were developed by reading through the exploratory notes and finding the central ideas in each of the notes. I used verbal quotations to give a title to a group of exploratory comments that captured the same idea. This was done with the first transcript and it served as a template for the rest of the transcripts. If a new idea was noted in the next transcript's exploratory comments, a new theme was developed. This process continued with each of the transcripts.

The next stage of the analysis was to group the themes according to the similarity of ideas expressed. The main theme, which captured the overarching idea, was identified and then subthemes, which are the themes that were related to the main theme, were grouped together in a hierarchy. Smith et al. (2009) define this way of summarising themes as abstraction, which involves putting alike extracts together and developing a new title for the cluster. I then developed a table of all the themes showing the main themes and subthemes.

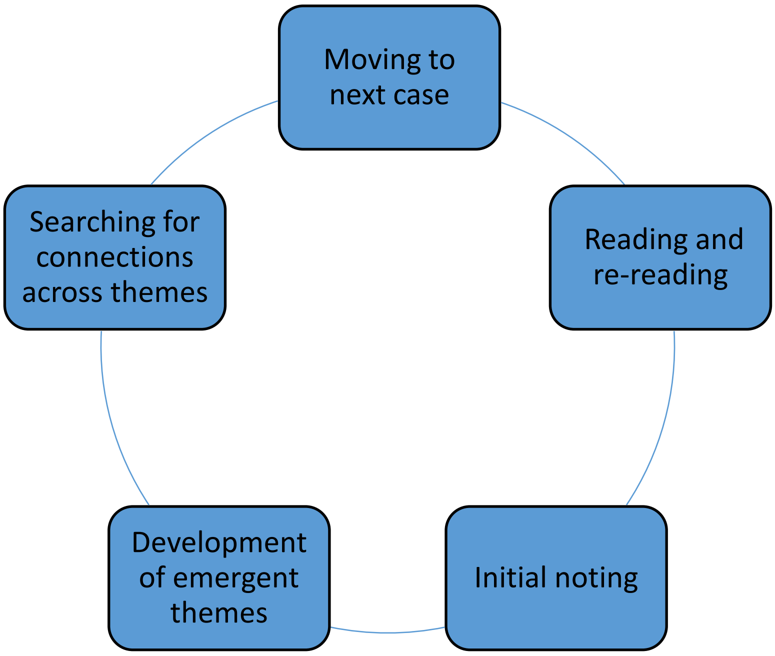

Figure 3.3: Stages in IPA analysis

Source: Smith et al. (2009)

The formal analysis started when all the interviews were transcribed and translated. This decision was taken for logistical reasons. While the degree was pursued in South Africa, at Rhodes University, the field research took place over a period of six months (September 2015 to March 2016) in Malawi. It was deemed necessary to block out six months of fieldwork to collect, translate, and transcribe all the data. This six-month field research period allowed me to go back to the participants to interview them again if gaps in the information were noted. Although the process proceeded by looking at each case separately during the analysis, the results were treated as a data set. When analysing the data, the three interviews that were conducted for each of the participants were treated as one case.

3.9 DATA MANAGEMENT

Data analysis was organised and facilitated by the QSR NVivo 11 software programme for qualitative data analysis. It has been suggested that computer-assisted data analysis may increase and help with rigour and consistency when analysing qualitative data (Weitzman, 1999). Furthermore, the use of software is merely for organisation of data to ease the retrieval of coded themes (Wong, 2008). It should be noted, however, that computer software does not replace conceptual analysis or analyse data for the researcher, but it can help to effectively store and retrieve information (Fossey, Harvey, McDermott, & Davidson, 2002). There was still active engagement and reflection with the transcripts, especially the initial codes and the sub-categories.

QSR NVivo software is ideal for an IPA study because it is easier to modify codes, search text for themes and nodes, store memos, and build on analysis rather than using manual traditional methods (Duff & Seror, 2005). The codes were not definite, as the researcher changed them to give them the most accurate label closest to the quotations. The transcripts could be uncoded and coded differently, depending on new insights gained from more work with the data.

Having experimented with qualitative data analysis manually during my master’s project, I had felt overwhelmed by the volume of the data after weighing the practicalities of analysing qualitative data manually for a PhD project. QSR NVivo was chosen over other programmes on recommendation because it is available at Rhodes University and I had received training and guidance on the use of the programme. The analysis process took three months and the write-up of the results was started immediately after completing the analysis.

3.10 ENSURING QUALITY AND CREDIBILITY

According to Lincoln and Guba (1985, p. 290), the main concerns of any research inquiry are truth value (how can one establish confidence), applicability (how the findings can be applicable in other contexts or with other respondents), and consistency (how confidently the findings of an inquiry can be replicated with the same subjects and similar context). To ensure the quality of the study, I strictly adhered to the guidelines outlined by Smith (2011) on conducting a good IPA study. Smith uses examples from a range of IPA studies to demonstrate how an IPA researcher can collect good data, analyse, and interpret the data.

Creswell (1998) points out that a minimum of two techniques are adequate to establish the trustworthiness of a study. With this understanding, quality issues for the study were addressed according to Yardley's (2000) four criteria for ensuring quality in qualitative research.

These are a) sensitivity to context; b) commitment to rigour; c) transparency, coherence, and self-reflexivity; and d) the importance and significance of research. Figure 3.2 is a diagrammatic presentation of how credibility was ensured in this study.

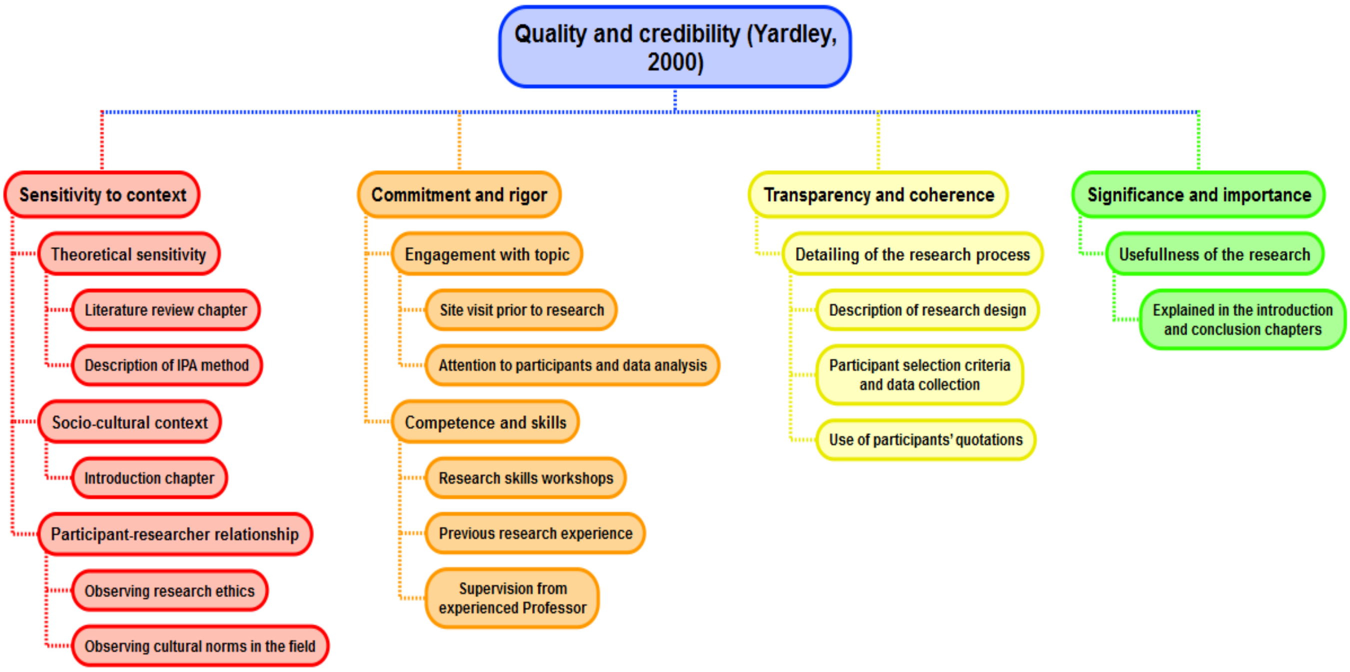

Figure 3.4: Ensuring credibility in the study

3.10.1 Sensitivity to context

This refers to an awareness of the theoretical and socio-cultural contexts of a study, which include the theoretical aspects, which are the relevant literature and empirical data. Most important is the socio-cultural context of the relationship between the investigators and the participants in relation to the balance of power during the process of investigation (Yardley, 2000).

3.10.1.1 Theoretical sensitivity

Sensitivity to the theoretical context implies that researchers must be aware of the empirical work conducted in the research area and the literature available on the topic. I have attempted to demonstrate this aspect through the literature review chapter included in the thesis, which critically presented the relevant studies that have been conducted in the area in order to locate the current study within that body of empirical knowledge. Yardley (2000) adds that theoretical sensitivity also applies to being aware of the philosophical roots of the approach adopted for the researcher to engage with the analysis in a sophisticated manner.

In this chapter, different philosophies of science that guide research are described in order locate and highlight the interpretivist paradigm that was selected for this study. Thereafter, philosophical underpinnings of the IPA method were also discussed in detail.

3.10.1.2 Sensitivity to socio-cultural context

In order to show sensitivity to the socio-cultural context, I have elaborated on the issues regarding the background of Malawi relevant to the study in the introduction section. The initial interviews were designed specifically to ensure an appreciation of the participants'' socio-cultural contexts. In the analysis chapter, I use verbatim extracts from the participants' material to support the interpretation and the arguments presented.

3.10.1.3 Participant-researcher relationship

Throughout the study, especially during the data collection phase, I paid attention to maintaining a good relationship with the participants. In addition to observing research ethics, my general presentation to the participants was sensitive to the traditional culture of Malawi; for example, during the interviews I dressed modestly and spoke respectfully to the women, as would be expected in this particular cultural context. This was done to enable the participants to open up to me without difficulty.

3.10.2 Commitment and rigour

These criteria refer to the thoroughness of the research process from the data-collection phase through to the analysis and reporting of data. Yardley (2000) states that commitment should be shown in prolonged engagement with the topic, development of competencies and skills in the method used, and immersion in the relevant data. Rigour implies that there was a completeness of data collection, analysis, and interpretation. Throughout the research, supervision of the process was gained from a professor with experience in IPA, qualitative methods, and the field of this research.

3.10.2.1 Prolonged engagement with the topic

My interest in WLHIV started when I worked in Malawian rural communities in my early years as a research assistant and witnessed how the realities of living with HIV impacted men and women differently. I embarked on the preliminary research a year before registering for my PhD studies, mainly by reading government reports and unpublished literature on HIV and women in Malawi and engaging with other researchers investigating related issues.

During the data-collection exercise, attention was paid to detail in conducting the interviews, and translating, transcribing, and analysing the data, as explained in the paragraphs above.

The use of three-part semi-structured interviews also ensured that each participant was given adequate attention and that their voice was heard. The criteria for choosing the participants also fitted the aims of the research. Although ethical approval is mandatory for all studies, it is also a component of rigour because the study was scrutinised to establish transparency of the research procedures and scientific usefulness of the topic under investigation.

3.10.2.2 Developing competence and skills

My research skills and previous experience were relevant to maintain rigour in the study. My fieldwork research skills date back to 2003 when I began working as a research assistant and supervisor in Malawi in community projects related to public health, and demographic and educational research. In these projects I was directly involved with administering questionnaires and conducting interviews and transcribing and translating interviews (refer to Appendix 7). During my Master's study in the UK at Bangor University from 2005 to 2006, I worked as a research assistant, maintaining, and managing data for a pilot study with people with Alzheimer's disease. I also administered computerised assessments, training sessions, and cognitive functioning tests.

I further sharpened my research skills during the first year of my PhD by attending Rhodes University Centre for Postgraduate Studies workshops for postgraduate students on formulating research questions, research proposal writing, research design, and academic writing. With this research experience, by the time I entered the field for research, I was confident and well equipped to independently conduct the study and thereafter manage the data to ensure quality.

3.10.3 Transparency and coherence

Transparency is the detailing of every aspect of the research process; from data collection, the rules used to collect the data, and backing the presentation of the analysis with corresponding texts and quotations. Most importantly, transparency involves disclosing all the relevant aspects of the research procedures, the method used to sample and recruit participants, any equipment used, and the tests used. I aimed to enhance the transparency of the research process through a detailed description of the research design, where I offered a systematic process of how the research was conducted, how the participants were selected, and how the data-collection process progressed. In addition, I kept a "PhD research diary" as an audit trail where I documented the important milestones of the research study. In the analysis chapter, the findings are supported by the participants' direct quotations.

3.10.3.1 Self-reflexivity

Tindall (1994, p. 150) describes personal reflexivity thus: "Personal reflexivity is about acknowledging who you are, your individuality as a researcher, and how your personal interests and values influence the process of research from initial idea to outcome." In this study, I was fully aware of personal reflexivity and how this might influence my understanding and interpretation of the data. I am a Malawian woman who has been working for the University of Malawi as a lecturer in Psychology since 2005. I grew up in peri-urban Malawi and I am one of the few women in Malawi who had the opportunity to attain a higher education. I therefore appreciate issues regarding the empowerment of women and the huge difference an education can make in a woman's life in Malawi. Compared to the women in the study, I represent the potential that can be attained when there is equality of educational opportunity that most women in Malawi are deprived of.

Thus, the choice of the topic was not only an intellectual decision, but it is an area that I feel passionate about due to my personal background, and I wish to develop the research area further throughout my academic career.

Most importantly, women with HIV deserve attention because poverty in Malawi mostly affects women and this renders them vulnerable to HIV infection. Theoretically, I would describe myself as taking an integrative approach. My philosophy background and phenomenological and humanistic approaches in psychology have mainly influenced me. I am not new to IPA, having been introduced to it at Master's level.

3.10.3.2 Reflexive journaling

According to Lincoln and Guba (1985), a reflexive journal is a kind of diary in which the investigator on a daily basis, or as needed, records various items of information, such as the daily schedule and logistics, personal reflections, and insights. The journal also provides information about methodological decisions and accompanying rationales.

From the beginning of the research, I kept a reflexive journal, mainly keeping track of my progress, but also documenting ideas about the study, possible ways to analyse the data, and reflections on feedback from the study supervisor. This also assisted in returning to the notes in the late stages of the thesis to see if the original ideas had changed and why. I also recorded observations, theoretical notes, and personal notes. During the fieldwork, I recorded the dates of the interviews and personal reactions to the interviews, which formed the basis of interpreting the results as the research progressed.

3.10.4 Significance of the study

In addition to showing sensitivity to the context and the thoroughness of the analysis and research process, the final criterion that Yardley (2000) emphasises is the impact and the importance of the study. To this end, in the introduction I elaborated on the importance of conducting the study and the significance of the research findings. To my knowledge, this is the first IPA study that explores in detail the lived experiences of Malawian women who are HIV-positive and receiving ART. The conclusion chapter includes a consideration of the relevance of this study to the Malawian community and policy in the area of women and HIV.

So far, this chapter has discussed the paradigm adopted for the study, and the reasons for choosing IPA as a method of inquiry and analysis. The chapter also detailed the participant recruitment and data-collection process and the measures taken to ensure the credibility of the study. Concluding this chapter is a discussion of how the study dealt with ethical concerns.

3.11 ETHICAL ISSUES

Ethical conduct in the study was based on the five moral principles which underlie ethical research, which include respect for persons and their autonomy, beneficence and non-maleficence, justice, trust and fidelity, and scientific integrity (Sales & Folkman, 2000).

According to Sales and Folkman (2000, p. 6), researchers should respect the fact that participants have made a choice and it should be an issue of concern if the person has diminished autonomy due to any circumstances that restrict their liberty. Researchers should also assess risk by planning the research process in a way that maximises the possible benefits and minimises possible harm from the research. In addition, there should be a trust relationship with the participants and there should be an explicit agreement about what participants will experience and the consequences thereof, as well as about the researcher’s obligation regarding confidentiality. Finally, and most importantly, the truthfulness of the findings is not open to compromise. Researchers should be committed to good science that is understood in the research community (Sales & Folkman, 2000).

Ethical clearance to conduct research was sought and granted by two committees; the Rhodes University Research Projects and Ethics Review Committee and the National Committee on Research in the Social Sciences and Humanities (NCRSH) in Malawi (refer to Appendices 3 and 4). The ethical guidelines that were adhered to when conducting the research comprised obtaining consent, debriefing, confidentiality, participant protection, giving advice, and allowing withdrawal from the investigation, as outlined in the Rhodes University Ethics Guidelines. The Rhodes University Ethical Guidelines for Human Subjects draw from the Human Sciences Research Council's (HSRC) code of research ethics. Other documents with similar ethical governing codes that were consulted were *Ethics in health research, principles, processes and structures* by the Department of Health (Department of Health, Republic of South Africa, 2015) and the British Psychological Society's (BPS) *Ethical principles for conducting research with human participants* (BPS, 2010).

Access to the participants involved three levels of authorisation (see Figure 3.5). Firstly, the Dignitas International research director had to grant permission for me to recruit participants from the clinic. The second level was the district health office in Zomba, where the district HIV coordinator had to approve of the study being conducted in the district. Finally, the director of Zomba District Hospital had to provide authorisation to conduct research in the hospital, which was granted after I presented the ethics approval documents for the study (refer to Appendix 5).

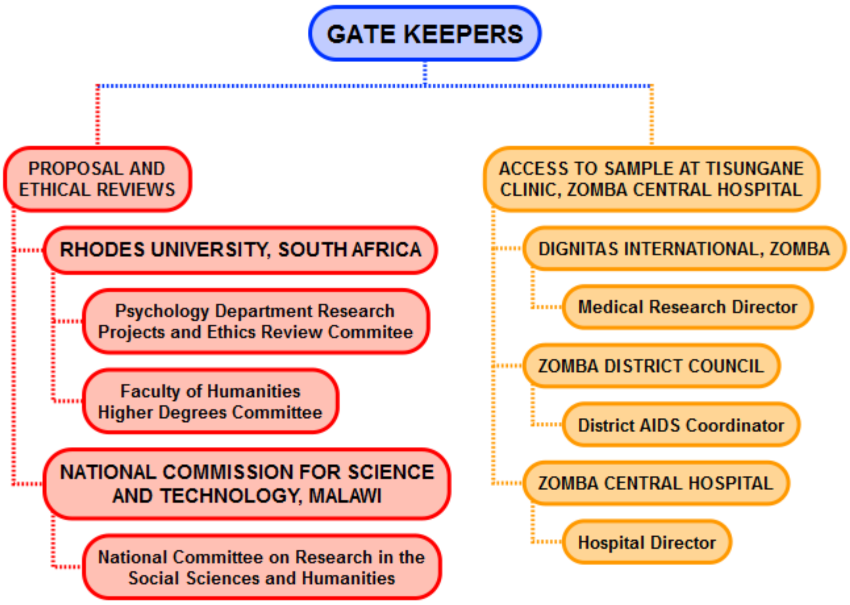

Figure 3.5: Authorisation to conduct research

3.11.1 Participants' rights and voluntary participation

The nature of this study required asking information relating to the women's HIV diagnosis, a topic considered to be highly personal. Ethical research entails ensuring that people participate voluntarily, ensuring the confidentiality of people's comments and behaviours, protecting people from harm, and ensuring mutual trust between the researcher and the people being studied (Silverman, 2010, p. 96). Outlined below are the safeguards that I used to protect the participants' rights; the participants were informed of these rights before the beginning of the interviews:

1. The participants were advised in writing of the voluntary nature of their participation in the study.
2. They were also advised that they could withdraw from the study at any point without penalty or threat to their visits to the clinic. They were further advised that if they felt any discomfort at any time during the interview process, they were free to decline to answer any questions.
3. The process and the aims of the research were clearly explained in writing and articulated to the participants before the interviews. All data-collecting methods and activities were explained to the participants. The participants were informed that the interviews would be audio recorded.
4. A signed informed consent form was obtained from each participant. Participants were assured in writing that the data collected would be kept confidential and that

pseudonyms or identity numbers would be used in the reporting, and at no point would their reports be identified as belonging to a particular person.

3.11.2 Informed consent

According to Kvale (1996, p. 112),

> …[i]nformed consent entails informing the research subjects about the overall purpose of the investigation and the main features of the design, as well as of any possible risks and benefits from participation in the research project.

Loue (2002, p. 114) states,

> Involvement of individuals in research without their understanding or their permission, or against their will, may lead to a distrust of science and scientists, harm to the individuals, and the questionable validity of the research findings – a result that could hardly be thought of as the maximisation of good, by any definition.

The consent form for the study was developed following the suggestions outlined by Seidman (2012, p. 63) regarding the relevant sub-sections and details that should be included in a consent form. These are as follows:

1. A section containing a statement inviting the potential participant to take part in the study.
2. A section outlining the potential risk of vulnerability and discomfort in taking part in the study.
3. A section informing the participants of their rights to withdraw from the study and that there is no penalty involved if they wish to do so.
4. A modest outline of the possible benefits of the study for the participant.
5. Steps that the researcher will take to ensure confidentiality.
6. An explanation of how the results of the study will be disseminated.
7. Special conditions for protecting vulnerable participants, i.e., children (in this case not applicable).
8. Details of the researcher’s contact information if the participants have any questions.

3.11.3 Confidentiality

One problematic aspect of HIV research is the stigma attached to the disease, and for participants the concern is that members of the community will learn about their status (Sieber, 1992). For example, there is a possibility of inadvertent disclosure of participants' status when seen talking to the researcher.

> Consequently, the privacy of participants in AIDS-related research must be protected in every conceivable way, and every effort must be made to let subjects know that they will not be stigmatised by their participation. (Sieber, 1992, p. 133)

Hammersley and Traianou (2012) state that in the research process, the commitment to maintain confidentiality should be present when recording and storing data, reporting feedback during data collection, and in informally sharing with academic colleagues, for example via seminars.

To protect confidentiality in this study, participants were interviewed in a private roomat the clinic where they recieve ART. Furthermore, identifying numbers were assigned to the participants instead of using their actual names. No personal details were used that might lead to the identification of the participants in any way. I was the only person who had access to the recorded and transcribed interviews on a password-protected computer that was kept in a locked office.

3.11.4 Risks

The study used in-depth interviews as a method of collecting data; thus the risks to the participants were minimal and manageable because it is considered a non-invasive method. "In-depth interviewing does not pose the life and death risk of biomedical research, but it is not risk free" (Seidman, 2012, p. 60). According to Seidman (2012), during the process of the interview, a measure of intimacy can develop between the researcher and the participants, and that intimacy may lead to participants sharing aspects of their life that may cause discomfort and a certain level of emotional distress.

The participants were informed that they were free to decline to answer any questions without any negative consequences. They were reminded that the interview could be stopped, and they could withdraw from the study if they felt any discomfort. They were also made aware that they could take a break from the interview if it became too much for them emotionally.

As a strategy to manage risk, I had planned to stop the interview if the participants showed any signs of distress. I also planned to refer them to the counselling support that was already present in the clinic. As it turned out, all the interviews were conducted without any participant showing significant emotional distress, therefore it was unnecessary to implement the planned measures for managing risks.

For this research, the major ethical concern was that the women were interviewed at the clinic that was also providing them with medication. It was emphasised that their participation did not affect their treatment in any way. Although numerical identification was used, another concern was that the research involved explanations of the women's unique histories and excerpts which might reveal their identities. When one considers that the women were given a rare opportunity to talk about their experiences and that the findings might inform strategies and policies to better the lives of WLHIV, while measures were taken to ensure their privacy, the benefits of the research outweighed this risk.

3.11.5 Potential benefits

There were no direct benefits for participating in the study apart from contributing to research knowledge and providing a safe space for the participants to express their issues. The conversations may have served as a therapeutic safe space for the women to express themselves about their experiences.

There is an increased probability for exploitation of participants if a research study offers any sort of intervention or treatment as an incentive for participating in the study (Richards & Schwartz, 2002), and the participants might be identified when the data are analysed or disseminated. Because of this, this study did not offer any incentive or reward for participating in the study; instead, participants were compensated for their time. Before field work, I considered this carefully to avoid exploitation of participants, as monetary compensation may sometimes alter respondents' participation and perception of the research process (Oliver, 2011). Providing compensation to the participants emerged from the concern that the participants should not incur any personal costs for participating in the study. The reimbursement was a minimal amount of K2 500 (Malawian Kwacha) for their time, lunch, and transport costs on each day of the interviews.

3.11.6 Source of funding

The source of funding for my PhD studies is a Beit-Rhodes scholarship. The Beit Trust funded the research costs for the data collection, equipment for the data collection, and reimbursement of participants’ travel and lunch costs during the interviews. The Beit-Rhodes scholarship had no conflict of interest regarding, or any influence on, the research outcomes.

3.12 CONCLUSION

The chapter detailed the qualitative methodology adopted in the study and why it was deemed suitable for the research question. The chapter also clarified the theoretical and practical orientation of IPA and why it was suitable for investigating the lived experiences of HIV. The chapter discussed the three-part semi-structured interviews that were conducted during the data-collection phase and how the data were processed to the final transcripts for analysis. The step-by-step IPA data-analysis procedures were outlined, including how the use of QSR NVivo facilitated the process of analysis. The chapter proceeded by outlining the strategies that the study employed to ensure the credibility of the research process and research findings. Finalising the chapter was a discussion of the measures taken to ensure that the study complied with the ethical standards expected of a research study on vulnerable populations. The three chapters that follow present the results and interpretation of the data.

CHAPTER FOUR:

RESULTS (PART 1): SETTING THE SCENE

4.1 INTRODUCTION

Following the analytical procedures outlined in Chapter Three, a total of 14 superordinate themes emerged from the analysis. The current chapter presents the first five themes, which explore the social context and personal histories of the participants to better understand their experiences of living with HIV. The themes capture what each of the women interviewed brought to the experience of living with HIV; their personal history, beliefs, and values. The themes also offer an understanding of the impact of the infection on the individual women and collectively, and in their individual personal, social, cultural, and spiritual context. The themes do not cover all aspects of women's experiences that were reported; instead, they were selected due to their relevance to the primary research questions. While the themes were common to the women's 12 accounts, there were also other areas of divergence and difference; most of which have been highlighted and commented on. Although the journey of every woman is different and uniquely her own, through their own words it was evident how they shared some commonalities in their daily experiences of living with HIV. Direct quotations from participants' accounts are written in italics and are bordered. It must be noted that there had always been some sort of struggle in their life and some women have been deeply closeted about their HIV status because no other disease is associated with as much stigma and raises as many personal questions directly and indirectly.

4.2 THE PARTICIPANTS

The participants comprised 12 women who attended Tisungane ARV Clinic at Zomba District Hospital in Southern Malawi. The study is thus about the experiences of these 12 women and where I use the term "the women's experiences", I refer to the experiences of the women who participated in the study. The results are not a generalization for all the women in Malawi, but speaks to the experiences of the interviewed women. Their experiences may however have commonalities with most Malawian women of similar characteristics and histories.

Table 4.1: Participant details

Participant alias	Age	Year of HIV diagnosis	Marital status	Children	Education*	Home village
001	36	2006	Married	Four	Standard 8	Chikowi
002	42	2004	Married	Four	Standard 1	Ngwelero
003	24	2010	Divorced	Two	Form 2	Buleya
004	34	2011	Married	Four	Standard 5	Jali
005	35	2005	Divorced	Two	Standard 2	Namikango
006	38	2013	Divorced	Two	None	Chikanda
007	36	2010	Married	Five	Standard 1	Makweza
008	36	2008	Divorced	One	Standard 8	Chikwenga
009	41	2005	Widowed	One	Standard 5	Chibwani
010	42	2005	Widowed	Three	Form 2	Mtokota
011	41	2008	Remarried	Three	Form 4	Chikanda
012	23	2013	Single	None	Form 4	Chikanda

*Primary school education consists of Standards 1 to 8. High school education comprises Forms 1 to 4.

Participant 001: Widowed, remarried, living with HIV

Participant 001 is 36 years old and has four children. After losing her parents, she dropped out of school in Form 2 to get married when her relatives could no longer afford to pay her school fees. Her first husband died, and she subsequently married to a man who was also HIV positive. She met her second husband at the clinic where they both received ARV treatment. She learned about her diagnosis after she fell ill with malaria and had severe headaches. She was very assertive and articulate.

Participant 002: Married, pregnant, and living with HIV

Participant 002 is a 42-year-old businesswoman who owns a shop selling various groceries. She dropped out of school in Standard 1 after her parents died. She has two living children from four pregnancies. Two of her children died at the ages of six months and three years before she knew she was HIV positive. She suspects that the children might have died of HIV-related illnesses. She started receiving ART when her CD4 count was 360. Initially it was 800 but it suddenly dropped. Her husband is also HIV positive and started taking medication after a tuberculosis attack. At the time of the interviews, she was pregnant.

Participant 003: Divorced, living with HIV, and caring for a child with HIV

Participant 003 is a 24-year-old businesswoman who owns a food shop in her home village. She dropped out of school in Form 2 and got married the same year. She has two children. She learned about her diagnosis when her youngest child, who was frequently ill, was diagnosed with tuberculosis before he was a year old. The child later tested HIV positive. After pressing her husband, they were both tested and discovered that they were HIV positive. Later, her husband left her for another woman because she decided on sterilisation after the birth of her second child. She is now taking care of four children on her own, two from her ex-husband's previous marriage, and two of her own.

Participant 004: Widowed, remarried, and living with HIV

Participant 004 is a 34-year-old homemaker who occasionally cooks and sells doughnuts when she has the resources. She dropped out of school when she was in Standard 5 because she, as the eldest daughter, had to take care of her sick mother. She was born in a family of 16 children. She got married at 15 years old to a man in the neighbourhood so that she could help take care of herself and her siblings. She has three children. Her first husband died in 2001 and she remarried in 2002, but at the time of the interview, she said that her husband had just left her. She had her last child when she was on ARVs and the child is HIV-negative.

Participant 005: Divorced and living with HIV

Participant 005 is a 35-year-old vegetable farmer. She dropped out of school in Standard 2 because her family could not afford to pay for her school fees. She got married in 1996 and has two children. She is currently separated from her husband because he was cruel to her. She said her CD4 count was around 568 and that she is now feeling better than she had felt when she started with ARVs.

Participant 006: Married twice and widowed, former sex worker living with HIV

Participant 006 is a former sex worker in her mid-30s. She never attended school. She has two living children from seven pregnancies. Her other children died before the age of one. Her parents were disabled and died when she was very young. She lived with her aunt, who introduced her to sex work at the age of nine. Her aunt used to bring various men to the house to sleep with her for a fee of K200 or K500. The aunt would threaten to kick her out of the house or not give her any food if she did not sleep with the men. She later contracted an STD. A neighbour who noticed the sexual abuse gave her some money to go to the hospital and get treatment. She also helped her to run away from the aunt to go to other relations.

She moved in with her other relations, who encouraged her to get married. Her husband was physically and verbally abusive. She then married her second husband and later discovered that he had two other wives. After learning about her diagnosis, she took several jobs but continued with sex work. She finally secured a job as a cleaner in a private clinic. She lost the job after her boss discovered that she was HIV-positive.

Participant 007: Remarried, caring for a child with HIV, and living with HIV

Participant 007 sells doughnuts for a living. She lives with her second husband and has five children. She was forced into her first marriage but she left the man after she discovered that he had another wife. She dropped out of school in Standard 1. She discovered that she was HIV positive when she was pregnant and was getting frequent infections. Her child was born with HIV.

Participant 008: Divorced and living with HIV

Participant 008 is a subsistence farmer and occasionally receives financial help from her relatives. She is 36 years old and dropped out of school in Standard 8. She had two children, but one died. She is currently single after being divorced from her husband. She learned about her diagnosis after becoming very ill and had to be put on ARVs straight away.

Participant 009: Widowed and living with HIV

Participant 009 is a shy and reserved 41-year-old woman. Her husband died in 2008. She dropped out of school in Standard 5 to get married. She had five children but four of them died when they were less than a year old. She suspected that the children might have died of HIV-related illnesses because she was not aware of her diagnosis then. Her last-born child died of tuberculosis. She lives with her mother and other relatives, who help her financially. She was in a relationship with a married man for financial reasons. She has never worked and does not have any skills to generate an income.

Participant 010: Widowed, living with HIV, and caring for a child with HIV

Participant 010 is a very articulate 38-year-old woman who makes a living from selling vegetables on the side of the road. She has three children; the youngest is HIV positive and on ARV medication. She dropped out of school when she was in Form 2 at the age of 19 after she got pregnant with her first child. The husband died of tuberculosis when neither of them knew that they were both HIV-positive.

Participant 011: Divorced, remarried, and living with HIV

Participant 011 is a 41-year-old woman who sells maize flour for a living. She dropped out of school when she was in Form 4. She has been married twice and has two children with her first husband, who left to work in Johannesburg (South Africa) and never came back. She learned about her status in 2008 when her child was suffering from severe malnutrition and was referred to the hospital where he tested HIV-positive. The child is now nine years old and is on ARV medication. After she tested positive, she was put on Bactrim and the child was put on ARVs. She remarried in 2010 to a man who is also HIV-positive and they have a daughter who is HIV-negative.

Participant 012: Young, single, and living with HIV

Participant 012 is a 23-year-old woman who found out that she was HIV positive in 2012 when she was tested at the antenatal clinic. She was 19 years old then and in Form 3 when she met the man who made her pregnant. She lost the baby while four months pregnant. She is single and lives with her maternal grandparent.

4.3 SUMMARY OF THEMES

The rich detail that the participants provided about their lives showed that their experiences of living with HIV are influenced by various factors from their childhood, their socio-cultural context, and economic status. They described their prominent early life experiences before their diagnosis and after. These were expressed in the following five superordinate themes: a) Enduring impact of negative early experiences, b) “I married early and had children while young”, c) “A woman’s life is about getting married”, d) “A woman is a slave to the world”, and e) Cultural norms surrounding sex. Figure 4.1 presents a summary of the results.

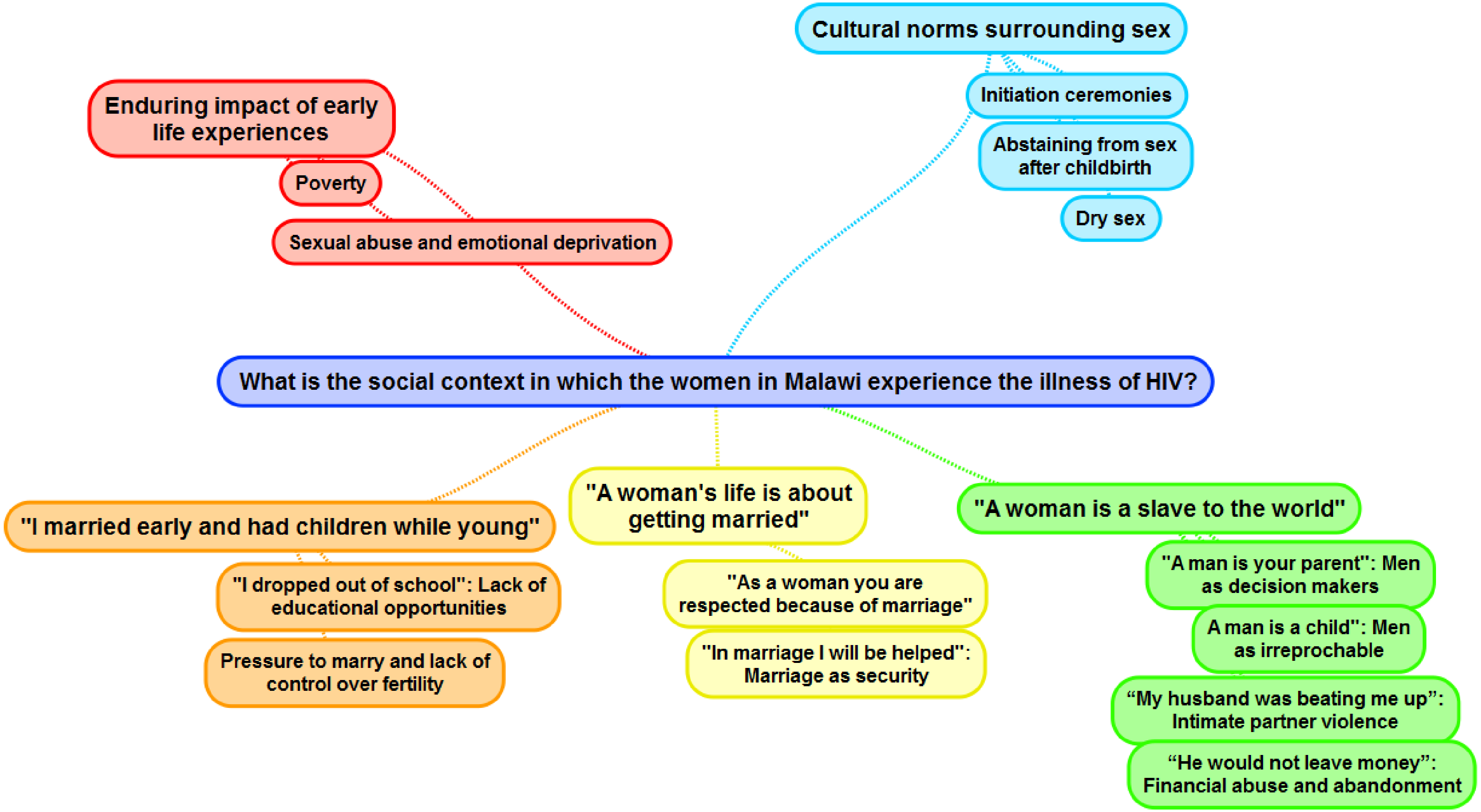

Figure 4.1: Summary of themes (Part A)

4.4 ENDURING IMPACT OF EARLY EXPERIENCES

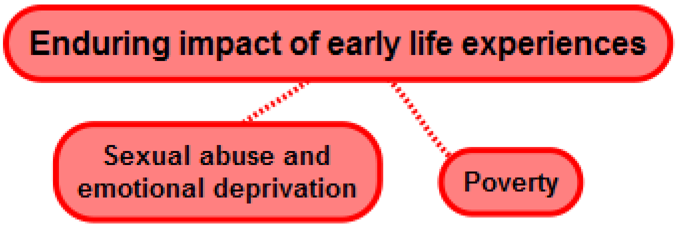

Figure 4.2: Abstracted themes contributing to superordinate theme "Enduring impact of early life experiences"

This superordinate theme illustrates how from an early age the women in the study as young girls in Malawi had a deleterious start in life, characterised by poverty, lack of opportunity, and lack of control over important life choices. While the women in the study have different life stories, the striking commonalities in their lives highlight the gender inequalities they encounter in their early life. These early experiences have had an enduring and direct impact on their current experience of living with HIV, which is why it is essential to describe these early life experiences to contextualise our understanding of the lives of WLHIV.

4.4.1 Poverty

The women in the study reported that the cycle of impoverishment begins in their childhood and continues well into their adult lives. As young girls, they were all raised in families that relied on subsistence farming and lacked basic needs. They thus had to take on menial labour at a young age to assist in sustaining the family. Participant 001 described how lack of resources for basic needs made it impossible for her to obtain a decent education.

> *Money was inadequate. Even to have decent clothes, other kind people would give us the clothes. My family was one of the poorest. To have nice clothes, oversized clothes from people were adjusted for us. When my mother or my father got some money from his house building, the care was not proper. Even getting an education was difficult. (P001).*

The economic desperation, which builds up from childhood poverty and lack of empowerment, usually leads to transactional relationships whether in an established arrangement or temporary as in the case of sex work. Eventually, their decision to marry is largely based on the same desperate need for financial support. Oftentimes, their main reason for having sex or starting a relationship is with the hope of gaining financially. Participant 010 takes care of three children, one of whom is HIV positive. She does not work but occasionally sells vegetables. She expressed that desperation has always been the driving force in her "romantic" relationships. At one point, she started a relationship with a married man while she was also married, hoping the man would support her financially. She later realised how she put her life at risk because she did not know his status.

> *What I did was to get into a relationship. But there were problems in the relationship because he was a married man. Sometimes he would bring some soap. Not even a whole shopping bag. The money would be like K500. But with the times I was going through, even though the money was not much, I felt that I was being helped. For me, I was after money. He was a popular and rich man. (P010).*

Without skills and education, exchanging sex for subsistence seems to be the obvious solution. Participant 006 had a very turbulent childhood and was introduced to sex work as a young girl by her aunt when her parents had died, and she had to earn money for her upkeep through sex with various older men the aunt brought to the house.

> *At that time, they were old men. With my age, they were not my age at all. I was just accepting because it was not my house and I had to do what she was telling me. She was telling me that in the middle of the night and sometimes I could even hear the hyenas making noise outside because where we were living was sort of near a forest. And I had no door to knock at if I was chased. And people were afraid of her [the aunt] because she used to talk a lot and tell people off so people were afraid to come and help me. When people, the neighbours, gave me some food in the afternoon and she knew that I had been given food, she would go there and shout at them. She would tell me that I should sleep with the men and that if I do not sleep with the men, I will not eat. (P006).*

This participant talked about her experiences as a sex worker in a matter-of-fact way, as if it was just any other job and a necessary thing to do. This detached manner can be indicative of how she managed the trauma of her repeated sexual abuse. When her first marriage ended, she had two children to support so she continued with the sex work. She was often underpaid, with the men taking advantage of her financial desperation. She would then sleep with more men in one night, in the hope of making some more money.

> *He took me to sleep at his house. We were all drunk. But I slept with him six times. But I was feeling pain. And I felt so weak. But the money that I left there with was K1 000. And one U fresh [bar of soap]. And a bottle of Clere [body lotion] already diluted. (P006).*

She described her position as difficult to negotiate safe sex, with most men refusing to use condoms. Participant 006 was always desperate and felt that she had no choice but to sleep with men without using protection. This suggests that sex work was a matter of necessity for her because she had no other way of satisfying her basic needs, even if it meant risking her life.

> *I could not tell how many men I slept with. I would sleep with five or six men in a day so that I should find some money. Those who would really use condoms were two or even one, those who were truthful, but the rest were just fooling me that they have put on a condom when they have not. (P006).*

The above quotations demonstrate the lengths to which systemic poverty drives women into transactional relationships. Despite the risks they take with their health, their financial needs are still unmet and they become stuck in a cycle of more sex work to earn more money.

4.4.2 Sexual abuse and emotional deprivation

This theme captures the women's experiences with sexual abuse they encountered as young girls. The abuse it seems is usually perpetrated by a guardian or older male in the community, but rarely reported because of fear and powerless position they are in, which prevents them from protecting themselves from the abuse in the first place. Participant 002 was living with her sister, who took her in to pay for her education, when her brother-in-law took advantage of her.

> *I was living with my sister at her house where she was married. But the behaviour of her husband was not very helpful. I started Standard 1; that was when my sister was pregnant. At one point, she went to the hospital*

> *and I was at home with her husband. I was preparing some bath water for her on the fire. He called me, "In-law, can you come here", and then he started touching me. He said I should not tell my sister, who was then at the hospital. (P002).*

This quotation illustrates that as young girls they are vulnerable to sexual abuse. Participant 006 expressed how she had no power over her own life and felt that being introduced to sex work by her aunt drove her into sex work as an adult, where she found herself returning to sex work in between jobs and marriages – a situation that exposed her to the high risk of HIV infection.

> *It depended on what my aunt said. If in a day she came with one person, that means I sleep with him. They would leave in the night and asked me to close the door. And then around 11 pm she would come with someone else and then leave again. She would then come with someone else at around 2 am and that person would sleep over until morning. It would be K600 and it was some money in those days. In the morning, when I was urinating, I would feel pain and even my stomach would be hurting just below my navel. She would then say, "You will be fine, you will get used to it." And I would still sleep with the men. (P006).*

Another childhood experience that featured in the women's narratives was emotional neglect. Losing parents at a young age and being raised by relatives exposed the women to emotional deprivation. In her narrative, Participant 006 felt that the lack of love and care from her family drove her to abusive relationships as an adult.

> *If there was care and love in our family, I would not have reached this point. I reached this point because there was no love in our family, nor care. I was just walking around like a sheep without someone to guide it because I needed to eat and have some money. That is why I fell into these problems. (P006).*

4.5 "I MARRIED EARLY AND HAD CHILDREN WHILE YOUNG"

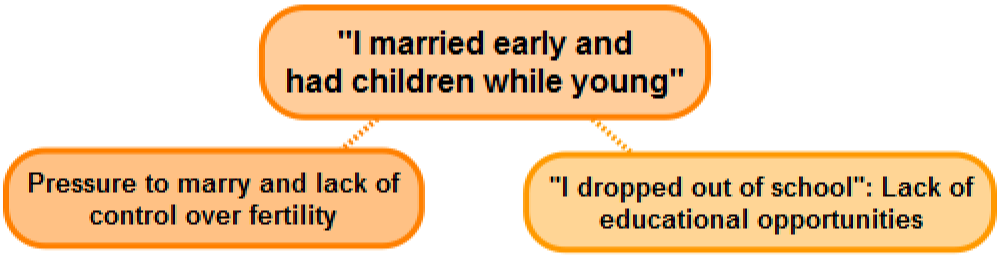

Figure 4.3: Abstracted themes contributing to superordinate theme "I married early and had children while young"

This second superordinate theme concerns the lack of control over when the women chose to marry. The women in the study reported that they did not make their own decisions about continuing with their education and when to get married. The women's narratives suggest that they were pressured into marriage as this was deemed the only way to facilitate their financial independence from their families. The women had no say over whom they wanted to marry as long as the parents and elders saw that they themselves would benefit from the marriage. It thus becomes difficult for young women to refuse to marry because respecting elders and obeying adults is a cultural obligation in Malawi. In addition, as young girls, they need their relatives' and community support in life, whatever path they choose to take. This is an example of how culture and poverty intersect as factors that contribute to early marriage and increase the girls' risk of HIV.

4.5.1 "I dropped out of school": Lack of educational opportunities

This subtheme captures the central characteristic of the roots of gender inequalities entrenched in Malawian society. From the interviews, it can be discerned that from an early age women are already in a disadvantaged position where there is not much expected from them because they are not perceived as capable of significant achievements in life. There is a lack of investment in girls' education because girls are assigned a lower status from birth. Girls rarely have the same opportunities for education as boys because investing resources in the girl child is perceived as a waste, as it is assumed that they will get married and will be under the care of their husbands.

Given this, families choose to maximise boys' education because they are regarded as a useful investment for the future. When resources are limited in the household, the girl child's education is not considered a priority. Participant 004, who did not receive an education herself, observed sadly how this scenario has replayed in her own life. In her own family, male children were given priority in getting an education, and in her marriage her husband openly favoured their only son over their female children.

> *He says that he will leave everything for the male child and not the female children. He says a female child cannot help him and is of little use. He is not very interested in female children at all. He thinks that female children cannot do anything because most girls quickly get married. (P004).*

Participant 010 reflected with bitterness about the unfair treatment she received when she fell pregnant while in secondary school and her education process ended there. On the other hand, the boy, who was responsible for the pregnancy, and who later became her husband, continued with his education while she was denied her wish to return to school after the birth of her child. She realised the lost opportunity to obtain an education and become independent.

> *Me and my husband were both in school. At that time when a girl got pregnant, they would dismiss you from school altogether. And my parents were also angry with me that I have failed my education by getting pregnant. Now I wish I had gone back to school but I wasted that time. I dropped out of school because I was pregnant. (P010).*

Most participants reported that they never completed their primary school education because their families were reluctant to encourage them to be in school as young girls and use their minimal resources on their education. Because there are fewer and fewer women in the communities completing their education, there is a lack of role models for the young girls, who consequently follow the same path of dropping out of school and marrying early. Participant 003 pointed out how she felt no motivation to continue with her education because there was simply no one to look up to.

> *I just observed that the girls that I used to hang out with have dropped out of school, so there was no reason for me to continue with my education. (P003).*

As demonstrated above, the absence of positive role models to encourage young girls to stay in school plays a role whether they complete their education or not. Interestingly, the women realised that obtaining an education would have made a difference in their life by giving them the independence that would have enabled them to support themselves and perhaps prevent them from living with the men who had infected them. The women also acknowledged with a sense of regret that they have seen their peers who completed their education going further in life and having better prospects and more options than only relying on marriage for survival.

> *What worries me is that I did not complete my education. If I did, I would have found a good job and would have been working and taking care of my children. I worry that I did not get a good education and I lost my parents early. Those are my main worries. I want my children to get educated but it is impossible because of the fees. (P005).*

Realising their low status in society, they desire to go back to school and continue with their education to try and empower themselves. However, they cannot fully realise those dreams because their husbands are the decision makers in the household. Participant 001 particularly felt oppressed by her husband, who sabotaged her efforts to go back to school.

> *I told my husband that I want to go back to school. He seemed to understand and agreed with me but he was choosing for me the school I had to go to. My husband said no. I think he is infringing on my rights. I think he sees that when I go back to school, I will go ahead of him. I just lost motivation but I would like to go back to school. (P001).*

This quotation illustrates how domineering men stand in the way of women when they want to make an effort to empower themselves. The women seem to be aware of their lack of empowerment and its implications in later life. As demonstrated above, the women are disadvantaged from a young age, with no opportunities to empower themselves, which leads them to relationships motivated by economic desperation.

4.5.2 Pressure to marry and lack of control over fertility

Following from the previous theme, this subtheme concerns how the women as young girls are pushed into marriage after dropping out of school. The women quickly learn that the major goal for them in life, as set by the society, is to find a husband and have as many children as possible. In all this, they are not involved in the decision of choosing whom they marry. Elders and parents usually recommend the man who seems able to provide financial support. In some cases, the prospective husband goes straight to the parents to seek permission to marry the young woman, without any regard for the girl's will. Participants 008 and 009's quotations demonstrate how such oppressive culture norms and gender inequalities work together to disadvantage their prospects for a good future through early marriage.

> *Life then was different from the way it is now. Because, as a child, if you tell your parents that you don't want to get married because you are not a grown up, they listen and understand. In the past, because of our culture, they would tell you that you cannot answer back at a parent. (P008).*
>
> *I was forced by my parents to get married. I refused but they told me that if you are refusing, you have to leave the home, they would chase me from the house. So I just agreed. Yes, both my parents, my mother and father, are the ones who forced me but at first I was refusing and then I just later agreed to marry the man. (P009).*

Relatives are at the forefront of encouraging marriage, or remarriage for divorced women, because marriage is perceived as a solution for the financial burden of caring for the young women. The expectation is also that when the young woman is married, she will be able to take care of other relatives with the financial support she will get from her husband. To the women, marriage is considered a sort of "career" or an investment that brings returns not only for the women, but also for their relatives. The women are thus openly discouraged to pursue education. Participant 001 demonstrates she had a mind of her own and desired to complete her education because she knew that education would give her a better future than marriage.

> *People were saying, "Why don't you drop out of school and get married?" So I got confused. Get married? Drop out of school? I wanted to get married because my parents were dead, so who would pay for my school fees? "Will you find someone to pay for your school fees?" they would say. All my books were dumped in the toilet. "Why are you refusing to get married?" I completed Standard 7 and Standard 8 and I passed. And when I reached puberty, they felt that I should get married. (P001).*
>
> *My grandmother forced me to get married. She says that I might be able to get help from that man for the family. I think that if I get married, it will bring a lot of problems and because I am also on medication. (P012).*

Participant 012, who was under pressure from her grandparent to find a man, recognised that marriage would put her in a more vulnerable position as a woman with HIV reliant on antiretroviral medication.

Just as the women do not choose to enter the marriage in the first place, they also lack the power to end the marriage. Participant 001 explained her disappointment with marriage such that at one point she contemplated leaving the marriage, and approached her brother to help her with the divorce proceedings. Her wish to end the marriage was dismissed and she was instead advised to stay in the marriage despite the hardships she was facing. She felt powerless over her life.

> *My brother said that a woman cannot end a marriage. He said there should be a valid reason to end the marriage, not just out of the blue, like just saying that you want to end marriage. He is standing in my way. I have no freedom. (P001).*

Some parents advise their daughter to get married to avoid them from falling into "temptation", which to them means getting into a relationship and getting pregnant while unmarried. As young girls, they are torn between their own wishes and obeying elders as part of the cultural expectations and to be accepted in the community in which they live. Fathers and older family members intervene to have their children married and girls cannot question their decision.

Taken as a whole, these lines of evidence support the idea that from early life, women have little control over when they get married, and do not exercise any right to choose a partner. This is a depressing insight into the fate of being born a woman in Malawi, especially in relation to HIV prevention, where the choice of a partner and the right to leave an unsuitable one are not their own.

Furthermore, because of early marriages, the women in the study have no control over when to start having children and the number of children they have because of their disempowered position. Participant 006 recalled negative experiences associated with her reproductive health, which she felt she had little control over:

> *I was having children every year and my life was so unhappy. I had a lot of problems. I grew so thin and had no care such that other people would give*

> *me food and clothes. And God was also taking away the children from me. (P006).*

Women also have more children to secure the marriage, especially for those who got divorced and remarried and the new husband usually demands that the woman has more children, even against her wishes sometimes. Participant 001, for example, who already had two children from a previous marriage, was pressured by her husband to have another child.

> *He was unhappy about me not getting pregnant. He was asking me why we are not having a child. When the problem was that, we were both HIV-positive. (P001).*

This demonstrates the lack of fertility choices that WLHIV have in their lives once they are married. Overall, in matters pertaining to marriage and childbearing, the women seemed to have no bargaining power because of their subordinate status. Solely depending on marriage for economic support creates a power imbalance, which, as will be demonstrated later, puts the women at a disadvantage to negotiate with their husbands about health behaviours that would protect them from the risk of HIV.

4.6 "A WOMAN'S LIFE IS ABOUT GETTING MARRIED"

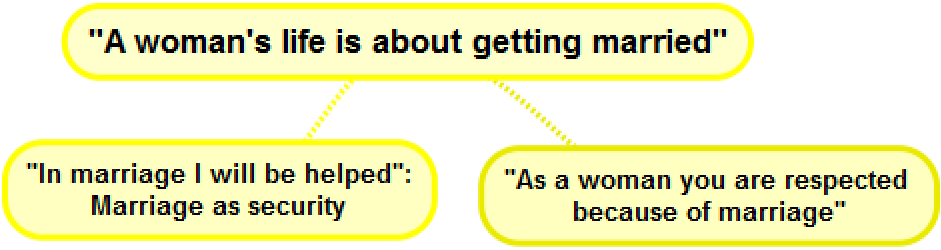

Figure 4.4: Abstracted themes contributing to the superordinate theme "A woman's life is about getting married"

This theme encompasses the meaning the women assigned to marriage and the role it plays in shaping their lives. The theme also details the complex realities the women confront in their marriages and the reasons behind their choice to stay in a marriage that places them at risk of contracting HIV. It is important to examine marriage because it is a partnership that women initially enter with the assumption that it is a safe primary sexual relationship. They expect that in marriage they will have a monogamous sexual life partner, and will be protected from HIV infection. Yet, despite being faithful to their husbands, they still became infected.

The notion of marriage in the Malawian context encompasses a gamut of relationship types, which include traditional, cohabiting, and legally bound marriages. The trouble, as clearly demonstrated by the excerpts in the section above, is that in the marriage they are often placed in a very vulnerable socio-economic position and are expected to play a subservient role to their husbands. The quotation below shows how one of the participants described what she sees as her goal in life.

> *But largely a woman's life is about getting married. Staying on your own, it just happens, but one's life is marriage. (P006).*

4.6.1 "In marriage I will be helped": Marriage as security

Although the women's experiences of marriage varied greatly, the common thread in their narrative was that marriage was too often a contract, in which they forfeited their agency for a measure of security. The women talked about their decision to enter a marriage as a way of securing financial support for themselves, and relying on the marriage for basic needs such as food, clothing, and shelter. The participants acknowledged that the decision to marry was made to alleviate poverty – both theirs and their families. The women also described that their choice of a marriage partner was not based on the man's character, but his resources, from which they deduced his ability to take care of their needs. Participants 004 and 009 explicitly acknowledged that their lives depended on their marriage. In particular, participant 009 illustrates that her desire for marriage is only for the financial security that it might provide.

> *Marriage is important because, as I have said, I did not go to school but my husband is working. He goes to find food and brings it home and helps the family. If I would get sick, he would take care of me when I am sick because there is nothing that I can do on my own. (P004).*
>
> *If I get ill, the man can help me because at the moment I am staying all alone at home. I do not live far from my mother but I still live alone. I feel like it is a big problem living alone. It's better to live with a man. Your relative will complain but a man knows what to do. I want to get married because I have no help. If I had a business, I would not want to be married as something to help me. That really worries me. (P009).*

Because the women's survival depends on marriage, the women endure living with oppressive and domineering partners. Even in the face of extreme marital problems, the women are likely to stay married. Participant 008 felt that since marriage is the only option for a woman, it is expected and acceptable that it involves a sense of struggle and ongoing pain.

> *They [elders overseeing her marriage] would just say persevere because that is my marriage. When the elders would come to talk to us, my husband would explain to them that I had started it because I was saying things to him. That he did not want to beat me up but I did things that made him hit me. I stayed on because I was there for marriage; I had to live with the man. (P008).*

The above quotation demonstrates that despite the adversity, the women reported going through within their marriages, they felt a moral obligation, underpinned by explicit sociocultural pressure, to persevere with an abusive marriage. They carry the burden of sustaining the marriage, which is to ensure that the husbands' needs are always satisfied. Participant 002, for example, felt that the responsibility of keeping the marriage working belongs to the woman.

> *The man's role is to find food. But for the marriage to survive, the woman should worship the marriage like an egg. If this egg falls from my hand, it will be broken. (P002).*

4.6.2 "As a woman you are respected because of marriage": Marriage as a source of respect

This theme regards the idea that the women perceive marriage as a symbol of moral status that earns them respect in their community and society. Because the girl child has a lower status in society than the boy child, marriage becomes a condition for a woman to achieve a higher status. The girl child does not grow up with confidence in herself; hence securing marriage validates her. Because of the perception, society has about married women as good and morally upright, psychologically the women seem to internalise that the main condition for self-worth is marriage. The women described marriage as a social currency, which gives them value and worth when they become a wife and a mother because it is only in relation to their husbands that they have a place in the community. Additionally, as one participant 009 below and then Participant 003 further below suggest, if you are unmarried, you are seen as a threat to other marriages.

> *To be respected as a woman in the community, you are respected because of marriage. People may think their husbands are at your house if you are single. In marriage, you are respected that this is Mrs so and so. But when you don't have a husband, you are not respected. (P009).*
>
> *When you are not married, you become lost. You just do things your way when you are not married. When you are married, you say to yourself, "I should respect myself." One just decides to stay married. Even when a woman is married to a poor man, not well to do, but you are still married; people respect you because you are married, even the people who see you around. (P002).*

In addition to the social enculturation that attaches a woman's worth to marriage and motherhood, Malawian society values group social identity, and marriage can sometimes be seen as a rite of passage that enables a girl to join the conventional group of elderly women and hence establish her identity and place in society.

For women who are not empowered, like the ones in this study, marriage gives them a sense of community, which enables them to be involved in contributing to their society. Women thus fear cultural deprivation if they do not marry or do not stay married. Participant 003's narrative shows that she liberated herself from attaching her value to marriage when she made a choice to leave her husband after she caught him cheating.

> *Single women are perceived as women who disrupt other marriages, as if they sleep with a lot of men. But to my side, I rubbed it off and said, "Everyone should say what they want as long as I know what I am doing." (P003).*

Surprisingly, this description of a woman as either married or a socially undesirable misfit seems to have been internalised by the women. Thus, a woman's only choice sometimes is to get married, even to the most unsuitable partner and this explains why most women remain married despite experiencing challenges, to avoid the stigma of being a ridiculed single woman. Participant 006 made a conscious choice to stay in abusive marriages to avoid facing social rejection and the stigma attached to unmarried women.

> *If you are not married, they just call you disrespectfully by your first name. But when you are someone's wife, they will refer to you by his name. When you are not married, you will be called a prostitute or someone who sleeps around. You just want people to say, "This woman is married." Even though you are facing problems, you just want to be married. (P006).*

This shows how the apperception that single women are promiscuous can further lock women into abusive marriages. Most of the participants in this study reported that their first sexual partner was their husband, who subsequently infected them.

> *Apart from him, I have never had any relationship. He was the first and only one. After him, I have never been in any relationship. (P012).*

In summary, marriage has a special meaning to women's identity in Malawi. Women stay married for basic survival and also to gain a certain status in society. To sustain the marriage, they must often subjugate themselves to the demands of their husbands. Additionally, this means that they are deprived of the psychological empowerment to make the decision to leave their marriages. Thus, vulnerability to HIV is not only about financial empowerment, but also the mentally disempowering attitudes that women have internalised about their self-worth as dependent on marriage. It also seems that marriage is important because women fear experiencing double stigma – as a single woman and as a WLHIV. Being HIV positive already attracts labels of immorality, and being single and HIV positive would only reinforce that stigma.

4.7 "A WOMAN IS A SLAVE TO THE WORLD"

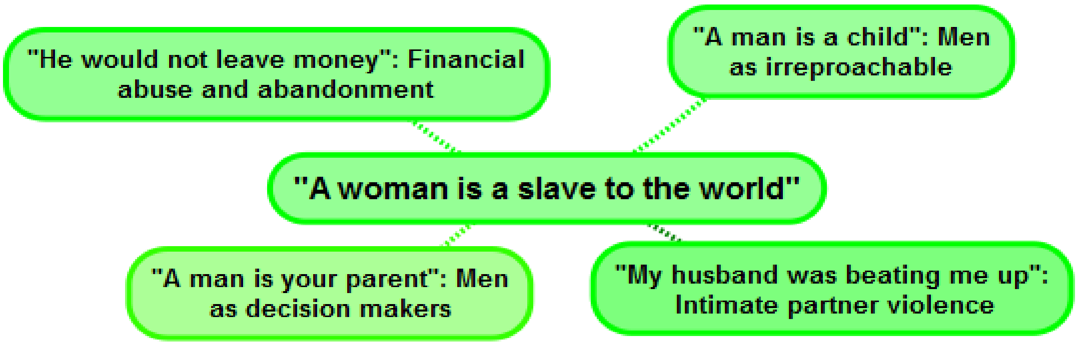

Figure 4.5: Abstracted themes contributing to the superordinate theme "A woman is a slave to the world"

This theme describes how the subordinate status Malawian society assigns to these women in relation to the men, positions them in such a way as to bear the brunt of the impact of HIV in their communities. The women in the study reported the unfairness they have to live with, such as being expected to take care of their sick husbands and children while they have no-one to take care of them. When the women are sick, on the other hand, the men leave them and find another wife. Usually when the men learned about their diagnosis, they abandoned their wives, and then returned to them when they fell ill to be supported and to recuperate from the illness. Despite being constantly subjected to rejection and abuse, some of the participants stood by their sick husbands when they needed care. The women feel that it is their role to take care of their husbands, although the men rarely seem to stand by the women. The women have to deal with their own diagnosis and care for their health but also take on a caregiving role for husbands who do not support them. The stress for these WLHIV is thus doubled because of caregiving roles. Participant 008 described how women are oppressed by cultural expectations of their role as caregivers.

> *What happens is that there are not many men who can take care of their wife when she is sick. For us women, when our husband is sick, we take care of the husband because if you would leave the man then, people would say that you have run away because the man is ill. When a man notices that the wife is sick and she is losing weight, because you have lost what made the man propose to you, maybe you were looking in a certain way, it is like a burden to the man. (P008).*

The women's stories also suggested that their oppression is characterised by the way men feel entitled to demand sex from their wives at their convenience, regardless of the emotional and physical state of their wives. The women found it unfair that sex happened when the man wanted it and not vice versa. Narrating her experience, Participant 006 felt that as a woman, she did not have a say about when sex should occur, and in her marriage she had sex to comply with her husband's wishes – violently at times.

> *I told him I had a problem, when I am at the toilet urinating I am feeling pain. And when I was sleeping with him, I was also in pain. He did not take it seriously; we did not do anything about it. I would feel itchy and then I would develop sores and the sores would burst and then I would go and seek some medication. I would use the medication and the sores would go*

> *but my husband did not stop sleeping with me. If I refused sleeping with him, he would beat me up. He would only stop when I was bleeding. He would tie up my hand and legs. He would stretch my legs and I would just feel weak and he would do what he wanted. I would think, should I take these issues outside my home? I just persevered because I wanted marriage. (P006).*

The comments suggest that for the participants, there is an expectation that the wife, as culture dictates, is the man's property and must yield to the husband's sexual demands even in cases where they suspect risk of infection. Seen in the light of HIV prevention, these patriarchal forces that shape the women's personal space render women powerless over their own health, undermining all the efforts geared at improving their health.

Women's subordinate position is also reflected in how the participants shoulder the responsibility of keeping the marriage together; failing which the woman is to blame for negative outcomes that may occur within the relationship. The women believe that their role was to make the marriage work and if it failed, it was due to something inherently wrong with them that they need to remedy.

> *Even in the Bible, they say that a wise woman keeps her marriage with her own hands but a foolish woman destroys her marriage with her own hands. (P001).*
>
> *A woman should listen to the man and not be above him. If you answer what he says in a rude way, he says, "This woman does not listen to me" and go and have many affairs. In the end he will bring you problems. If you will be rude, he will go to other women and when he comes back to you, you cannot even refuse to sleep with him. He may bring you problems because you are not talking to him in a polite way. (P006).*

These reflections about women being solely responsible for what happens in marriage might explain why many women are blamed and stigmatised for bringing HIV into the family. The women's use of Christian scriptures to justify shouldering the burden of keeping a marriage together extends to blaming themselves and having feelings of guilt and shame because of their HIV diagnosis. It also illustrates the way in which biblical and cultural discourses are combined to keep women in their marriages, even abusive ones.

4.7.1 "A man is your parent": Men as decision makers

This subtheme concerns the perception these women have of men as the head of the family, responsible for making decisions in the household. The women in the study explained that upon leaving the families in which they were raised, getting married gives them a new parent to look up to – their husband. The man is considered the parent because he sustains the lives of the people in the household and as such, he has total authority over the members of that household.

> *A husband is like your parent. The way a parent takes care of their child, is the same way a man takes care of a woman. (P002).*

The notion of men as decision makers becomes a problem for WLHIV when they need to make decisions about their own bodies. In such circumstances, if a woman were to decide to take care of her health against the husband's wishes, it may be seen as a sign of disobedience and a challenge to his authority. To avoid confrontation, the women listen to the men even though it might not be good for their health. For example, Participant 003 did not want to have any more children and decided to protect her life after traumatic birth experiences by getting sterilised. The matter was discussed in the family and, at first, the husband seemed to half-heartedly agree but was not happy when she went on with the procedure and the husband abandoned her.

> *I opted for sterilisation. My husband did not like that I decided to get sterilised. Because of that reason he decided to marry another woman. I told him to go ahead with the other marriage because he may have wanted to have children. (P003).*
>
> *I wanted to be sterilised but it was difficult for me and my husband to agree. We did not reach an understanding. Yes, I did not agree with my husband. At first he agreed that I should be sterilised after I have the last child. Then when the child was born, I was ready to be sterilised. The day that I wanted to go, my husband refused me going to the hospital. (P007).*

From the comments above it seems that the women have little power over their own bodies, with the men as the decision makers. Their subordinate position in relation to men denies these women their SRH rights. What this demonstrates is that contraceptive methods might be made readily available for women, but if they have no support and power in their personal spheres, as the quotes above suggest, they will not fully benefit from these services because they fear disrupting their marriages especially when men are considered the decision makers.

4.7.2 "A man is a child": Men as irreproachable for having extramarital affairs

This subtheme encapsulates how the women encounter and explain the rampant infidelity in their marriages. Stories about men's serial extramarital affairs featured frequently in the women's accounts. Despite the men's behaviour, the women largely condoned the affairs, took away responsibility from the men, and found ways to explain away their actions. The metaphor "the man is a child" means that in the same way a child is not responsible for his or her actions, the man is not responsible for the sexual exploits he has outside the marriage that endanger both of their lives by heightening the risk of HIV infection. As such, the women should be quick to forgive the men for the infidelities because they are not fully aware of their actions. Participant 011 explained that women should instead be more understanding of the nature of men as lacking self-control like a child.

> *Well, there are some men, but it is acceptable, but some control themselves while there are some who do those things [infidelity]. They want everything to be theirs. So we put those men in the group of children. You give them [children] an object, they want something else. You give them something else, they want something else and they will start picking other things. (P011).*
>
> *The woman is supposed to work harder at keeping the marriage, because between a man and a woman, the child is the man. (P006).*

The women rarely, but mostly never, have any affairs outside marriage but still tolerate multiple affairs by their husbands.

> *He then had a second affair when we were living at this other house that we moved to. He would never show up in the evening and he would lie to me that he was at work. And then he would also disappear for two days and say he was at work although he would still take care of the home. (P004).*

These infidelities took place with full knowledge of their HIV-positive status as a couple. The women, on the other hand, became much more careful with their health in general. Indeed, HIV infection may be seen as giving permission to be unfaithful and have multiple sexual relationships. Participant 004 explained how her husband reasons that because he is already infected, things could not get any worse if he continues having affairs.

> *With my husband, he thinks that just because he is HIV positive and taking medication, he should just keep on doing what he does [having affairs] randomly. (P004).*

The women also spoke of sexual double standards whereby women are expected to be sexually faithful while it is acceptable for men to pursue multiple sex partners. The women recognise that infidelity is a moral issue, where men and women are judged according to different standards. Participants 001 and 012 appeared to accept this dynamic.

> *There is a difference between affairs that women have and affairs that men have. To find a man with a woman, the marriage never ends. But when a woman is caught having an affair, the marriage ends there and then. (P001).*
>
> *If it is the woman who has an affair, the marriage can end, while if it is the man who has an affair, the marriage survives and you can discuss. (P012).*

The women are reluctant, if not unable, to leave the marriage despite evidence of infidelity. In some cases, the men's affairs result in a pregnancy, clearly indicating that the man was involved in unprotected sex at some point, which might put both of them at risk. The women acknowledge affairs as a form of cruelty because of the fact that the men put both their lives at risk. The women seem to take comfort in the fact that the man always came back to the wife when they have the affair. Participant 005 explained how she lost count of the times her husband left her to live with other women, only to return to her.

> *My husband has been with a lot of women. While with me, he has married five women. He would go and marry another woman and stay there for a month, and then come back to me after the marriage ends with that other woman. (P005).*

The women seem inclined to quickly forgive the men, lifting responsibility from the men's shoulders and firmly placing it on theirs. This is a self-defeating tactic, which lets the guilty party off scot-free while the women are left to wallow in failure and self-blame for the infidelities of their husbands. They internalise the perspective of men, which is that if the woman provides for every need, the husband would not seek extramarital sex. Participant 011 seemed to believe that she has to sleep with her husband at any time, even at times when she is not happy about it to prevent him from having affairs.

> *I think they are not satisfied. They don't want to be satisfied with the women they have. The men want to see a difference. We women also have a problem. Women are rude and we also refuse to sleep with the man without any valid reason so the man gets frustrated and the man goes out to sleep with other women. (P011).*

This excerpt illustrates how wives can be blamed for their husband's infidelity, and how the threat of an unfaithful husband brings pressure on wives to meet all their husband's sexual demands. The coercion that results from the threat of infidelity goes further: the women are coerced to be compliant, submissive, respectful and humble towards their husbands, as the following excerpts show.

> *Men have affairs because the woman is not giving the man enough love but also because of the way you talk to him. A woman has no power to challenge a man that she can leave the marriage. As a woman, your place is to be humble. (P002).*
>
> *Most men have affairs because the woman is rude. With us women, we are of several kinds. There are other women who do not take marriage as a marriage. And there are other women who take care of the marriage. They know that this is my husband but also my parent. If I have left my family, everything else about my life is in the man's hands. (P006).*

All participants appeared to think that men have affairs because the wives are not properly intimate or are unaware of the man's needs. Participant 008 specifically mentioned a lack of open communication between wives and husbands about their sexual preferences as a cause of extramarital affairs.

> *Maybe in the bedroom you are not being free with your man. There might be things that he wants or likes, instead of telling you that this is what they want, if you do these things for me I will be satisfied. And when they go somewhere else, they experience those things with other women before they*

> *even tell them. Those women are after the man, to lure him. But for us women who are married, we ignore all those things. It does not matter that we went to various initiation ceremonies, that when we get married this is what we are going to do. When you are married, you don't think that the marriage will end. A lot of women let go. When the men go and have affairs, that is when they find a woman that is free with them. (P008)*
>
> *Yes, there are other women who are not free and open with their husbands and some women cannot initiate sex. Some women also sleep with their clothes on. But also if the man is not free with the woman. We should be free with each other. (P001)*

The interviews also exposed why the women tolerate and even blame themselves for the men's infidelities. The apparent perception that men possess an innate, biological predisposition to have multiple sexual partners confers on them a 'right' to pursue women. The conviction appears to be that men have an insatiable sexual appetite are therefore incapable of fidelity. Alongside this is the perception that men are lured by other women to be unfaithful, further alienating men from their actions.

> *It's not possible for a man to have one woman. (P005).*
>
> *There are also women who are prostitutes who sleep with men to find food to eat. They should be restricted. Not let them go to bars and do whatever they want to do. Renting rooms and the like. One woman may sleep with five men. (P011).*

While these infidelities clearly put the women at risk of sexually-transmitted infection and reinfection, the secondary consequence of extramarital affairs are that financial resources are diverted from the household to the home of the man's new sex partner. Hence, women are reluctant to question the man about his infidelities for fear of being cut off from financial support. Thus, the social dynamics of infidelity are shaped by economic inequality, where men have several women because they have the financial power.

> *When he started seeing this other woman, he forgot all about taking care of me and his home. I did not know what was happening. When he did not show up at home, he would lie that he is in Blantyre selling the planks.*

> *After he spent all his money, he had a motorbike, he sold the motorbike and now the affair came to light. (P004).*
>
> *He would be away for three days without coming home. He was not sleeping with one woman only. He would say that he has a lot of money. (P006).*

Because there is a sense that the man's infidelities are a result of the woman's inadequacy, some women try to remedy the situation with traditional medicine. The women feed the men traditional herbs in an attempt to make the men love them and stop being promiscuous. Through their actions, Participants 006 and 011 embodied the self-blame or responsibility that women carry in marriage when things go wrong and the belief that they are responsible for men's behaviour.

> *I was using traditional medicine because I thought that he would settle down. (P006).*
>
> *I have used traditional medicine before. It has these thorns and we mix with some roots and some sticky things and you give it to the man in the food like vegetables. Something that the man will not detect. The reason is that the man should settle down, he should not be having affairs. (P011).*

Important to note is the sharp contrast between this view of "the man is a child" and the theme discussed earlier of "the man is a parent" as the decision maker in the family. Both these contradicting notions of masculinity have been internalised by the women and they use them to justify and make sense of the challenges in their relationships.

Exploring the same issue further, the women described how they exercise agency over their health. Although the women are already infected, when they suspect their husbands of cheating, they attempt to protect themselves by confronting them about their affairs. Agency involves assessment of risk and an attempt to change risky behaviours. If the men do not change, the women attempt to protect themselves by refraining from sex. Against the behaviour of the men, the effort to withhold sex to keep themselves safe is insufficient and inadequate to protect them. A few months before her diagnosis, Participant 007 attempted to protect herself by confronting her husband about a woman he was seeing.

> *I told my husband that from the look of the woman you are seeing it is possible that she has got a problem [HIV]. She looked very thin and it did not look like it was her natural body [the thinness]. She looked sick and her lips were red. My husband said, "No, she is fine, she is just like that." We agreed that we should continue living together. While we were still living together, that is when I fell pregnant and got ill. Then I went to the antenatal clinic and they found me HIV positive. (P007).*

Another self-protective strategy the women employ is to ask their partners to use condoms in the relationship. Participant 011 described how these attempts to protect themselves sometimes backfired:

> *When you suspect that your man is sleeping around and there is real proof, you can also feel like you don't have to be intimate with him while he is having other affairs. You want to take care of yourself. You might ask him to use a condom but he might not want to use a condom so he might go out to other women and not use a condom. (P011).*

One participant suspects that by refusing her husbands' sexual advances, he retaliated by having sex with other women to punish his wife.

> *I started to refuse to sleep with him when he was not taking the medication and having affairs. It is possible that could be the reason he went out and found another wife. (P003).*

On other occasions, to control the men's infidelity, women might initiate sex to try to 'satisfy' their husbands so that they would not seek it elsewhere, but this shift in roles might also cause them some discomfort. Often leaving the marriage is not an immediate option, because they are dependent on the man for financial support. Given empowerment and financial independence, the women said they could opt to leave the marriage. Others might be resigned to remaining in the marriage when the man had been having affairs for a while, as there was little reason to leave if they had already been infected with HIV.

> *Well, he had already started having affairs even before I asked him about it. I had heard that he was having an affair with this woman and that he was sending some things to her home village. That is when I got angry and*

> *asked him. So he said it was better for him to marry another woman. (P009).*

With the traditional setup of marriage, where elders are involved, making an independent choice about staying or leaving the marriage is difficult for women because family matters are decided by the elders. Therefore, they might not necessarily support the decision for a woman to leave her marriage.

Malawian tradition dictates that elders preside over the marriage matters of their nieces and nephews. The women thus have little power to leave the marriage without consulting the elders, who might advise otherwise. Autonomy is thus not fully exercised by the woman because consent is gained from the relatives and their choice depends on who proposes (Mwambene, 2010).This demonstrates how culture works against women when they wish to exercise agency to protect themselves when the husband has sex outside of the marriage. They lack the moral support structure and financial independence to enable them to leave a risky marriage.

Enduring these frustrations encourages some of the women to have affairs themselves to deal with the disappointment of their men's affairs. These are in retaliation to the men's infidelities and provide temporary relief to the women for failing to control their men. Participant 001 explained that her husband had an affair with her friend, who was also attending the clinic. She clearly did this in response to her husband's behaviour and to feel desirable again.

> *Because my husband was in other relationships, that is why I also started this relationship. I also wanted to show him that other men ask me out so I did it to get even. (P001).*

She further explained that the affair helped her to feel happier because she was usually worried and sad when she thought about what her husband was doing.

> *He [the man she was having an affair with] was just removing my worries. I would just differentiate with what I was experiencing at home. The way he was treating me just made me happy and not be worried but at home I was all worried. (P001).*

Women are also tempted to have extramarital affairs because of economic desperation. Participant 006 explained that she had three affairs to find resources for herself because her husband did not take care of her in the marital home.

> *One of the men gave me money. And the other gave me a bag of maize. The other one gave me a mosquito net. The only thing that I found of benefit was the maize. The man who gave me the bag of maize and K200. He [her husband] caught me with the bag of maize and started beating me. I told him the truth, that I had an affair and someone gave me the bag maize. Because my husband also liked having affairs, he did not say much and said we will all do what we want. (P006).*

To summarise this subtheme, from the women's experiences, it would seem that their partner's infidelity and less often their own infidelity pose the greatest risk of HIV infection, but infidelity is often tolerated by women so as to keep the marriage intact. It has become apparent from the quotations that being married does not mean sexual monogamy for the women. Despite their husbands' infidelities and the risk, the men's affairs pose to their health, the women prefer to stay married rather than face the social stigma attached to being unmarried and HIV positive. Culturally, men's extramarital affairs are seen as normal masculine behaviour because it is believed that the men naturally have an insatiable sexual appetite. Marriage unions characterised by affairs means that marriage does not protect these women from HIV infection but in fact put the women at a higher risk of HIV infection and reinfection.

4.7.3 "My husband was beating me up": Intimate partner violence (IPV)

This superordinate theme captures the violence that women often encounter in their marriages. Several of the participants reported experiencing violence and some form of abuse from their husbands and partners. The violence could be triggered when the woman questioned the man about his affairs, disclosed her HIV status, and in some cases when the woman refuses to have sex.

Although the women acknowledge that violence is unacceptable because it has negative consequences, financial dependency forces the women to endure the abuse. This helplessness affects their self-esteem to the extent that they start to blame themselves for the violence.

Most cases of violence in the marriage are not reported to the police because of fear of upsetting elders, who believe marriage matters should be kept confidential to protect the man's dignity. In addition, they reason that in the case that the man, who is the breadwinner, is arrested, the wife and children will suffer. Participants 009 and 006 spoke of their experiences of violence in marriage, with no repercussions for the men on the rare occasion when they reported the abuse.

> *My husband was beating me up. He beat me up because I asked about another woman that he was in a relationship with while we were married. I said a lot of things and he did not like it so he would beat me and my face would get swollen. If I had reported it to the police, they would have arrested him so my brothers just said I should leave it. (P009).*
>
> *In my second marriage, my husband was just putting his fingers in me to inspect me. He would do that anytime he comes home. He would tell me to take off my clothes and he would put his fingers in me and inspect me. He would then go out and come back at 11 pm at night. We would not even sleep together. He would just do that for a period of up to two months. I reached the point where I got sick. My pelvis would hurt when I was urinating and I had to go to the hospital and explain to them. They asked me if the man I was sleeping with has a problem. I told them that we are not sleeping together but that he had been putting his fingers in me to inspect me. So one day he put his fingers in me but hurt me, I was bleeding. I went to the victim support unit where they deal with domestic violence in marriage. I explained to them. The victim support unit gave me a letter summoning him to go the police unit. He did not go. (P006).*

With Participant 006, her jealous husband constantly physically abused her but faced no consequences for his actions. Confronting her husband about his affairs was met by violence, seemingly to reasserts his authority.

> *When I heard that he is with another woman, I was disappointed. And then I gave him a call. I told him that I had heard that he was with another woman. I asked him what he was doing with another woman. So he came back home all wound up, so he beat me up. He slapped me. (P001).*

Aware of the women's desperation that marriage is their only means of survival; the men dismiss the women when they stand up against the violence. Participant 006 expressed an awareness that violence in marriage is wrong and the fact that the man provided material needs should not be a justification of the abuse.

> *He was not sleeping at home and when I ask him where he slept, he would beat me. He would cut me in my buttocks and I would be covered in blood and wounds. When I ask why he was doing it, he would say, "What do you need here? Am I not feeding you?" And then I would say being fed and marriage are two different things. (P006).*

This excerpt reveals remarkable strength in the face of such chronic abuse, but it also illustrates the lack of support for women who experience violence, and that there are few consequences for the men who inflict the violence, to deter them from repeating the abuse.

4.7.4 "He would not leave money": Financial abuse and abandonment

This subtheme captures other types of abuse that the women experience in addition to violence. Emotional and verbal abuse is most commonly experienced after disclosing their diagnosis to their husbands. The participants in this study also reported being abandoned by their husbands, without regard for the marriage contract and the obligations the husbands have in the family unit. The following quotation captures this.

> *I have experienced that [emotional abuse] before in my marriage. After the diagnosis, he was saying I have deteriorated and I am not as I was before, especially with the way my body was looking. He was saying that even if I leave the marriage, there is nothing for me when I go back to my home village. (P008).*

Women are susceptible to the abuse because the men control the finances. Although women contribute to the household, they lose out when the marriage ends and they are left without any financial support for basic needs. This lack of support affects the women severely as they also have the responsibility of taking care of their children. The following quotations illustrate how women feel unsupported.

> *When he has money, he goes to sleep with women. He is a painter and he gets a lot of money when he finds a job. But he goes and gets women with the money and leaves nothing for the home. (P001).*
>
> *He would not leave any money. I rely on my garden. (P005).*

Within this setup, divorce, separation, and remarriage are common occurrences, because most unions start out as traditional cohabitation and remain that way with men benefiting more from the arrangement than the women. When the marriage ends or when the men die, the women suffer, with no arrangement for proper sharing of property accumulated in the marriage. The women find themselves in a desperate position and the only solution for them is to seek another man to marry to alleviate their poverty. The following extract demonstrates this relationship cycle.

> *My husband died and then we were back to having a burden of having no care. We were in dire straits. At that time, I started making doughnuts. And that's when I got remarried to find some financial help. (P004).*

These serial and concurrent marriages sometimes lead to a polygamous setup. Polygamy may be "official" when it is for religious purposes, or unofficial when the man just decides to marry another woman. In some marriages, the women do not even know that their husband is married to other women. Participant 006 explained how she learned that her husband was in a polygamous marriage.

> *My husband spent two months at my house and did not go to the other woman's house. The other wife followed him to my house and started insulting me that I am just holding the man to myself. I should know that there are three of us in the marriage, so I should not just spend a lot of time with the man. (P006).*

The men marry and even father children with the other women they marry, sometimes without the knowledge of the wife, but they still live together as husband and wife. Participant 003 was in denial at first when she learned that her husband had another wife.

> *I knew that he had married again when there was a child born there at the house of the other wife. Some people told me but I did not believe because the woman used to come and buy things at my shop. When I asked him, he*

> *refused. So this other day I walked to the house and caught him there. (P003).*

In these newly established relationships, there is no disclosure of HIV status or past sexual history. As a result, when the HIV diagnosis is known, it becomes difficult to understand "where it came from". Participant 004 recalled how she heard rumours about the HIV status of her husband's ex-wife but failed in her attempts to get him tested for HIV.

> *I asked my husband, "Did you ever go to the hospital with your ex-wife to get tested because she is saying that you have HIV because when she got sick, she got tested?" My husband refused and told me that the woman was just trying to spoil his reputation because the marriage had ended. (P004).*

To summarise, these interview extracts demonstrate how married women are at risk of being infected with HIV by their husbands because they lack the financial independence needed to leave the marriage and stay on their own. Polygamy, multiple sex partners, and concurrent marriages mean the women cannot control the risk of infection or protect themselves from infection.

4.8 CULTURAL NORMS SURROUNDING SEX

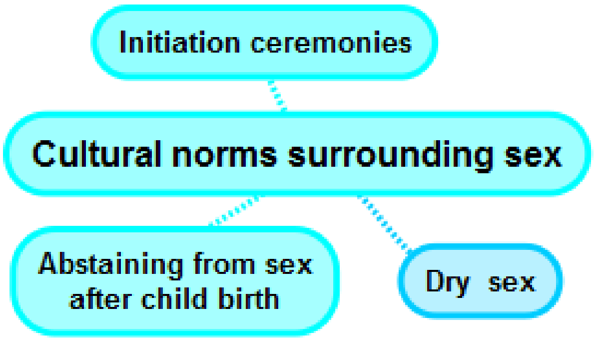

Figure 4.6: Abstracted themes contributing to the superordinate theme "Cultural norms surrounding sex"

This final superordinate theme in this chapter captures some of the cultural traditions, practices, and attitudes that influence sexual behaviour and define the value of women in the society. The initiation ceremonies are loaded with sexual messages, and groom young girls for their role as women.

4.8.1 Initiation ceremonies

Participating in an initiation ceremony is a rite of passage for many Malawian women and acts as a mechanism for social cohesion and a condition to be accepted in the community as an adult (Munthali & Zulu, 2007). Initiation ceremonies symbolize that one is not a child anymore and can have sex (Munthali & Zulu, 2007). At these ceremonies, they impress on young girls the role of elders and parents in society as authority figures that one cannot question. The ceremonies are centred around advice given regarding the expected ways of being a socially desirable woman and a good wife.

> *They were talking about traditions surrounding how women should behave when married. (P003).*
>
> *They tell young girls things they are not ready for, things that happen in marriages, because they don't tell you about school, they tell you about marriage. You learn about those things from the initiation ceremony and start thinking about those things. (P011).*

The advice offered to the young girls in these initiation ceremonies is carried well into womanhood and influences their attitudes about marriage as they easily slip into the subordinate role of a wife.

4.8.2 Abstaining from sex after childbirth

This subtheme captures cultural beliefs about reproductive health and their relationship to intimacy. Culturally, women are advised to abstain from sex with their husbands for six months after childbirth. There are beliefs that resuming sex earlier than the six months' wait has a negative impact on the health of the child and the woman. Participant 010 described how she practised abstinence with both her first and second child to protect her health and that of her baby.

> *They told me that I should stay for about six to seven months without sleeping with a man. They said that at that time it was easy to get pregnant again. They say that time the uterus has not gone back to its normal size. They also said that if a woman sleeps with the husband too soon, you might hurt the husband because you still have bad blood in your body. They also*

> *told us that for the child to grow healthy, we have to wait for six to seven months without sleeping with a man. (P010).*

She further explained that during this waiting period, she worried about how the man would satisfy his sexual urges and that if he was ignored, it might drive him to sleep with other women. Thus, the elders taught her how to temporarily relieve the man during this period.

> *You can take the man's member and put it between your legs and just make sure that there is enough friction until he climaxes so that the sperm does not get inside your body. (P010).*

This prolonged period of abstinence from sex may be a contributing factor to extramarital affairs for domineering men who are unsatisfied.

4.8.3 Dry sex

This final subtheme regards men's sexual preferences for having dry sex. Although the men do not communicate about their sexual needs, the women get the impression that men do not like it when women produce fluids during sex. Dry sex indicates to the man that the woman has not been seeing other men.

> *Some men don't want the vagina to be wet, they want it to be dry. Men say that they want a woman to be dry and not wet. They want the woman to be dry and he should be the first one to release discharge and not the woman. (P001).*

Knowing that the men prefer dry sex, the women use herbal concoctions to dry their vaginas to make sex pleasurable for the men. Participant 006, who was in sex work, described how she used traditional herbs to drain the fluids from her vagina to make it dry so that she could sleep with more men in one night.

> *There is traditional medicine. A woman can sleep with several men, four or five, like I said I did. You can put the traditional herbs there [in the vagina] and sleep with a man. Then another man comes and he does not feel that you have slept with a man. There are some herbs that you can put in the vagina in the morning and your husband will not know if you have slept with another man. (P006).*

Such practices may in fact increase the risk of HIV transmission by disturbing vaginal flora and causing irritation and inflammation to the vaginal lining (Levin, 2005).

4.9 CONCLUSION

This chapter reported the themes that reveal the socio-cultural context in which the participants of this study exist. The information contextualises the circumstances surrounding their relationships, and how these circumstances have a strong influence on the decisions they make about their health. The participants' disclosure about their life stories provided a rich contextual backdrop and how they frame their experiences of living with HIV. The women reflected on their deprived backgrounds, lack of educational opportunities, and conditions that led to their early marriages. The themes also demonstrated that marriage plays a pivotal role in their lives and constitutes a large part of their identity. Yet marriage often comes with financial dependence and abuse that, in turn, increase the risk of HIV infection. While the themes reported in this chapter are drawn from the experiences of the 12 women who participated in the study, it is worth remembering that the experiences of poverty, culture, and low education are common in Malawian rural communities. Despite the challenges the women face in their marriages, the women do not just helplessly accept their circumstances. However difficult it is in their position, some attempt to resist the oppression and subjugation but in the cases of the participants, their efforts are usually unsuccessful as a variety of cultural and financial constraints tie them to their situation. Important to note is how all these factors overlap and sustain each other. Having described the socio-cultural context, the next chapter presents themes that illustrate the actual experiences of receiving an HIV diagnosis.

CHAPTER FIVE:

RESULTS (PART 2): THE EXPERIENCES OF BEING DIAGNOSED WITH HIV

The journey of healing then starts with personal stories, personal histories
which become 'a river or life'.
- Mamphela Ramphele -

5.1 INTRODUCTION

This chapter follows from the previous chapter, which discussed themes concerning the life stories of the women and their prominent socio-cultural experiences, and moves on to discuss the themes representing the actual experiences of being diagnosed with HIV and issues related to receiving the diagnosis. The research question addressed in this chapter is: *What are the actual experiences of being diagnosed with HIV?* The interpretative level of analysis identified four main themes that capture how the women psychologically experience their HIV diagnosis, how their diagnosis affects their decision-making about matters related to their health, and their experiences with accessing treatment.

5.2 SUMMARY OF THEMES

Four main themes regarding the actual experiences of receiving an HIV diagnosis emerged from the data, namely a) Learning about diagnosis, b) Psychological reactions to their diagnosis, c) Impact of diagnosis, and d) Access to treatment and SRH services after diagnosis.

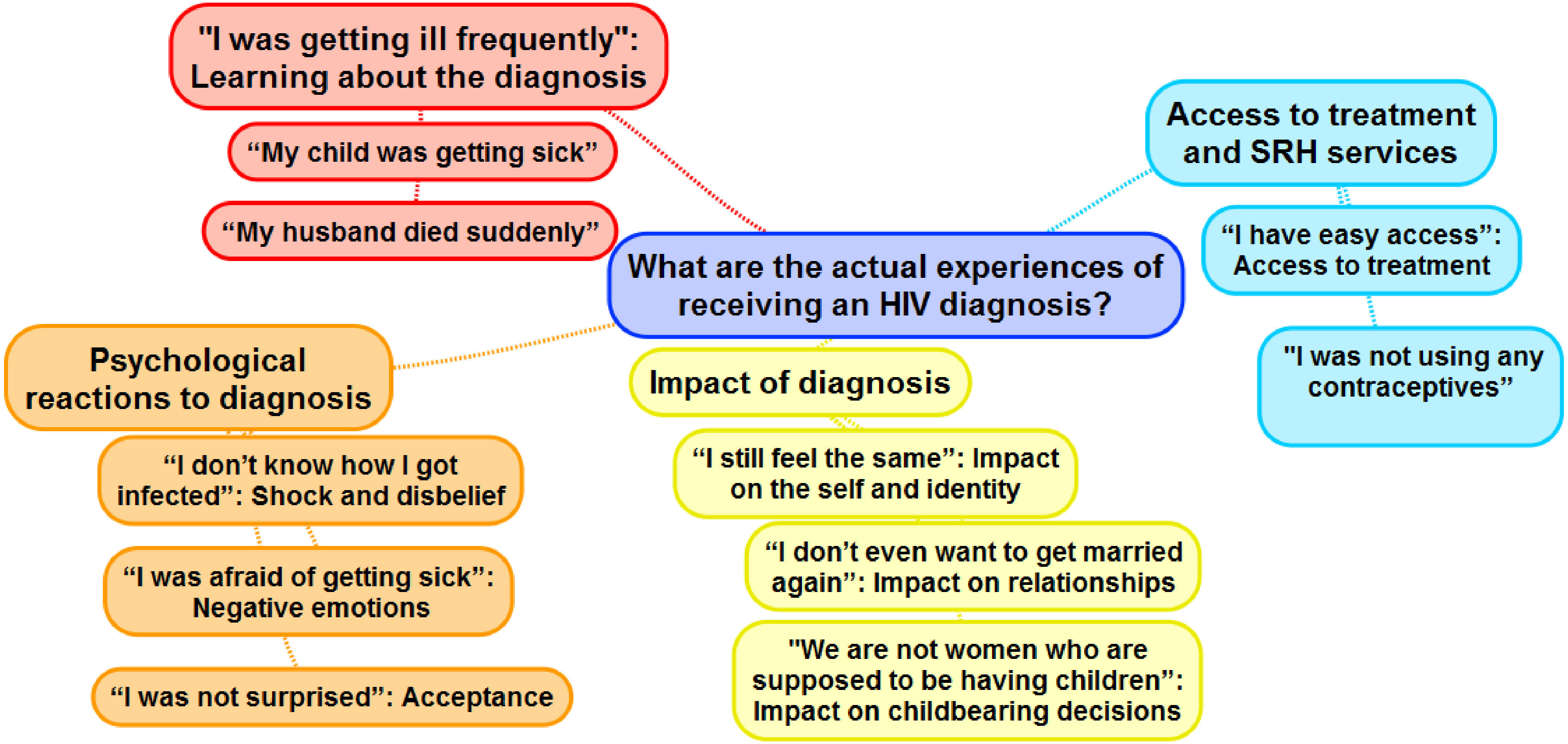

Figure 5.1: Summary of themes (Part B)

5.3 "I WAS GETTING ILL FREQUENTLY": LEARNING ABOUT DIAGNOSIS

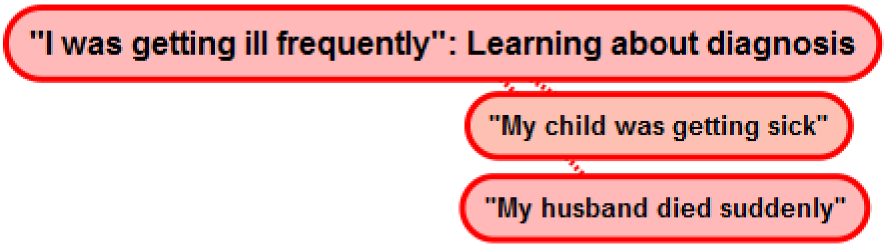

Figure 5.2: Abstracted themes contributing to the superordinate theme "I was getting ill frequently": Learning about diagnosis

This superordinate theme concerns what drove the women to have an HIV test and how they learned about their status. Although the women discovered their HIV status in various ways, including during routine antenatal healthcare, learning about their diagnosis was a traumatic experience. The decision to be tested for HIV at that time was often prompted by their failing health or the poor health of their husband and/or children, or after the sudden death of a partner. Some of the participants expected a positive diagnosis because of the poor health they had been experiencing for some time. After frequent bouts of illness, some decided to be tested because they became suspicious about their own health and had an inkling that they might be infected with HIV. This implies that they had a realistic appreciation of the risk of HIV infection before being diagnosed, and hence they took the initiative to find out about their health status. For Participant 001, being tested for HIV was prompted by repeated illness and presumably also anxieties about her health.

> *I learned about my diagnosis and my HIV status when I was getting sick frequently. Headaches and malaria. I would have a headache, sometimes malaria. Another headache and then it would go. Then malaria. I would have high fevers, feeling very cold. Then I went to the hospital. They admitted me the first time and then I got discharged. I got admitted the second time and then got discharged. (P001).*

Others earned of their HIV status when they were pregnant and were tested during the antenatal clinic's routine health check, as HIV testing is compulsory in Malawian hospitals. Participant 007 appeared unprepared for her HIV test that was a routine component of her antenatal care. A lack of mental preparation may have a bearing on the way one reacts to the news of the diagnosis, as will be described in later themes in this chapter.

> *For me to know that I have HIV, I was pregnant. It was in 2009, so I was just getting sick frequently and then I decided to go for antenatal care because with all the other children I would start my antenatal check-ups at three months. So when I went there and at the antenatal clinic they explained to me that I should have my blood tested to know how I am. And also to protect the unborn child. So we went into the room and they took my blood sample. After some time they were calling us in one at a time and then when I got in, they told me that I have been found HIV positive. (P007).*
>
> *I found out that I was HIV positive when I was pregnant. When I was having a child. (P009).*

5.3.1 "My child was getting sick"

Some learned about their diagnosis as a result of their children's poor health. This is perhaps the most traumatic of all pathways to a diagnosis of HIV. It also illustrates that though HIV testing is meant to be a routine part of antenatal care, some only learn of their status long after giving birth. As the participant below describes, a diagnosis might only come after a long period when the child does not develop as expected and has poor health.

> *For me to know that I am HIV positive, first my child was just looking malnourished and not healthy, vomiting after eating and having diarrhoea but also the weight was just going down. The child was not appealing to other people. But I was also just getting smaller, losing weight and my weight was just going down. So we went to the hospital, where I was admitted with my child in Ward 10, the malnutrition ward. So they sent me here to get tested. (P011).*

Similarly, Participant 003 cared for her child for a year before repeated illness led to her finding out that the child, herself, and her husband were all HIV positive.

> *My son was a year old. We stayed in the hospital for several weeks and then they gave me medicine that he should be taking and sent us home. After finishing the medication, he started getting sick again. When we came back here at the hospital, they said that he has had a relapse of the*

> *tuberculosis. When he relapsed, they suggested here at the hospital that the child should get tested for HIV. So they tested him and found that he was HIV positive. They suggested that we, his parents, should also get tested, so we got tested at that time. (P003).*

Learning about the child's diagnosis and her own at the same time was a double blow and a severely traumatising experience. When processing the news of the diagnosis, Participant 003 experienced a foreboding fear of being overwhelmed in terms of managing the health of the child and her own. The child's diagnosis also caused her much distress and guilt because of the idea that a mother is supposed to be protecting, nurturing, and caring, and knowledge that she had infected her child contradicted these expectations. She also worried about how she would disclose the HIV status to the child in the future when he grew up.

With time, managing the child's diagnosis, beginning treatment, and witnessing the returning health of the child assuages the guilt of some of the women who were mothers to children with HIV. They make sense of their child's HIV infection by acknowledging that they lacked knowledge about their own status and had no information on how to prevent vertical transmission. In contrast to Participant 003, Participant 010 appeared to have come to terms with her child's diagnosis by telling herself that she did not intentionally infect the child and that if she had known earlier, she would have taken the necessary precautions.

> *I did not know how I could protect my unborn child from the illness. So it is possible that I infected him at that point. I came to the hospital because my child was getting sick. So they tested me and tested the child too. At that time, although I had the virus, I was still looking very healthy. (P010).*

5.3.2 "My husband died suddenly"

Another pathway to a diagnosis of HIV was the illness or sudden death of their husbands. After a shocking awakening, namely their husband's death, the participants who lost their husbands had little option but to be tested themselves. In some cases, participants reported feeling perfectly healthy when they went for an HIV test following the deaths of their husbands.

> *What happened in 2001 was that he started to get sick. He would have difficulties breathing. So we went to Zomba Central Hospital and when*

> *they examined him, they found out that he had tuberculosis of the bones. We stayed at the TB ward for almost a month and we were discharged and sent home. When we were at the hospital, he did not look too ill or weak. So when he got well and was continuing with his business, one day as he was going to town to get merchandise for his business, he just collapsed. When we arrived at the hospital, the doctor said we should find out what went wrong and they thought that maybe he still had the tuberculosis. In the morning, that is when he died. (P004).*
>
> *He had high blood pressure and he started coughing. So one day it got worse, he was coughing blood, and he was taken to a main hospital. That is where he died. (P009).*

Regardless of the manner in which they learned about their diagnosis, overall, most of the women who were interviewed perceived knowledge about their status as empowering. The diagnosis meant that they discovered what was wrong with their bodies and they would initiate treatment and improve their health, which would prevent being struck by a sudden death. In addition, this awareness about their status gave them a sense of control over their health.

> *My diagnosis, to me, made me happy because I knew what my status was but also how I can protect myself. I can say that sleeping around without using condoms scares me because you are adding the virus to your body. But when you know how you are, you know which stage you are, and you know how to take care of yourself. But when you are not taking medication and you have not been tested, you do things out of ignorance and it does not end well. (P011).*

The women received counselling at the clinic as the initial step to treatment after their diagnosis which seemed to focus on the knowledge required to take the medication as prescribed.

> *They give us counselling because before you start taking the medication, you go in class to learn about how to take the medication. That is the first stage, and then you come to the second stage again to get your medication for a whole month or three, like the way I came last month. (P012).*

Counselling tended to be brief and impersonal. Participant 001 reveals how she wanted to get on with the testing, which was provided without any counselling.

> *When we were there, it did not take a long time. There was no counselling such as asking me what I have come to do. I just told them bluntly that with the way I have been living, I have been sick and I have taken all sorts of medicine but it is not helping. Maybe I am HIV positive. Please test me. If I am HIV positive, tell me and don't lie to me and I will not be disappointed. I will know why I was getting sick. If I know what the real problem is, I will be helped and I will stay alive. After I told them that, they tested me and found me HIV positive. (P001).*

Testing seemed not to include much help to deal with the psychological ramifications of the positive diagnosis, though they were, perhaps unhelpfully, warned about the impact of worry on their physical health. One might argue, too, that the often traumatic pathway to a diagnosis of HIV detracts from the participants' abilities to process the emotional shock of their own diagnoses. As illustrated above, in some cases, the diagnosis was received while newly bereaved or immediately after the traumatic news about the health of their children and husbands. The lack of adequate psychological care before and after the diagnosis may have exacerbated their emotional reactions to the diagnosis, some of which are described in the section that follows.

5.4 PSYCHOLOGICAL REACTIONS TO DIAGNOSIS

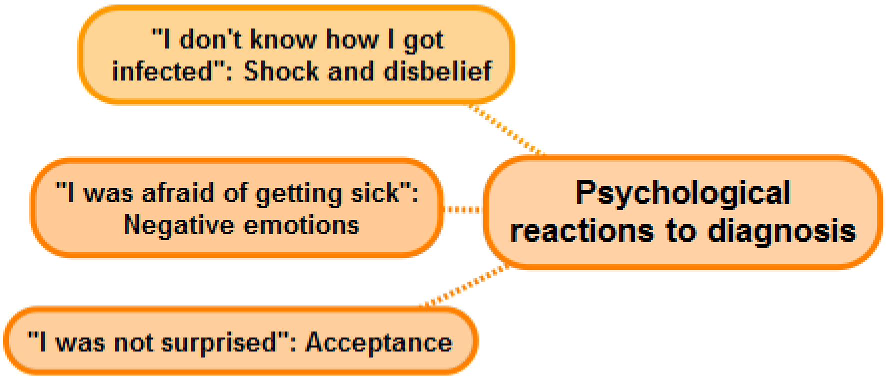

Figure 5.3: Abstracted themes contributing to the superordinate theme "Psychological reactions to diagnosis"

Following from the previous section, which discussed how the women learned about their diagnosis, this superordinate theme provides insight into the psychological impact the diagnosis had on the women. From their life stories, it is clear that the women come from backgrounds fraught with personal struggles and adverse life experiences and it seemed almost inevitable for them to end up in relationships that would put them at risk for HIV infection. Nevertheless, the women described the moment when they received the news of a positive diagnosis as an extremely pivotal and difficult one, which aroused a myriad of negative emotions, namely shock, anger, denial, and sadness, as well as a fear of impending mortality and anxieties over their children's future. Mostly, they feared that this was the beginning of their experiences of stigma and rejection from family members and the community as persons with HIV. They had minimal time to process the news, but their powers of adaptation demanded that they quickly accept the diagnosis in order to start moving forward with their lives, just as they have done in confronting the many adversities they had encountered before.

5.4.1 "I don't know how I got infected": Shock and disbelief

This subtheme captures the initial emotional response shock and disbelief when they were informed about their status. The shock came about because, as married women, some had not previously believed themselves to be at risk of acquiring the virus because they had only been sleeping with one partner, their husbands (with the exception of Participant 006 who was working as a sex worker). From their perspective of these participants, to confront the reality that they had contracted HIV in a marriage union considered sacred, evoked confusion in trying to make sense of the diagnosis.

> *Because I believed that I was 100% fine, because my husband was well behaved. We used to stay peacefully; he was not someone who used to move around. The thought of me having HIV was non-existent. It was not possible. (P010).*

Though the source of their infection would seem to be obvious, some nevertheless seemed unsure about how they were infected. The excerpt below hints at an inability to accept that she had been infected by her husband because he was dead and to do so would somehow be disrespectful to his memory. An inability to accept how they came to be infected may also be a result of the cognitive dissonance they experience, which comes from two contradicting cognitions. One is that women who have HIV are promiscuous and the other is that they have contracted HIV while married and completely faithful to their husbands.

> *I was married to him and then we separated and I got married to the man who died while with me and we did not get tested to know how his body is. I think we stayed together for only three years. In that three years, we did not get tested, he just started getting sick until he died. I was just wondering, perhaps it is that husband of mine because I did not go to get tested. Maybe he infected me with HIV, I don't know if it is him. I can't mention him because maybe I got it through other ways but I cannot mention him because he died. (P001).*

Some of the women's reports suggested that they were genuinely ignorant about their partners' past sex behaviours, and this made it difficult to ascertain risk or anticipate infection. It was possible that their partners or the women themselves might have been infected in previous relationships and marriages but they may not have been aware of it because no conversations about sexual history and HIV status take place.

For those who suspected that their husbands were cheating on them, the diagnosis was a shocking confirmation of the suspected infidelities. For example, Participant 011 expected the diagnosis because she knew that her husband could not be trusted after he had had an affair.

> *I was not surprised because I knew that he was not a reliable man. When I discovered that he was having an affair, sometimes he would leave me at home without any food and I would struggle. (P011).*

For others, the source of their infection remained unknown or unacknowledged because there were no opportunities for an open and honest discussion in the marriage about their sexual history and HIV statuses. Participant 010 struggled to make sense of how she became infected.

> *Well, I would say that I trusted my husband very much and my husband trusted me too but I don't know. I think only God knows. Because at that time he made me drop out of school to marry me; we have had the first child with no HIV problem. We then had a second child. When I had the third child, it is when I discovered I was HIV positive. And maybe between*

> *the two of us, it could be him or me who brought the problem but we don't know who the owner of the problems was. (P010).*

The denial about the source of infection may serve the purpose of not holding themselves or their husbands accountable to maintain the notion that being married protects one from HIV infection. Participant 009 emphasised her marital status as the reason why she was unaware and uncertain of the source of the infection.

> *I don't know because I was married. So maybe my husband brought the HIV into the family. I was married, you see. (P009).*

Others had no such difficulty in stating how they were infected. Participant 008 had no difficulty stating that it had been her husband who had infected her.

> *He [her husband] is the one who infected me with HIV. I said in the first conversation that I never had any affairs behind his back so I don't know because I was the one taking care of him when he was sick, right, but I was also sleeping with him. (P008).*

Similarly, Participant 011 also candidly faced the reality that her husband was leaving the marital home despite having trusted him before and that he had infected her, as the quotation below illustrates.

> *I know because that time, the father of this child would leave me. At that time, I was working for Knitwear and I was living in Blantyre. Almost every weekend he would tell me that he was going to his home village in Ntcheu. I got suspicious that he was going to his home village every single week. I started investigating to find out from his relatives. That is when my husband's cousin told me that he had been lying to me, he goes to another woman. He was having an affair with another woman. I know that it is my husband who infected me with HIV. (P011).*

Those infected by their husbands must deal with the painful possibility that their husbands may have known or should have known that they were infected, and by having unprotected sex with their wives, and behaved with wanton disregard for their health and wellbeing (and presumably also the health and wellbeing of their children). This would only add to the psychological burden of an HIV diagnosis. For example, the youngest participant, who got infected in her first and only relationship, explained that she felt the man knew he was HIV positive but he consistently refused to use condoms.

> *I got it from that man. If I got it from my parents, then it would have been all the children in our family. It is painful because maybe he knew that he was HIV positive but was having unprotected sex with me to infect me. (P012).*

In contrast, Participant 006, who was previously a sex worker, could not know when or who infected her.

> *I would say I might have gotten it from him or maybe not. Because I have slept with a lot of people and I cannot be sure that they were all HIV negative, or this one has the problems. They would sometimes put on a condom but when they ejaculate I would see that they have done it on me when they said they put on a condom. So I cannot really tell who infected me with the illness. (P006).*

The women's experiences suggest that their reactions to their diagnoses depended to some extent on how they made sense of how they were infected and to whom they assigned the responsibility of their HIV diagnosis. Their reflections suggested that the emotional shock of the diagnosis came from the difficulty to comprehend that being married and remaining faithful to their husbands did not save them from HIV infection. Because marriage implies trust, care and fidelity, there is little opportunity to take preventative measures. Their diagnoses were thus a contradiction of the core value of marriage – being faithful to one's partner and their own beliefs about being married as a symbol of being a good woman. It was especially hard for those of them who had to come to terms with the possibility that their husbands had infected them knowingly. It is perhaps this inherent contradiction – that they were infected in the sanctity of their marriages – that made it hard for some to acknowledge the source of their HIV infection, and harder still to process the shock of the diagnosis.

5.4.2 Negative emotions

This subtheme captures the intense negative feelings of anger, fear, and anxiety that the women felt for being infected in circumstances they had little control over. They also expressed feeling sad and being in denial for some time after the shocking news. As seen above, an HIV infection in the marriage context is difficult to fathom because of the implication that someone they had trusted and loved deceived them and put their life in danger. One of the women reported feeling bitter because she felt she *"did not do anything wrong"*.

> *The results came out that time; there was Medicines Frontiers and they explained to me and I knew then that my husband had that problem [HIV]. I refused to start medication. I refused because I did not know the reason to begin taking the medication. It hurts me. It really angers me a lot. (P008).*

Their anger and disillusionment mainly stemmed from the fact that HIV is associated with having multiple sexual partners or women who sell sex, and marriage is usually perceived as the mark of being a well-behaved woman. An HIV infection potentially tarnishes the women's image in society as they are unfairly judged by people who cannot appreciate their circumstances. The most desperate anxiety seemed to be to be able to live long enough or to be healthy enough to take care of their children.

> *I was very sick and I started wondering if I could really make it to the following week. I was just praying to God for help. I was just praying that God should help me so that I would be able to take care of my children. If I am having these problems while I am still alive, who will take care of my children when I die? (P001).*

Others described anxious hope that they will at least live long enough to be able to provide for an education for their children so that they will be able to look after and provide for themselves after their mothers have gone.

> *I would have loved if God gave me a long life. If I am to die, I should leave my children with something that they can rely on. Even though one of them has a problem, at least if I give them enough education to rely on himself, he will not worry much about me just leaving them while too young. They are not yet self-reliant and independent. (P003).*
>
> *I was worried who will take care of the children because I am HIV positive. I was worried if they would complete their education. (P005).*

Another of their greatest worries was their capability to manage the strict medical regimen of taking ARV drugs for the rest of their lives.

> *There was one thing that bothered me in my heart because I did not know how I will manage taking the medication, especially swallowing the pill. I thought to myself, will I manage taking these pills? They are saying we should take these pills in the morning and in the evening. Am I going to manage? That worried me a lot and then I just accepted that I will be able to manage, how are other people taking the medicine? I received the first bottle and I managed to take the medicine in the morning and in the evening. (P002).*

Another source of their anxiety was thinking about how their bodies would adapt and respond to the drugs. The participants reported having had to change their medical dose after experiencing severe side effects after taking the drugs. Participant 010 reported having taken the drugs for three years and then experiencing "treatment failure" where the medication was no longer working efficiently. Her physical appearance changed as her immunity was still deteriorating despite her adherence to the correct dosage. This period of her life was filled with chronic worry and anxiety. A change in medication resulted in the desired response and she is much better, though she hints that compliance requires that she take the pills with food, but she cannot always be sure that she will have food.

> *They found that my immunity was still going down so they left me on second line but since they changed my medication, I am doing fine. I was afraid of getting sick because I know that there can be a lot of illnesses when one is not on ARVs but now I am fine. There is no problem. The only problem is that, as you know, the medication goes together with food but you can't really say it to people that I have no food.* (P010).

Although ARV compliance requires major lifestyle changes to accommodate the strict regimen into their daily routine, Participant 003 explains how her need to care for her children is her motivation to take care of herself. Such an adaptation is likely to lessen her anxiety about her health.

> *I know that for my body to function well, I have to eat this and this. While in the past, I would just eat anything. I did not even eat anything some*

> *days. Now I am also careful and I think about what I do because I have to take care of my children. (P003).*

It appears that worry and anxiety has an impact on their physical health. For example, Participant 010 developed high blood pressure from being stressed about thinking about her situation. However, she quickly became aware of the impact of the stress on her physical health and started to seek means to have peace of mind.

> *I used to worry a lot. My blood pressure used to shoot up. I used to wonder why I was having the high blood pressure. I used to feel sorry for my children. That they were young. I knew that worries cannot help and can make you sick; the immunity can go further down. So I have to control those things, my worries. (P010).*

The disappointment, fear and sadness associated with the diagnosis could spiral into a state of hopelessness. Despite ARV treatment, an HIV status is still experienced as a life-threatening, uncontrollable situation.

> *When I learned about my diagnosis, although I accepted it, I was still disappointed. Disappointed because at that time we would hear these things like when one is HIV positive, that's when you start taking ARV medication, that means you will die. I would hear some people saying those things. I would usually think to myself that although I have accepted this and that I will start medication but people say that when I start medication, I will die. (P001).*
>
> *I was so hopeless and I thought that everything about my life has reached an end and that I can even die. (P010).*

Participant 003, who spent much of her time ruminating and thinking about how she ended up being infected by her husband, explains how their diagnosis robbed her of her peace of mind.

> *Before I knew that I had HIV, I had peace in my life because when one gets tested and is found free of HIV, it is God's grace. So at that time I was happy, but when I got tested the second time and was found HIV positive, I was very disappointed and it was hard for me to understand. It took me some time to understand. (P003).*

Similarly, Participant 010 also speaks of losing her peace of mind and becoming despondent following her diagnosis.

> *While at home, I did not have any peace at all. I cried day and night for two weeks. I had no peace, just reflecting, and I thought that anything in my life now will be impossible. (P010).*

Unable to control their emotions, some women had a break down because of the emotional exhaustion and fatigue as the situation became too much for them.

> *Sometimes I found myself crying without a reason. (P004).*

Participant 008 was in denial and had struggled to accept that she might have HIV after her husband told her to get an HIV test following his own diagnosis.

> *He told me to go and get tested. I told him that I will never go to get tested and that I will never take medication and that I will resort to praying. (P008).*

Overall, dealing with an HIV positive diagnosis, whether one expected it or not, is an experience that causes psychological distress. The events leading to the test and the actual moment of the diagnosis found many of the women unprepared to deal with their negative emotions. Unfortunately, as noted above, the counselling that was provided to some appears wholly inadequate to help them cope and manage the anxieties, worries and anger associated with learning about their status.

5.4.3 "I was not surprised": Acceptance

This subtheme is about how most seemed to have finally arrived at a place of acceptance after the initial barrage of conflicting emotions when they learned about their HIV status. It seems that they came to realise that without hope of a cure, all that remains for them is to deal with their emotional responses, and prepare themselves for life changes necessary to survive. Participants 002 and 009 accepted the diagnosis not in a defeated manner but in a way that empowered them to take action.

> *Even though the man has infected me with the HIV, and when I get angry, will the HIV disappear? It will not disappear. It has entered my body, that's it. (P002).*

> *I just accepted it because it has happened and there was nothing I could do. So I stopped being disappointed and started taking the medication. (P009).*

For those who experienced frequent illness and anticipated a positive diagnosis, there was already a certain level of acceptance and relief after learning the truth about their health. Excerpts from the interviews with Participants 001 and 002 illustrate this finding.

> *I was not surprised because I had already seen the results of my husband's tests. So I did not find it surprising. Even when he came here to get tested, I just found it was grace, because many of my relatives have died because of the same illness, so I found it was grace that I have known about my status because I need to get counselling and get the proper treatment. (P002).*
>
> *I was not surprised because I had already accepted before I got tested. I concluded from the illnesses I was having that I was HIV positive because I had taken all sorts of medicine and had not been feeling better. What was left now? Isn't it the HIV? So I accepted before I got tested. (P001).*

Acceptance and resolution came after acknowledging and working through the shock and painful feelings of being diagnosed with HIV. For Participants 006 and 012 this acceptance was a crucial step towards initiating the necessary actions to improve their health and to move on with their lives. Accepting and acknowledging their status enabled the necessary support.

> *I just accepted that I have HIV and I will start taking ARVs when the time is right. I am just thankful because I am able to do things that I was not, like work. I also can take care of my children, as opposed to the past before I accepted it. In the past I was not accepting. (P006).*
>
> *When I learned that I was HIV positive, of course I was sad and worried but I just accepted it and I tried to follow the advice that the doctor gave us. So they tested my CD4 count, which was very low. They told me that I should start taking medication. (P012).*

For some the diagnosis could come as a relief of sorts as it would provide an explanation for poor health and an end to the uncertainty and speculation. `

> *When I tested positive, I just accepted because I said, "Well, my husband is already HIV positive". (P002).*
>
> *According to my health, the way I was getting sick, I expected the results. I was supposed to be found HIV positive. (P012).*

This acceptance of their status is empowering as it appears beneficial to managing their diagnosis and containing the trauma, and the long-term demands of adhering to the ARV medication and maintaining healthy lifestyle changes.

5.5 IMPACT OF THE DIAGNOSIS

This superordinate theme regards how the diagnosis affects how the women perceive themselves and how it shapes their decision-making about significant life choices such as establishing relationships and motherhood, which also form part of their identity as women.

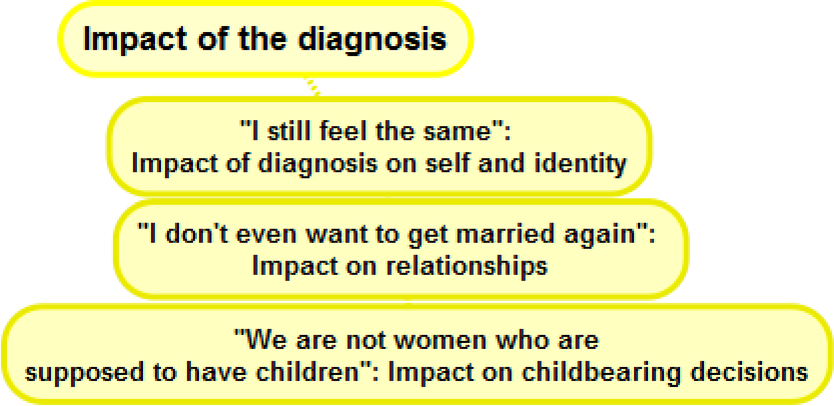

Figure 5.4: Abstracted themes contributing to the superordinate theme "Impact of the diagnosis"

5.5.1 "I still feel the same": Impact on self-perception

This subtheme captures how the women felt that having HIV did not change how they perceive themselves. They explained that they did not feel any different from the time they did not know they had HIV and their current predicament. Although they initially experienced a range of emotions and dealt with the shock of the diagnosis, the way they perceive themselves remained primarily the same. Below is how two of the women described this.

> *I haven't changed much. I think I am still living the way I used to live. And I don't feel like I have HIV. I still feel the same way that I used to feel. I see myself in the same way. (P001).*
>
> *I see myself the same way as I saw myself in the past because I have never been very ill. I don't really see a big difference. I live exactly the way I was living in the past, because some say that they got very ill before they started receiving the medication but I have never experienced that but I have been the same. If I get ill, it's just the same illnesses like malaria but not very serious to the point of going to the hospital. I would not say that I am suffering too much in my life. No, I am not feeling sick. (P002).*

For those who recovered from the bout of illnesses that led to their diagnosis, taking medication helps them to regain their self-assurance. Improving health through medication re-establishes a sense of normalcy in their lives because it means that they will continue with their daily activities without any limitations.

> *The difference is that I am not getting sick frequently. I can go to the garden and do my farming properly. (P005).*

For some, a diagnosis of HIV enables them to be more forgiving in their view of those who are HIV-positive or those who have other problems in their lives. Participant 003 reported feeling transformed from judging and blaming others with HIV to becoming more tolerant and understanding.

> *On my part, when I saw people living with HIV, I saw them as people who have done very bad things or people who have caused a lot of damage. I did not even think that the disease can just find you without doing any bad thing and the one who got the disease was the other person but I was just saying that this person was promiscuous. My views have changed because looking at my background, I could not find any point in my life where this illness came from so I realised that not everyone who has this problem are to blame but someone got it and brought it to them. (P003).*

> *When I saw other people who were on medication, I thought they were useless but when I reached the stage where I started taking medication, I knew I was wrong. (P011).*

A more realistic and accepting stance to those who are HIV-positive is likely to be a necessary component in accepting themselves. The development of empathy towards others, as will be explained in the next chapter, enables them to support and help others with HIV.

5.5.2 "I don't even want to get married again": Impact on relationships

This subtheme refers to how the HIV diagnosis influences and changes the women's decisions about pursuing intimate relationships. Once the women learn about their status, their romantic relationships typically became unpredictable. Those who expressed their wish to stay unmarried explained that they imagine it would emotionally be draining for them to deal with the challenges of living with HIV and maintain an intimate relationship at the same time. Overall, they felt that having HIV complicates relationships. The decision to stay single helps them to have peace of mind and to focus on raising their children and taking care of their health.

> *I am no longer sad or disappointed about things, especially about the end of my marriage. I don't even want to get married again. I don't have that idea anymore. (P003).*

Staying single seems to be a reasonable option because it enables control their health. The women in the study reasoned that they could end up with a man who has multiple sex partners and their health would be at further risk. In addition to being unable to control the man's behaviour, they are not sure if the new partner would adhere to medication if he were HIV positive or agree to using condoms. The excerpt below illustrates how, after the betrayal of infection, for some celibacy is the surest way of retaining control over one's sexual and reproductive health.

> *I made the choice of not having a man for myself because when we were having sex, there was a problem. He did not want to use condoms. And that is why I do not have a man up until now. This has happened to me twice, in two relationships. I had a relationship and he agreed to sleep with me the first time with a condom and then he said he does not want to use condoms.*

> *But because I was desperate and thought that well, when I sleep with him, he will give me money, I was sleeping with him without a condom. (P010).*

Participant 010 had to go through the decision-making process of weighing the benefits and risks of having a partner to her health. It appears she values her physical health over her emotional needs.

> *It's not like I was in a business that the man should be doing things for me but there was not enough support. I was running around myself to look for help for my children so I saw that I was not benefiting anything. I was doing most things for my children at my home so it was not wise to add having problems with a man. I decided to drop it and just live the way I can live. (P010).*

Another participant explains below how the only person that she truly knows and can trust is herself.

> *I don't have those thoughts because I have resolved and made a decision that I will not get married because as I am now on ARV medication and I am not supposed to be with a man. I don't know where he is coming from and I don't know what his body is like, while I know how I am, so I don't want to have someone who I don't really know. (P012).*

Celibacy not only ensures control over their health but also their decision to have more children, as the participant below describes.

> *It's what I was saying, that it can be a problem for me to get married again. Why I am saying this is because with this child, I agreed with my husband that it will be the last born and because we know how we are [HIV positive]. My thinking is that if he knew that I had this problem and asked me to have another child, although I had other children, that means the man I would marry would also want another child. (P004).*

For another participant, marriage would be viable only if both partners were HIV-positive and both on medication. Otherwise, a difference in status or adherence, from this perspective, inevitably puts somebody at risk.

> *Only when they have been tested. When maybe the both of you are on medication. Even some men who are not taking medication [not HIV positive] can marry a woman who is not HIV negative and stay together. (P005).*

In contrast to the views expressed above, for the purpose of achieving financial security, some women do decide to remarry. However, this decision brings new challenges in light of their HIV diagnosis. To develop an intimate relationship, they need to disclose what they consider highly personal information, namely their diagnosis. The women gamble with the risk of being rejected, abandoned, or subjected to violence after disclosing their status to a potential partner. Some fear that the men might change their mind about marrying them if they disclose their status.

> *I have been proposed to before. The person might ask me out but they don't know how I am, so I tell them how I am. I tell them that I take medication. Sometimes they think I am lying to them, some just change their mind and never come back. (P008).*

Participant 009 feared rejection and expressed that her preference is a partner who is also HIV positive. A partner who is also HIV-positive is unlikely to disclose her status, and would understand her needs and be more accepting of her.

> *Maybe if I find a man who is also HIV positive. It is not going to be difficult. One who is negative will announce to people about your status. (P009).*

Their stigmatised social identity as a woman with HIV is a barrier to being accepted as a suitable partner, not just be potential husbands but also their families.

> *I met this man from my home village but his sister told him that he should not marry me because I have HIV. So most of his family did not want him to marry me, but the man accepted it and said that he did not see a reason not to marry me and he said that to him it is not a problem because his wife was also on ARV medication. I explained to him that I am on ARV medication. I did not want to hide from him, I told him that I go to Tisungane Clinic. (P011).*

A fear of rejection and exposure is a major barrier to forming new romantic relationship. Participants 004 and 009 describe being plagued with feelings of self-doubt and worry about finding a relationship because of their status.

> *Maybe it will be difficult to meet someone and tell them that I am HIV positive and for them to accept me. If he is on medication but maybe they can agree then and change their mind. I still don't know how he will take it. But I just think I will not be able to find another man and get married again because I have HIV. (P004).*
>
> *That means if I want to find a man to marry me, I should go very far away to another area. But for people who know you, they will say I have HIV. I worry about that. (P009).*

Despite reluctance to hand sexual and reproductive health control to another man, women can be pressured by their families to marry again, seemingly because they dread the burden of caring for their HIV-positive relatives or their children. Participant 006, who was married twice before and had a poor relationship with her family, is given little choice in the matter.

> *My family forces me to find a man and get married. I ask them why, and they say, "That's because of the illness you have, when you get sick, who will take care of you?" I know that my relatives will not take care of me. If I am, well, like this now. I am not sick but they are telling me these things. It means they will not take care of me when I am sick. (P006).*

In summary, their social identity as women with HIV makes romantic relationships complicated. For some, celibacy is seen as the only way to retain control over their sexual and reproductive health. Others will consider a relationship but only if their partner is also HIV-positive and similarly motivated to maintain his health and avoid disclosure of his and her HIV status, while others have little choice in the matter as another husband or boyfriend is the only means for financial security and in some cases their only hope for support and care, though, as we have seen earlier, this comes with risk.

5.5.3 "We are not women who are supposed to be having children": Impact on childbearing decisions

This subtheme captures the women's experiences and decision-making about reproduction and motherhood. Asked about their wishes to have children, the predominant view was that it was wrong for WLHIV to have more children, especially if they already have other children. Participant 010 shared the perspective that having HIV is incompatible with motherhood. Participant 006 put her health first and reasoned that her body would be unable to handle the stress of childbearing, which might also affect the child's health.

> *We are not women who are supposed to be having children. But because we want to please our loved ones, we are getting pregnant when we are HIV positive and on medication and have many children already. (P010).*
>
> *For someone who thinks quickly or wishes her life well, and their body, you should not continue having children. For someone who has been found with HIV, HIV is not something that is very scary but it relates to reproductive health. They can have a child, get pregnant and have a child, but that child will not be as healthy. The mother will also be getting sick and she may die and leave the child an orphan. (P006).*

Though Participant 005 indicated that it may be acceptable for WLHIV who have never had children to do so in order to experience motherhood, for her this should only be allowed under medical care to minimise the risk of vertical transmission. However, she agrees with Participant 012 that pregnancy compromises the health of WLHIV.

> *I don't think it's a good thing if you have HIV to continue having children because the immunity goes down. (P005).*
>
> *I think having children takes a toll on your health, the energy you give to the child; you can deplete your own energy. It can also happen that the child is born with the virus and I may die and leave the child an orphan. (P012).*

Fear of infecting the unborn child emerged as the main reason that the women did not desire to have more children, despite some having knowledge about the medical advances that prevent vertical transmission. Perhaps it is the pessimism if enduring multiple adversities that explains the reluctance of Participant 009 to hope that her ARV adherence would prevent vertical infection if she became pregnant again.

> *Now that I am taking medication and I know I have HIV, I don't want to see my child getting infected with HIV, like all my other children did. I just think that if I get pregnant, it will also be like that. (P009).*

While the women's desire not to have children seems genuine, negative reactions received from the health workers upon informing them of their pregnancy plays a role in discouraging them from having more children. The women described the experiences at the ARV clinic during their pregnancies as unpleasant and fear inducing. They reported that during counselling, the health workers directly discouraged them to have more children. The nurses, they recalled, emphasised the negative aspects of living with HIV and being pregnant. Participants 001 and 011 explained how the nurses warn them now and again that they will endanger their lives and that of the unborn child if they get pregnant.

> *They were saying that now that we are HIV positive, your husband is also HIV positive and you are now pregnant but expect that the child can be born HIV negative or HIV positive. They told us that the child can get infected when being born or when breastfeeding. They prepared us that the child can be born HIV positive or not. They even told us some of the risks of losing life if I have low blood levels and low immunity because of my status. They were very blunt and told me all the possible risks that I was exposed to by being HIV positive and pregnant. (P001).*
>
> *The nurses shouted at me, asking me why I got pregnant. They said I was selfish and I was not thinking about my health and they told me that I will die because I have fallen pregnant. (P011).*

Incidentally, a consequence of the reactions of the nurses is that WLHIV are less likely to go to them for sexual and reproductive healthcare and advice.

Lastly, a fear of dying during childbirth, presumably because of having compromised health, is the reason that Participant 011 is reluctant to ever become pregnant again.

> *My main worry was the health of my child. I was worried how will this child be. The second worry was that I was thinking about how my life will*

> *go on, or not [dying]. My other worry was the labour itself, that will I come out alive or not. (P011).*

Those who already have children with HIV struggle with the guilt of feeling responsible for infecting their own children. Coupled with this, no doubt, is the anxiety about how to disclose to their child that they have been infected by their mother and that they will need to be on medication for the rest of their lives. Participant 003 was wrecked with guilt and made a conscious decision not to have more children.

> *I was also riddled with sadness because I had infected an innocent child. I have put the child in this position. The way this child is, he should take this medication all his life. I was so sad because the child is so innocent. (P003).*

For a variety of reasons, the participants are reluctant to have more children. Foremost amongst them is the fear of infecting another child. They also worry about dying themselves and leaving their children without proper care. Some are concerned about the effects that pregnancy and childbirth will have on their precarious health. There is also a fear of negative reactions from healthcare workers if they were to become pregnant again. Implicit in some of the excerpts is that once a woman has been infected by HIV, she forfeits the right to motherhood. Clearly it will yet be some time before medical advances or knowledge of these advances makes the choice of becoming pregnant while HIV-positive viable and acceptable in this Malawian context.

5.6 ACCESS TO TREATMENT AND SRH SERVICES AFTER DIAGNOSIS

This superordinate theme captures the women’s experiences in terms of accessing treatment and using SRH services. After their diagnosis, the next step is to initiate treatment. They described the ease of adhering to the drugs in terms of accessibility and availability. This theme is significant because the measure of success of the fight against HIV is based on access and consistent adherence to medication, especially for women as a disadvantaged group. With SRH services, the women did not feel entirely supported or adequately informed about contraceptive methods available to them. As mentioned in the literature review, SRH issues pose unique challenges to WLHIV, especially when one thinks of contraceptives as drugs, which might interfere with ARVs, and the issue also being closely related to their reproductive rights, hence the need to include WLHIV's experiences with SRH services in relation to their HIV status.

Figure 5.5 Abstracted themes contributing to the superordinate theme "Access to treatment and SRH services"

5.6.1 "I have easy access": Access to treatment

This subtheme regards the positive experiences the women in the study reported in relation to access to treatment after they received their HIV diagnosis. No barriers to accessing treatment were reported in the interviews and they praised the consistent supply of the medication. In addition, they reported having good relationships with the hospital staff who monitor their progress. Participant 002 gave the impression that she is confident about the treatment she receives.

> *Since starting my medication, I have never experienced anything unpleasant or any discrimination or any mistreatment such as not giving us the medication that we need. When sick, you get to see the doctor. And they take their time to establish what the problem is and not just rushing through. (P002).*

The women commended the clinic for giving them a three-month supply of drugs at a time, an arrangement they considered helpful especially for those who live far from the clinic. They explained that the approach reduces the number of people who are at the clinic at a given time.

> *The challenges that I faced initially was that there were a lot of people here at the clinic. You would come to get treatment and find a long queue of people waiting to be treated. It has completely changed. (P011).*

This demonstrates that the easy availability of the drugs guarantees the continuity of treatment, which is an empowering feeling for the women in that they will be able to manage their illness. The ease of access to medication also helps to change people's perceptions of them as PLHIV as normal because the medicine keeps them healthy.

The only challenge they reported in relation to taking the drugs is poor nutrition, which they felt the clinic should make an effort to assist with as medicine and nutrition go hand in hand.

> *Like when I have come to get the medication at the hospital, they should give us at least a bowl of porridge. So that we combine the medication and the food. It would be nice. (P001).*

Still on the issue of treatment, the women talked about the pressure to persuade them to seek spiritual healing or alternative medicine and stop taking their medication but they are not influenced by this. Participant 008, for example, uses nutritional supplements but still adheres to her medication, while Participant 012 ignored the pressure of her religious community to discontinue her medication.

> *I don't go to traditional healers since I was diagnosed. You hear about them on the radio, medication for body cleansing and the like. I don't pay attention. If I did not have ARVs, I would not have been the way I am looking now. I don't mix treatments. I only used some garlic before, and is usually in tablet form. I was taking the garlic morning and evening, but all the medication that is popular these days, I don't take them. (P008).*
>
> *I like fellowships to get rid of my worries. It is a lot of people who go there and are told to stop taking medication. I went and they prayed for me. I was told to fast for two weeks. I had told them everything, that I am on medication and I have HIV. They asked me how strong my faith was and that if they would pray for me the disease will disappear and I will stop taking medication. I told them that I have that belief and I believe in God but I cannot stop taking medication. (P012).*

The participants' experiences indicate relative easy access to the treatment that they require. The ready availability of healthcare provides psychological benefits to the women by lessening worries about their health, and making it easy for them to continue with a normal life. Generally good relationships with clinic staff gives them optimism and confidence that their condition is under control. Significantly, some of the participants were able to resist social pressure outside of the clinic environment to discontinue their medication. One could speculate that their community of practice as HIV-positive women receiving treatment enables their continued adherence despite the social pressures to conform to other illness models. If this is the case, then the regular visits to the clinic and opportunities to interact with supportive healthcare workers and especially other HIV-positive women is probably very important.

5.6.2 "I was not using any contraceptives"

This subtheme concerns the experiences of the women with SRH services at the ART clinic. The common experience amongst all the participants is that there is a lack of specialised counselling for WLHIV in relation to SRH issues. In addition, their intentions about childbearing and family are not openly discussed after their diagnosis. From the brief interactions they had with the healthcare workers after their diagnosis, they got the message that they should not have any more children. What is more, the only contraceptive method the women have ready access to is condoms.

> *The health workers said that we should be using condoms, so when I came here at the clinic at that time and when they asked me if I was pregnant and I told them that I was pregnant. They did not say anything about that. When I was coming here, when the child was born, I was asked what method I was using. So I started asking myself that they don't advise us not to take any medication and I told them that I am not taking any medication. One of my friends then told me that she uses contraceptives. And then that is when I also started using them. The other time that I came for check-ups, when they asked me if I was using contraceptives, I told them. But the doctor did not say anything but suggested that I was doing something wrong. (P004).*

Other methods of contraception like injections are avoided because of the side effects. Participant 002 reported experiencing negative side effects with contraceptives.

> *I was afraid of using the injections because I was just menstruating every day when I was injected with the Depo [Depo-Provera]. I would not stop bleeding, so I stopped. (P002).*

The information that the women received on the use of contraceptives seems unclear and confusing, such that their decisions about what contraceptives to use were based on information they received from their peers. Part of the misinformation was the belief that injections makes one's partner to lose his libido when the "chemicals" enter his body through the woman's bodily fluids.

> *They say that when you are using the injection, the man does not desire you [lowers male libido]. They say for people who use the injection, something is killed in their bodies, in the man's body. (P002).*

Participant 011 wanted to be sterilised but was discouraged by her friends and she never consulted the clinic for professional advice.

> *There were some people who told me fearful things about the sterilisation method and I was put off. They said that I will just be getting sick. (P011).*

Two of the women in the study reported that when they discovered that they were pregnant, the counselling they received did not prepare them for the mental anguish that being pregnant while HIV positive would bring. They explained that they were constantly worried and anxious. This is how Participant 001 described her experience:

> *At that time when I was pregnant, I was so disappointed and worried. I was not chatting with anyone. I was just staying on my veranda quietly. When I finish my domestic chores, I would just get in the house and sleep. Because I had worries about delivering the baby, I would think about my health, I would think about whether I am going to live or not. I would also worry if my baby would be okay. I had those worries. (P011).*

Participant 002 described being shocked when she fell pregnant despite the fact that she had received contraceptive injections.

> *When I went to the antenatal clinic, I told them that I don't know how many months my pregnancy is, when I was on the injections. They told me that it [getting pregnant] happened sometimes. So they said it could be the lack of the effectiveness of the injection which I was given. (P002).*

Most of the women in the study understood the recommendation to use condoms given by the clinic to suggest that it is the only contraceptive method that can be used by WLHIV. Nevertheless, condoms proved to be unreliable as a family planning method in the long term due to the inconsistent use in their relationships.

> *What happened was that we had been using condoms but this one day my husband said that he was tired of using condoms and that for that day we should have fun. So that day I got pregnant with this child. I discovered that I was not menstruating that month and then the second month so I came to the hospital to have myself tested and they told me that I was pregnant. (P011).*

Participant 010 initially thought she had no use for contraceptives because her husband had died. After her diagnosis, she later got into a relationship where the man refused to use condoms and she ended up getting pregnant.

> *When my child was born, the last one, I have not been on any contraceptives. There was no reason to use them since I had no husband or a man. But when I started these relationships, the first man I had a relationship with, I found that I fell pregnant. (P010).*

From the women's experiences, it also seems that there is a lack of coordination between SRH services and ARV clinics. As participant 004 reported, she preferred getting her monthly contraceptive injections at another clinic where they did not know about her HIV status. The clinic proceeded to give her injections every three months without any form of counselling in relation to her HIV status.

> *They helped me but they did not give me any counselling. The only counselling they gave me is when they were giving me the injection, because the child was already grown, they said one should start using contraceptives. They told me that I should go and have tests to see if I am not pregnant. We cannot just start you on contraceptives before testing you because the child is older now. When they found that I was not pregnant, they administered the injection. (P004).*

The experiences of the participants suggest that there should be better coordination or integration of HIV healthcare and SRH services. Without this, they may continue to make decisions about which contraceptives to use on, sometimes inaccurate, information from their peers, without specialised counselling to guide them on what methods would best suit them. It can also be deduced that the women do not have full control of their fertility as some of the women had unplanned pregnancies.

5.7 CONCLUSION

This chapter focused on themes representing the women's actual experiences of receiving an HIV diagnosis and related experiences. In most cases, the women described learning about their status as being very traumatic, which included the experiences of a range of negative emotions, before arriving at a degree of acceptance necessary to care of themselves to live their lives. For some, the path to a diagnosis included the traumatic experiences of a very ill husband or the sudden death of a husband, or sometimes the serious illness of their children. In these cases, their own diagnosis was the culmination of multiple traumatic events.

In addition to discussing the themes related to the psychological reactions of the women after their diagnosis, the chapter also highlighted the themes pertaining to how an HIV diagnosis affected the women's decisions regarding entering into new romantic relationships, which are sometimes fraught with the conflicting need for financial stability and need to retain control of their own health. Some choose celibacy, other seek relationships under very specific conditions, while some have little choice but to put themselves back in the relationships that put them at risk in the first place.

The predominant view was that HIV women forfeit the right to have further children, reinforced by their interactions with some healthcare workers. This is mostly driven by fear of vertical transmission, but also a fear of subjecting their HIV-positive bodies to the rigours of pregnancy and childbirth.

Lastly, while the experiences of accessing HIV care and treatment were positive, there is clearly a need for better integration between their HIV and reproductive healthcare. Though to some extent the experience related to diagnosis and the experiences of living with HIV are overlapping, the next chapter presents themes regarding the women's actual experiences of living with HIV.

CHAPTER SIX:

RESULTS (PART 3): LIVING WITH HIV

We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. For what then matters is to bear witness to the uniquely human potential at its best, which is to transform a personal tragedy into triumph, to turn one's predicament into a human achievement. When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves.

- Victor E. Frankl, Man's search for meaning -

6.1 INTRODUCTION

This chapter follows from the previous chapters by presenting the themes that answer the research questions *What are the actual experiences of living with HIV and what meaning do they attach to those experiences?* and *How do they cope with challenges?*

The analysis developed five superordinate themes, namely a) "I struggle to find money": Economic challenges, b) "I feel hurt in my heart": Psychosocial challenges, c) "My husband refused to come to the hospital": Lack of male involvement, d) "Now I am strong, I don't worry": Coping, and e) "It's the beginning of a new life": Meaning of living with HIV (see Figure 6.1).

Figure 6.1: Summary of results (Part 3)

6.2 "I STRUGGLE TO FIND MONEY": ECONOMIC AND PHYSICAL CHALLENGES

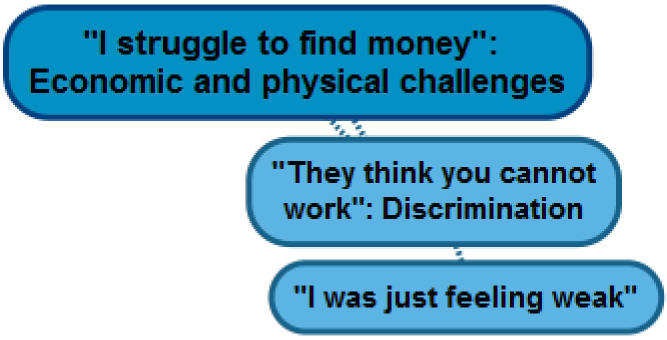

Figure 6.2: Abstracted theme contributing to the superordinate theme "I struggle to find money"

Being diagnosed with HIV makes the women's pre-existing conditions of poverty worse because of the lifestyle changes they have to make to manage the illness, which usually require financial resources. Some of the women in the study are responsible for their children's education and the provision of basic needs.

> *We have a responsibility for our relatives as well as ourselves. The result is the children suffer because they have no care. You cannot work as much or as hard as you used to in the past, like someone who had no HIV. (P008).*

Poverty and lack of empowerment emerged as common challenges of living with HIV because without any income, their situation becomes desperate at times because of additional costs and this affects their ability to take care of their health.

> *My home budget has really changed, that is what I was saying, that the money that we were spending at that time, I can't compare to now. Now I am using a lot more money to afford the things I need to afford. (P003).*
>
> *I tell my children that we have to eat what is available. Sometimes we eat porridge without even sugar in it. (P010).*

Those who are still married talked about the lack of financial support from their spouses, who control all the household resources. They also lack access to credit to start small businesses that could generate income to help them attain financial independence.

> *I am a housewife. I was making doughnuts but I am not doing anything now to generate income. I was thinking I should borrow money and start making doughnuts over again. When I asked my husband for money to start a business, he would not give it to me so things became difficult. (P004).*

This illustrates that the women have to deal with challenges of finding financial support for their daily needs in addition to managing their health. Furthermore, the type of poverty the women experience renders it impossible to find adequate food and meet their nutritional needs as they take their medication.

> *The main problem for me is finding food to eat. I have no proper help. I do not earn any money. As for the medication, I have no problem. (P010).*

Generating an income requires that the women do intensive manual labour, for example, gardening and then selling the produce because that is the only skill set they have. Because of their delicate health, it becomes difficult for them to work as much and as hard as it is required to yield more produce, which could translate to a decent income when they sell it.

> *My financial life has changed a lot because I cannot work as efficiently as I used to work when I had no HIV because you treat your body differently, you force it. (P008).*

The above quotation illustrates how the women have to push their bodies to the limit for survival. Driven by desperation for money to cater for her needs, Participant 006 described how she kept going back to commercial sex for survival.

> *In the evening, we go to bars to find money. At the end of the month, we go to a bar to find money. I think it is work. When you don't have money, even when you are on your periods, you have no boyfriend, what do you do? You go to a bar and find a man and make money. (P006).*

The participants also commented that there was a general lack of financial support structures for women who had no partners who wish to establish some financial stability for themselves. Most of the women rely on their husbands for financial support, a set-up which makes them susceptible to financial abuse and neglect. Below is how one of the women explained this:

> *Because what happens is that women just decide to have a man to help them and then they find out they are pregnant. It is like adding problems in your life. Adding a problem to another problem. It's what happens. If we had something to do. Even if they tell us to give back the money and tell us how to return the money. (P008).*

The women are aware that this financial desperation makes them more vulnerable as they remarry or enter relationships purely for financial reasons. They acknowledged that they feel helpless to end the vicious cycle of poverty that drives them to marry for security, only to be abandoned. They feel a sense of injustice towards the situation they are in as they try their best to manage their lives.

6.2.1 "They think that you cannot work": Discrimination

This subtheme captures the women's experience of socio-economic exclusion with limited opportunities to participate in income-generating activities to empower themselves because of their status. The women in the study explained that they are not invited to take part in community projects because according to the people in the community, HIV means that the women have poor and failing health, which makes them unfit to work. The quotation below illustrates this:

> *I asked for a part-time job at a neighbour's house to work in his garden. He said that I have HIV, I have a disease. I asked him how that will make me not be able to work. As if I am going to leave the illness there in the garden. He still said no. He said I could die in the garden. (P001).*

The women also encounter downright rejection when seeking employment once their status becomes known to prospective employers. Without any education, the work that they can find to generate an income is menial labour and housework, but they encounter an unwillingness from potential employers to employ them. Participant 011 felt that her honesty about her status cost her two jobs, which she desperately needed.

> *I asked for work in two places and they asked me if I am on medication. I was asking for work because of the problems that I was facing. I wanted to have something to do to earn some money. They told me that they wanted a woman who would be cooking for them, but said with the way I was, they*

> *did not. Well, they did not say the truth but I knew that it was because I take medication. Because they asked me whether I take medication and I told them that I take medication. I did not lie to them, so they told me to come another day. When I went the following day, they told me that they had found another woman to work for them and told me that they thought I would not manage with my condition because the family has a lot of work. It is not that I don't want to work. I want to work. (P011).*

Participant 006, who worked as a cleaner in a private clinic, recounted her experience of being dismissed from work because she was considered a danger to others because of her HIV status. Her employers coerced her to talk about how she became infected and threatened to have her arrested for not disclosing her status during her job interview. Apart from losing her income, she felt that she had lost her dignity and she felt humiliated.

> *What happened was that supervisors from the hospital came, and everyone was supposed to get tested. They found out that I was positive. And they asked me questions. I told them that I have been found with HIV for a while. They asked me if I receive medication. They told me to wait for five days. After five days, they gave me a paper and on the paper they wrote that I should quit working because it is a hospital setting and I am washing cups and touching other utensils and I may have a sore that is open and that it may infect other people, so I should stop working. (P006).*

The women seem unaware that being dismissed unfairly from work or being denied employment is a violation of their rights. It is also clear that the women are not aware of any fora to table the issue of socio-economic exclusion for them to seek justice on these matters. By being denied an opportunity to generate their own income, they are not only disempowered financially, but psychologically as well. When they are unable to work, they are not capable of taking care of their needs and manage their illness. Lack of financial empowerment directly threatens their wellbeing and that of their children. This is a major source of worry and psychological distress.

6.2.2 "I was just feeling weak"

This theme concerns the impact of the women's HIV diagnosis on their bodies, which subsequently affects economic productivity and their ability to provide for their children and themselves. Several women reported having bouts of illness and feeling that their bodies are losing strength and because they rely on menial work to earn a living. Their poor physical health directly affects their ability to perform income-generating activities. Participant 011 explained how she felt helpless after the initiation of medication interfered with her ability to work in the garden (but then later was able to benefit from the efficacy of the medication).

> *I had no energy, I was just feeling weak. Then later I became strong and I would go to the maize field. I regained my strength. Then my body got used to the medicine. (P011).*

Their physical health depends on maintaining optimal nutrition, in conjunction with the ART, which to most proves to be a major setback. Due to household poverty and a lack of income, the women are unable to find nutritious food for themselves to complement the ARV drugs. They are aware of what they need to do to stay healthy but have few resources to do so.

> *I am not really managing well, with what they told us at the hospital that we should be eating a variety of foods and paying attention to our nutrition. It is difficult with the way things are now. Farming is not going well and food is very expensive. Sometimes you just eat in the afternoon and not in the evening. (P005).*
>
> *When I get heart palpitations when I take the medication, what I noticed is that I have not eaten well because the medication is strong so the medication should find enough food in one's body so I cannot blame the drugs. The problem was that I was not eating enough food. (P010).*

In summary, the women reported experiencing discrimination in economic activities as well as difficulties with their physical health, which directly limit their ability to work. Although they take medication to boost their immunity and control the virus, lack of income and resources means that they cannot manage their health, in particular meeting their nutritional needs. Because HIV is an illness that affects their physical bodies, poor health means that they are not strong enough to work. To keep their bodies healthy, they need proper nutrition, which requires that they afford good food. In the absence of proper nutrition, their bodies will not be strong enough to work. Thus, these challenges create a synergistic relationship.

6.3 “I FEEL HURT IN MY HEART”: PSYCHOSOCIAL CHALLENGES

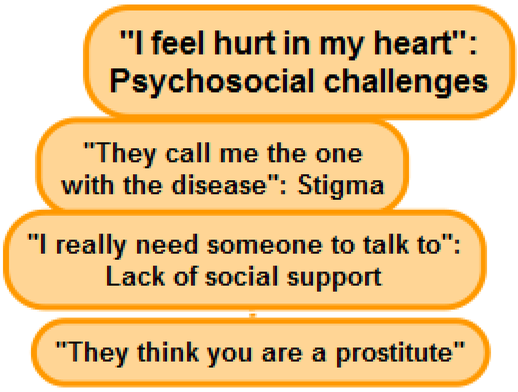

Figure 6.3: Abstracted themes contributing to the superordinate theme “I feel hurt in my heart”: Psychosocial challenges

This superordinate theme refers to the emotionally and socially challenging situations the women experience because of their HIV status, which cause them distress. The women reported how their families would treat them differently for being HIV positive, how the community perceives them as WLHIV, and their challenges in finding support.

6.3.1 “They call me the one with the disease”: Stigma

This subtheme concerns the stigma commonly experienced from immediate family members and the community at large. In the community, taking ARV medication is referred to as “putting credit in a cell phone” because people with HIV rely on medication to sustain their lives.

> *When I leave home and in another area, they say some things, they call us the TOP UP ones. (P011).*

The above quotation illustrates the pervasive attitudes and mockery the women have to put up with because of their status. Stigma also comes in the form of labelling the women with derogatory phrases and making them the subject of malicious gossip. Participant 006 described how people in her community once ganged up against her and how she could not defend herself from disparagement, especially because it was her own family revealing her status to the community.

> *They [her family] call me the one with the disease. When I bathe a child at home, and they say I hope you wore gloves. They tell the children in the*

> *community that I have a disease. And the children ask me, "Do you have a disease?" Sometimes it affects me and I just go into the house. When I confront them, they ask me, "Is it not true that you have a disease?" So it's difficult for me to answer back. (P006).*

Participant 006 felt a sense of betrayal because she expected support from her relatives. The women rationalise these experiences by explaining that those who stigmatise others are uninformed about issues of HIV.

Instead of assuming that those enact their stigma as HIV-negative, Participant 004 obtains some measure of comfort by narrowing the perceived social distance by dividing people according to whether or not they know their status. Similarly, disregarding the remarks as ignorance makes it easier for the women to endure those who subject them to stigma because to them unawareness about HIV means that people were not just acting out of spite.

> *When I thought about it, about the people who were avoiding me, I thought that it is possible that they may not have gone for testing themselves at the hospital and that most of them do not know their HIV status. So it is possible that they could be laughing at me but if they would go to the hospital, what results would they come back with? I just concluded that they are ignorant and let it go. (P004).*

The women perceive themselves as possessing knowledge about HIV, and that those who call them names have no access to information about HIV. They feel they are well informed about how to manage the illness, while the others who ridicule them are not sensitised. To them, it is simply impossible to stigmatise others once one has gone through HIV testing, whether the results come out positive or negative. Getting the test means that one is open to the possibility that one could have HIV, hence will be less likely to mock others who have the virus.

Participant 007 used the metaphor "*fire burns where the bush is remaining"*, which captures the idea that those who mock them might become infected in the future because of their ignorance. Thinking about her diagnosis in this way helps her accept that HIV can happen to anyone and that being HIV positive does not mean the end of hope.

> *Even parents would say things like that to my children. That you are all taking medication in your family, we have seen you with your mother. I tell*

> *my children not to worry because the fire burns where the bush is remaining [if they do not have HIV, they could be next]. Maybe it cannot be them but their children could have HIV. (P007).*

This idea is key in understanding the root cause of stigma in communities. There is still a lack of awareness about the nature of HIV as an illness that can be managed, and hence the existence of attitudes that largely alienate those with HIV. The women's quotations illustrate that they live in an environment where people empathise less because they see themselves as less vulnerable to the disease. The distinction between those who know their status and who are knowledgeable about HIV and managing their condition, versus those who do not know their status and those who may not be HIV-positive now but could become so in the future appears to be an important way of coping that blurs the boundaries and levels the perceived moral standing of the two groups.

6.3.2 "They think you are a prostitute"

This subtheme captures how the women are labelled as being immoral and how they are blamed for their HIV status. In their communities, being HIV positive is associated with high-risk sexual behaviour such as commercial sex work and having multiple sex partners. What makes this label more psychologically damaging to the women is that most of them are infected in their marriages. As the women are struggling to accept the fact that they became infected while being faithful to their husbands, suggesting that they are sex-workers for having HIV stigmatising.

> *Yes, they would look at you as a prostitute. By this I mean that at that time when you have been diagnosed with HIV, they think that one was sleeping around with different men. This is a prostitute; they say those things. You see. They said my husband died so now I will spread the disease. But I did not have any relationship with anyone other than my husband, I did not even start sleeping around, I was just staying at my house.*

The women are further accused of putting the lives of people in the village at risk, as if their mere presence in the village will endanger other people's lives. In the case of Participant 008, living in the village as an HIV-positive divorced woman attracts double stigma, and at one point she was openly told that she was not welcome and was embarrassing her family.

> *They would say that I have brought HIV and I want to kill people. I did not know at first what the people were saying behind my back. Then my brother called me and said to me that he wants me to go back to my husband because when he came here to marry me, I was not looking like this. People were asking my brother why he would keep a corpse. (P008).*

Participant 008 confronted the people in the village directly and challenged this stereotype because she knew with certainty that she was married when she contracted the virus, and that the assumptions the people in the village were making were incorrect and unfair.

> *I was not promiscuous and I did not get HIV because I was all over the place but I am sure that it's in my marriage where I got the virus. So I forced them to apologise. (P008).*

6.3.3 Decision to disclose one's status

HIV disclosure emerged as a powerful subtheme of the participants' experiences and challenges of living with HIV. The decision to disclose one's status is accompanied by anxieties about breach of confidence and betrayal of trust. For those who decide to disclose their status, it means opening up the possibility of receiving social support. At the same time, it means risking exposing themselves to stigma and discrimination.

When they first learned about their diagnosis, it dawned on the women that their relatives and people in the community would have to know about their status at some point. Participant 001 expressed how she felt a sense of lack of control regarding how to manage the information about her diagnosis when she first learnt about her status.

> *I had to tell them because when one is about to start taking ARVs there is a need for a guardian to come with you to the hospital. When they informed me that my CD4 was very low, the hospital staff told me to come back to the hospital with a guardian so that I could be started on the ARVs. In my heart I was still uncertain that my relatives or my siblings would accept me. I decided to try telling them anyway. I called all my siblings, all eight of us. Before, some of them had died but our parents had died already. I told them that during my frequent illness, I got tested for HIV and I have tested HIV positive. (P001).*

Disclosure to relatives becomes a matter of necessity because, after the diagnosis, it is mandatory for the women to be accompanied by a guardian to the clinic to support them during their first counselling session where they learn about managing the illness. Those who have supportive relatives receive encouragement and the crucial initial support needed to cushion the shock of the diagnosis. Participants 002 and 007's quotations exemplify the benefit of having someone trustworthy to talk to about their status.

> *I told my sister about my status. I also told my sister's children. My brother also knows and two of my neighbours also know. They just accepted and said that I should not be disappointed. Even my neighbours, one of them is on medication, even the one who is not on medication, she encourages me that I should not be worried. (P002).*
>
> *I have a neighbour whom I really trusted and at the very beginning when I got very sick, I explained to her that I have been found HIV positive. At first she did not believe me, so I showed her my hospital health book. We used to talk and I would explain things to her and what I should eat and some of the issues that I heard from the health education talk. She was encouraging me on what foods to eat that were nutritious. She would help me make those food choices. (P007).*

Disclosure of their status to their children serves as preparation for the children in case of the women's sudden illness; or worse, death. It also serves as a way to warn or caution their children about the illness. Women with children who are HIV positive struggle with the idea that they will at some point have to explain to their children that they are HIV-positive.

> *Maybe when she is eight years old, she would be able to understand as opposed to now. She just comes to the hospital to get medication, so sometimes she tells me if she did not take medication. I ask the older siblings when I am away if she had taken her medication. So I will have to be open to her when she is older and tell her why she takes the medication. (P007).*

Participant 008 was concerned that should she die suddenly; people may assume that her death was result of a bewitchment. To prevent this, she disclosed her status to her nephew. This is significant in that it is a partial disclosure: she has not announced her status to the community that would speculate about the cause of her death, but rather to a family member who would be able to confirm the actual cause of death only after she has died in the event that she dies suddenly. It suggests, too, that HIV is less stigmatising than the belief that she has been killed by bewitchment.

> *I told him [my sister's son], he was in Form 3 at that time, that when I went to get married, I have been "damaged". I came back with HIV. And I am now on ARV medication and I showed him my hospital health book and this is my medication. I told him because I was afraid that one day I might just suddenly collapse and die; there should be no rumours or arguments that someone has bewitched me in this village. I am simply on HIV medication. (P008).*

Attributions of immoral behaviour discourage some to disclose their status because not all the women experience support from relatives after disclosing their status. Participant 006 narrated how close family members, instead of giving her support and sympathy, judged her.

> *They were not very encouraging. They told me that they knew that I will contract HIV. We went to the chief's house and explained to them because I was afraid that I might get sick suddenly. I got very sick last year; I got really sick, but I had no one to care for me. My relatives kept on saying that they told me not to move around. By the grace of God, I got better. (P006).*

Those who kept their diagnosis confidential from relatives and the community do so to protect themselves from stigma and discrimination. This fear of disclosure for some may be due to internalised stigma. Perhaps they may not have experienced direct stigma as yet, but in the case of Participant 004, she directly experienced a betrayal of trust from a close friend and it opened a barrage of negative social interactions with people in her community.

> *The person I confided in went and told other people that I am HIV positive. And people told other people that I have started to take ARV medication. People started to isolate me. I knew that they would continue avoiding me. (P004).*

The idea of disclosing one's status to a prospective partner presents a quandary for the women. The general feeling is that disclosing their status ruins their prospects of getting into relationships.

> *I want to find marriage first. Because now I will just be called someone with HIV if I disclose my status. It is better the man should come and propose to me first and I can tell him myself in confidence. But if I come out now, people will be saying, "That woman has HIV". (P009).*

To have a solid base of acceptance and support, they choose to first disclose to the people whom they attend the clinic with because they share the same experiences. By building alliances with their fellow patients, they feel safer in their first step of disclosure.

> *We made a partnership with one of my neighbours. He was a man whose wife had died and I had just lost my husband. We were supporting each other. When it was time for one of us to go to the hospital, we would escort them, when the other one needed to go the hospital, we would escort them. (P010).*

The quote above demonstrates, again, that some of those with HIV benefit from knowing others who are also HIV-positive. Knowing others who are coping with similar experiences enables some practice for the riskier task of disclosing to others and to also receive emotional support from one another.

One of the experiences the women in this study described is that they had to disclose their status out of necessity to gain some form of support. For example, when they register their details with the village chief so that they are included in community development projects that offer support to vulnerable people. Although the registration process is necessary for them to receive the material support, they dislike the idea because their status is no longer private.

> *Some friends told me that I should go to the hospital in Chingale because people who have been found to be HIV positive were being given a bag of maize flour and some porridge flour. I showed them my hospital book. They told the health assistant to register me and gave me some food. (P008).*

> *I told the chief about my status and that of my child. That helped because the chief started to include me in programmes in the village. We would receive material help. (P010).*

For some participants, disclosure enabled a sense of personal empowerment. Some of the women make a deliberate choice to disclose their status as a way of encouraging others and as their own way of coping with the diagnosis. Participant 012 took on the role of advocacy to educate those who had not yet undergone HIV testing in her community.

> *Sometimes in the communities, we have organisations that come to test if people are HIV positive. They come from all over. I am open and explain to them that I take medication and that I have HIV. They take it well and they encourage us that I am supposed to be open that I take medication because some people do not come out in the open to tell people the truth but I am open and tell people that I am HIV positive. (P012).*

From the discussion above, it seems as if disclosing their diagnosis means allowing strangers into a very private world, a scenario that leaves the women open to judgements. Given the choice, many of the women would keep the diagnosis discreet, but disclosure becomes a necessity to receive support. Some disclose to be able to provide support for others who are HIV-positive. This identity as an advocate who provides support to others who are HIV-positive may be a crucial countermeasure to the stigmatised identity. The following subtheme further explores the women's experiences of receiving support.

6.3.4 "I really need someone to talk to": Lack of social support

This subtheme concerns the experience of feeling alone in their journey of being diagnosed and adjusting to living with HIV due to the absence of support. This follows from the above subthemes that discussed the stigma the women experience and the attitudes in the community towards them as WLHIV. They feel a lack of support when their relatives betray their trust by revealing their HIV diagnosis to people in the community, leaving the women vulnerable to stigma – as was the case with Participant 001.

> *My relatives were telling other people that I have started taking ARV medication. Men were talking about me and my taking medication. I would*

> *sometimes wonder that is taking ARV medication a bad thing that I should be stigmatised and bullied. (P001).*

The women also expressed the dilemma of having to find a healthy way of dealing with the emotions that an HIV diagnosis brings and being unable to find a safe outlet for those emotions where their privacy would still be respected. Participant 006 describes the loneliness of not having somebody who is knowledgeable and supportive.

> *I usually worry in my heart and I have no one to encourage me with my daily life. I have not found anyone to encourage me that this is how HIV is like. After this stage, it will go to this stage, there is no one to help me. At the clinic they just talk to us now when we come here but what I lack is someone who I can stay with the whole day and encourage me about my life. (P006).*

A counsellor may be able to perform the role that Participant 006 is missing, but the comment below illustrates that not only is the counselling at the clinic brief at the time of their diagnosis, there also is a lack of follow-up support outside the clinic to help the women manage the psychological burden of living with HIV.

> *Most of this counselling is only accessed in hospitals when you are getting tested. (P003).*

As discussed in the previous subtheme, the decision to disclose their HIV status is made in the hope of receiving support. Confiding in friends or relatives proves to be risky as some of the women reported experiences of betrayal of trust after their HIV status was revealed to others without their consent. Participant 008, for example, talked to a friend about her diagnosis and ended up regretting it and feeling bitter when she learned that the friend discussed about her diagnosis with other people in the village without her consent.

> *The person went and told other people that I am HIV positive. People told other people that I have started to take ARV medication. People started to stigmatise me and isolate me. (P008).*

While there may be benefits to being a part of a support group or community of practice, as is described in section 6.5.2 below, this also brings some risks. The participants seek support from groups they feel safe. The reluctance of some to join support groups is significant as this is the current model of providing emotional support for PLHIV in Malawi. Attending a support group risks involuntary disclosure by association with people known to be HIV-positive. Participant 006 describes the risks.

> *They [support groups] exist but it is also common to encounter more stigma. It's not like people don't go but when you go there two or three days, people know about it in the village. They start talking about you attending these groups and they broadcast what you were doing at the support groups. So things like that discourage me to go to those groups. (P006).*

As noted earlier, Participant 006 has a history of childhood sexual abuse and sex work that is perhaps something that she is unlikely to want to share to a group, suggesting that alongside support groups, there should also be provision of individual counselling services.

Participant 005 mentioned some practical barriers to maintaining the groups. According to some of the women, previously the support groups provided material support like food and blankets, but those provisions are now no longer available.

> *In our home village the support groups are further apart and the people don't get very coordinated and when someone asks for money [from the support groups], they are not really given the money and it's difficult to find money the way the business is not really working well. It's difficult to invite people to the support groups. (P005).*

Much of this illustrates that while psychological support is required, for many the more important challenge is to find material support. Overall, it seems that for many, psychological and material forms support is generally lacking in their lives. While it is reported in 6.3.4 that they experience a lack of support there are other types of support the women report that they actively seek in section 6.5.

6.4 "MY HUSBAND REFUSED TO COME TO THE HOSPITAL WITH ME": LACK OF MALE INVOLVEMENT

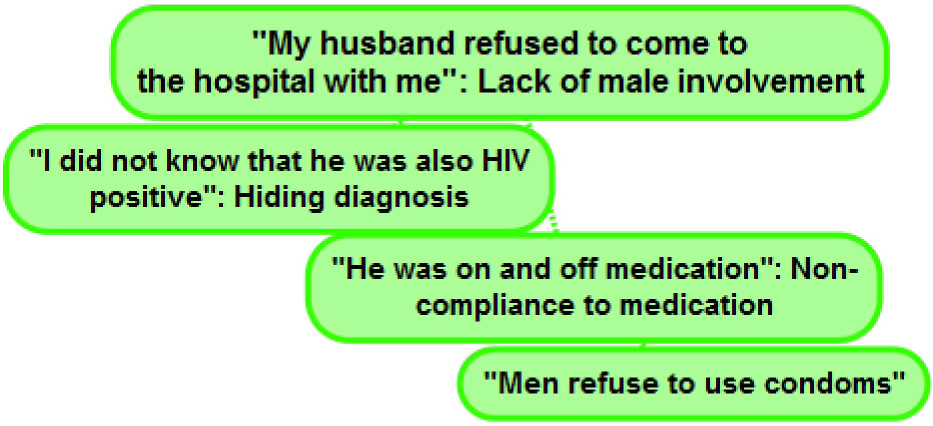

Figure 6.4: Abstracted theme contributing to the superordinate theme "My husband refused to come to the hospital with me": Lack of male involvement

This superordinate theme describes the difficult situation the participants find themselves in when their partners sabotage their efforts to maintain their health by being uninvolved in actively managing the illness. Living with HIV becomes even more problematic for the participants because their partners and husbands are often hesitant to take the initiative to be tested for HIV, comply with medication after diagnosis, and use condoms as per the clinic's advice. As mentioned in Chapter Five, sometimes men who know about their HIV status never bother to inform their wives in the first place until they became sick. The women in relationships feel particularly worried about this issue because the management of HIV as an illness requires that both parties are proactive in taking care of their health.

From the women's stories, it appears that when the women learn about their diagnosis, it brings about behavioural change. Most take the initiative to eat well, learn more about the illness, and seek support. Their men, on the other hand, often continue to engage in risky sexual behaviours and, as one women put it, "*they become uncontrollable and still have numerous affairs*". The nature of their affairs was discussed in detail in Chapter Four. In short, after the diagnosis, it takes time for some men to accept their diagnosis and make the necessary lifestyle changes. Some of the women expressed their views from observations about how men and women differed in how they manage the HIV diagnosis.

> *Most men do not accept. They do not even get tested so that they do not spread the virus. When men have the virus, they want to go and spread it. If*

> *the man sleeps with five women who were alright, they are infected. But how many men can each one of those women sleep with? Can HIV be controlled like that? (P001).*

Participant 001's quotation suggests that men and women respond differently: according to her, women are more likely to take the necessary measures to protect themselves and others, while men do not. Participant 012 also locates the problem amongst men. While this is obviously an overgeneralisation, it does suggest that there should be a more gendered approach to HIV that reaches both men and women.

> *In marriage, men usually infect women. They have affairs and infect the women but they don't know how they got the illness. The women come to the hospital and get tested and they find that they have been infected by their husbands. But they don't know how they got it. Most men get infections, where they go and bring it in the marriage. (P012).*

6.4.1 "He was on and off medication": Non-compliance with medication

This subtheme reveals that married couples who are both HIV-positive and on medication do not necessarily support each other in adhering to their ARV prescriptions, which must put some of the women at risk of reinfection and possibly undermines their own efforts to adhere to the drug regimen. Participant 006 recalled how she had a hard time making her husband take his medication despite reasoning with him to take care of his health:

> *He [the husband] was failing to take the medication properly. He would spit out the medication when you gave it to him. He would say he would take the medication but as soon as I leave the room, he would throw the medicine away. He would put them under the mattress and when I would sweep the room, I would find six or seven tablets under the mattress. (P006).*

Similarly, Participant 003, who discovered that she was HIV positive after her youngest child fell ill, spoke of how it was almost impossible to get her husband to take the medication after his diagnosis, while Participant 004 had a similar challenge.

> *He was on and off his medication. He would come here at the hospital to get medication, sometimes he would not come to get medication. He was*

> *not even taking the medication. He was just keeping the medication at home. (P003).*
>
> *He usually skips his medication. I really don’t know how he is doing, where he is now. (P004).*

Some of the women rightly realise that their efforts to maintain their health are jeopardised because their men consistently refuse to take their medication. One might have assumed that HIV concordance amongst couples would enable mutual support, but the excerpts above illustrate that this is not always the case.

6.4.2 “I did not know that he was also HIV positive”: Hiding diagnosis

Similar to the theme above, the women participants were inclined to share their status to their husbands, but this sharing was not necessarily reciprocated. In some cases, men continued to conceal their HIV diagnosis from their own partners.

> *He started taking medication [ARVs] but I would not know when he started because he was doing it secretly. His relatives would come and bring him the medication. I was surprised the time I heard that. I went to the hospital and then the doctor asked me if I would like to know what my husband was suffering from. I told them that yes, I want to know. They told me he was HIV positive. (P008).*
>
> *He knew and hid it from me, he was not taking medication. And then he just stopped finding work and started doing his philandering. (P005).*

One of the participants described how she explained to her husband about the symptoms she was experiencing in an attempt to alert him that something could be wrong with their health and that they should both be tested, but he refused, so she went alone.

> *At that time, I was just having these headaches frequently and I would feel that my body was not as strong as it was. So I told my husband that I want to go to the hospital to get an HIV test. My husband was refusing and asking me why I wanted to get tested. I told him that I just want to know how my body is. My husband refused to come to the hospital with me so I went with my in-law. As a friend. My friend asked me why have I decided to*

> *get tested and why I am brave to do that. I just told her that I wanted to know how my body is. So I went for testing and they told me that I am HIV positive. (P004).*

Participant 006, a former a sex worker, also describes her experiences of men do not reciprocate her honest disclosure and protective measures.

> *There are some men who know how they are in their bodies [their HIV status] but for them to tell you at that time that they take medication, they don't. They pretend to put on the condom and they make a hole in front of the condom. And they tell you that the condoms burst. They tell you when the act has already happened. In my case, when someone finds me, I tell them the truth. That I take medication. It is up to them whether they want to sleep with you or not. If they don't, you know that the person has had some doubts. So you part ways. (P006).*

Participant 006 also had experience of a partner who did not disclose his status until she confronted him, even though he knew that she was HIV-positive.

> *I did not know that he was also HIV positive. In the end he got sick. Malaria and the like. He came to my house and then asked for water. He then took out two pills, one ARV pill and Bactrim, and I asked him what was going on. He then said that he was on medication. I asked him why he did not mention it. He said that it was because he learned that I was HIV positive and there was no reason to tell me and that he knew he would tell me at some point. [They had sex without protection]. (P006).*

In the case of Participant 003, her husband never admitted that he had infected her, even though there was no other explanation. She was certain that it was him, because with their first child, she tested negative at the antenatal clinic but had a positive result with her second pregnancy.

> *It was just that he could not admit to my face that it is true that the problem was brought in the family by him. But the truth of the matter is he brought HIV in the family. (P003).*

This subtheme demonstrates how the participants are often constrained in taking total control of their health because their male partners do not necessarily reciprocate their honest disclosure or the efforts to maintain their health. It would seem reasonable to conclude that the very gender inequalities that put them at risk in the first place continue to undermine their efforts to remain healthy. Further examples of these experiences are the topic of the next subtheme.

6.4.3 "Men refuse to use condoms"

This subtheme reports that some of the participant's experience resistance from their male sexual partners against using condoms, often disregarding the counselling given at the clinic. The women explained that after their diagnosis, getting their partners to use condoms can be very difficult.

> *My husband was refusing to use condoms. He would say that the condoms were useless. (P004).*

This shifts the onus of responsibility onto the women to care for their own health and their husband's health, which is sometimes an impossible task because to insist on the use of condoms is sometimes used as justification by men for having unfaithful, unprotected sex elsewhere, as Participants 001 and 003 reveal.

> *To even suggest to the man to use condoms, the men don't agree. They want plain. When you refuse to have sex with them without a condom, they have affairs where they can do it plain. Because they don't want to use a condom. (P001).*
>
> *The clinic said we should use condoms. My husband never wanted that. That is why he found another wife and they even had another child there. He was refusing to use condoms, as per the hospital's advice. (P003).*

Worryingly, according to Participant 010, some men justify unprotected sex on the grounds that they are taking ARV medication. Yet, as illustrated above, not all of these men are necessarily taking their medication consistently.

> *They [the men] say that because we are taking medication, the virus is sleeping, that the virus is weak. When we are on ARVs, the virus does not*

> *die but it is weak, so when the man and woman are on ARVs it is possible to sleep together because the virus is weak. (P010).*

It seems that the women are caught between two difficult choices on the issue of condom use. On the one hand, there is the risk of reinfection if they do not use condoms; on the other hand, there is the fear of withdrawal of intimacy by their partners, whom they depend on, if they insist on using condoms. When the women take the initiative of protecting their own health by insisting on condom use as per hospital advice, it causes discord in the family.

> *When we both received the counselling at the hospital, when he went home, my husband and I were sleeping on separate beds. And the days when he felt like sleeping with me, when I just give him the condoms and remind him that the hospital says we have to use condoms, he would say I am a woman without manners and that we should just live together without sexual intimacy. That is why a lot of women nowadays are just getting pregnant and adding the virus to their bodies. We women are experiencing hard times because we want to keep our marriages. (P008).*

The women make sense of this situation by explaining that it is difficult to establish condom use, especially when there were not previously using condoms in their married life. Their husbands tell them that they do not get any pleasure when using condoms. In new relationships, when the first sexual encounter is without protection, it is difficult to demand condom use on the next occasion. Participant 009's explanation suggests that it is impossible to break already established sexual behaviour in marriage.

> *He said that he could not have a proper erection when he uses condoms. These things are difficult. You can imagine, you have been married for 10 to 15 years, and all of a sudden you are told to use condoms. So the man is already used to that feeling, he knows that the woman feels this way. And when the condoms are introduced, it is difficult. That's why they might leave you and sleep with other women without condoms. (P009).*

Although the women in the study make efforts to take care of themselves and effect positive changes to manage the illness, they lack total control over their health because their partners do not cooperate with them by refusing to use condoms, not disclosing their status at the onset of the relationship, and not adhering to the medication after their diagnosis.

6.5 “NOW I AM STRONG AND I DON’T WORRY”: COPING

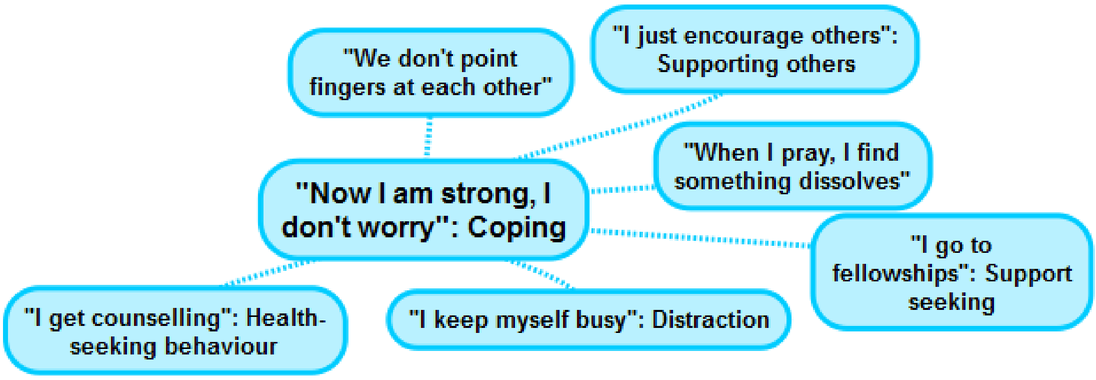

Figure 6.5: Abstracted theme contributing to the superordinate theme “Now I am strong and I don’t worry”: Coping

This superordinate theme regards the strategies the women use to protect themselves from overwhelming emotions related to their HIV status. Themes 6.3.2 and superordinate themes 6.5 are both true for the participants because even though they reported a lack of support they engage in behaviours to compensate for that lack of support. The two themes are not contradicting each other rather they are bringing to light the unavailability of formal support and the efforts the women make to find their own support systems to deal with the impact of their experiences of living with HIV.

The women find resources to learn and understand more about their illness to monitor and manage their health. The superordinate theme also talks about how the women deal with negative experiences relating to their diagnosis. Six subthemes capture these strategies: a) “When I pray, I find something dissolves”: Spiritual healing, b) “I go to fellowships”: Support seeking, c) “I get counselling”: Health-seeking behaviour, d) “I keep myself busy”: Distraction, e) “We don’t point fingers at each other”, and f) “I just encourage others”: Supporting others (see Figure 6.5).

6.5.1 “When I pray, I find something dissolves”: Spiritual healing

This first subtheme describes how many of the women deal with psychological distress through prayer and attending religious activities. Prayer to them signifies relinquishing control over their circumstances to a higher power. This brings them a feeling of peace, while knowing and accepting that there are other aspects of their life they cannot change or control. Feelings of hope spring from the belief that they can only do what they humanly can, and the rest will be taken care of by a higher power. Praying is a ready inner resource that they use to immediately deal with their negative feelings.

After the emotional exhaustion experienced when trying to make sense of their diagnosis, prayer restores their emotional strength by allowing them to let go of their worries. Participant 004 utilised prayers after receiving her diagnosis to minimise rumination and to find closure regarding the answers she did not have about how she became infected when she was faithful to her husband. She describes how her religious faith has strengthened since being diagnosed with HIV.

> *The HIV diagnosis has changed my life because in the past, although I was going to church to pray, I did not have much faith. When something disappointed me, my faith would weaken. But now, I make sure that if I have any problems at all, I just leave it to God. (P004).*

Participant 008, who had her privacy violated by a friend regarding her diagnosis, turned to prayer to manage her worries rather than risk a further breach of trust.

> *I just accepted it and I also pray a lot because it's only God who helps. Because when you tell your friends about your worries, they don't go away exactly. What I do is to put God first. (P008).*

Other participants describe how their religious beliefs help them to cope with the emotional demands of their HIV status.

> *I would just accept it and leave it in God's hands. It was disappointing at that time but I would get out of it quickly because God knows everything. (P001).*
>
> *To accept that you have the disease is a very difficult thing but when you lean on God, when God is helping you, it becomes easy. (P010).*

In addition to prayer, Participant 006 describes how attending church has helped her to make changes in her life.

> *When I compare my life with how I was living in the past, I think I have changed. In the past I never cared about religion or spiritual life. I was just concerned with being a prostitute, even on Sundays. Instead of going to*

> *church, I was going to see men. Maybe the man would come to my house and I would be sleeping with the man instead of going to church. Even if I had already taken a shower to go to church but I would be sleeping with the man. Now that I go to Pentecostal church, since I started going to this church, my life has changed and I am no longer concerned about men as I was in the past. (P006).*

It appears that prayer and religious activities are an effective way of regaining the emotional equilibrium that was disrupted upon hearing the shocking news about their status. Prayer is easily accessible in one's own privacy or in groups such as churches. Most importantly, "speaking to God" about their worries assures the women of privacy and confidentiality, unlike when they confide in other people. It is also possible that religious participation helps to displace internalised stigma: being holy is the opposite of the many the stigmatising beliefs about those who contract HIV.

6.5.2 "I go to fellowships": Support seeking

This subtheme describes how some of the women actively seek support by accessing wider social support networks to be in other people's company and to cope with and adjust to the illness. Some of these women attend religious gatherings and support groups to feel less lonely and less isolated. This subtheme is different from the above theme where the women use prayer, usually done in privacy, to ease their emotional pain from the diagnosis. The physical act of attending religious gatherings and support groups gives them an opportunity to meet with different people. Through socialising with others in these gatherings, they meet potential friends whom they learn to trust, confide in and receive support from. Significantly, while some have mentioned their reluctance to join groups for support, as mentioned in section 6.3.4, others found this to be a very significant component of support.

> *I would go to several support groups and organisations when I hear that they talk about HIV. Other people would invite us, and when going back home, they would give us some porridge or beans, those times when you did not have anything. That encouraged us and it was important because even when I had worries, we would share those worries and the worries would lessen. I would go to these groups, these support groups, several of*

> *them, and I would learn different things from those groups. That is how I have found peace of mind up to this point. (P010).*

Fellowships and religious gatherings comprise diverse members of the community, and through interaction they forge friendships with like-minded people and share experiences. For Participant 002, attending religious gatherings does not make her feel exposed or known as “the woman with HIV” and this gives her a sense of security. Significantly, her support group is not an HIV support group, and so membership does not risk exposure.

> *It encourages me and gives me hope every day. For example, I meet with my fellow women group members at church at a certain time and when we meet, I always learn something that encourages me. It is also a happy time to meet with fellow women. (P002).*

The interview extracts above suggest that some of the women are able to identify sources of support at their disposal and are drawn to safe spaces that make them feel secure and unjudged. This also shows that they have an awareness that they need encouragement and motivation to stay on course with the treatment.

In contrast, Participant 005 uses isolation and distraction, rather than social support, to cope, though presumably as significant cost to her social life.

> *For me, not to think about what people are saying about me, I just do my own things at my home. I just work hard at doing my business and finding my own food and eating well. Maybe I stay without seeing anyone in the village for three or four days. Just keeping myself busy in the garden or the market, so you avoid those sort of things. (P005).*

As beneficial as social support can be, not all the participants are able to take the risk.

6.5.3 “I get counselling”: Health-seeking behaviour

This subtheme encompasses how the participants were inclined to seek more information and expert advice useful for optimising their physical health. Most of the women claim lack of proper knowledge about matters relating to HIV prior to their diagnosis. They also hold inaccurate notions about HIV, for instance that it is a hopeless medical condition. To deal with the fear brought about by the misinformation learned from their peers, the women actively sought accurate information to understand the clinical course of the illness to ensure that they have some control over their health.

For example, Participant 010 explained how anxious and discouraged she felt after her diagnosis, until she obtained as much information as she could about HIV through the media and reading leaflets. She used that information to demand the services she needed at the clinic.

> *I found some doctors, there were also some nurses, and I asked them that they should test my CD4 count because I read about the information. At that time, it was a misunderstanding because people were saying a lot of things. I was getting information from newspapers and the radio and other government information but my greatest fears were brought to me by people. People were saying things that were not true. They would say when you have a child with HIV, they will be dead in five years and when your immunity lowers, you could die and you would not be able to have any children as an adult. (P010).*

This suggests that the participants actively confronted their condition, and learned new information to control and manage their condition despite the limited resources at their disposal. Instead of feeling sorry for themselves, they learned from various sources about how to stay motivated and live positively.

> *I listen to radio messages and programmes about people giving their testimonies of living well with HIV. In the beginning, they had worries and they felt that they can never work again. And then they became strong and stopped worrying and accepted [their condition] and their lives went on. Those things encourage me that I can do well. (P004).*

Medical information eases their worries and establishes the confidence that they will be capable of managing the illness. Participant 002 explained confidently that obtaining information from the clinic, however brief the counselling was, greatly improved her outlook after she her diagnosis.

> *They explained to me that ARV medication prolongs one's life and they increase one's life span. They also said ARVs are not a cure but they just prolong life. (P002).*

After receiving the information, they were able to employ a number of self-care strategies, including eating well and exercising. Getting accurate information from the experts helps them to make lifestyle changes and gain control of the illness by removing the feelings of helplessness often felt after their diagnosis.

> *Apart from eating well, I make sure that I exercise every morning before doing anything and I don't want the children to know what is happening so I just tell them let's go and have a run outside so I exercise together with the children. (P003).*

6.5.4 "I keep myself busy": Distraction

This subtheme represents a cognitive coping strategy some of the women use to distract themselves from worry. Participants who reported occupying themselves with activities explained that it made them worry less about their diagnosis. They attend group activities to distract themselves from being preoccupied with negative thoughts that spiral into negative mood states.

> *The time that I am running my business, I am always doing something until the evening. I don't have time to worry that I am HIV positive. When I am back at home, I just talk to my family. (P002).*
>
> *I just keep myself busy at home. The first thing in the morning is I take a bath and organise my business. You keep yourself busy and you don't have time to worry or complain to the neighbours. (P003).*

The efforts to distract themselves from their worries may be motivated by a fear that worry itself is dangerous, as Participant 011 explains.

> *And with the medication I am taking, you don't need to be worried. You should have peace of mind. But if you are worried you don't have any peace of mind and you might get more sick because of worry and then die. (P011).*

A concern though, is that metaworry – the worry about worry – is, according to a prominent cognitive model of generalised anxiety disorder, a key factor that maintains worry (see Wells, 1995). While distraction may be a useful tool, it would probably best that this not be motivated by inaccurate beliefs about the danger of worry.

6.5.5 "We don't point fingers at each other"

This theme relates how the women seek the company of their fellow patients at the clinic for support as individuals going through the same experience. Among themselves, many of the women develop supportive friendships and safe spaces where they receive mutual support and understanding.

> *The friends I relate to are the ones that I meet here at the clinic, so when we meet at the hospital, we greet each other and ask each other when we will be back at the clinic. (P007).*

The women also expressed that connecting with those living with HIV gives them a sense of belonging, which removes the feeling of being "the others" in their communities when people talk about their diagnosis. Participant 002 described the profound sense of belonging that she experiences with other women who attend the clinic.

> *For us, the people who attend Tisungane Clinic, we don't feel like there is something wrong with us. We do not point fingers at each other about how or why one has the disease. We are happy there. And even for some, when we meet in the streets, we chat because we all remember that we met at the clinic. You develop a friendship. (P002).*

By mobilising themselves and sharing their experiences of living positively with HIV, the women create a healing environment. This support further extends to their communities.

> *I went to the chief to ask him about finding us a place to meet where we would support each other. Sometimes we would use the house of the chief. Sometimes we would meet in the church building, so we formed a group. The group started growing, we would approach others. (P010).*

Apart from emotional support, they also support one another with the practical aspects of their lives.

> *When someone is ill, we go to their house to help them. If they do not have any food, we give them; or if their house needs cleaning, we wash their clothes and encourage one another. (P005).*

Again, not all of the participants were willing to participate in group activities, but for some the shared support of those with similar experiences is invaluable.

6.5.6 "I just encourage others": Supporting others

Captured in this theme is the use of altruism to derive a sense of purpose by encouraging those who have just learned about their diagnosis. Helping others emerged as a positive experience, which enhance feelings of efficacy. By extending their support, the women feel that they are using their own experiences to inspire others to live positively.

They voluntarily support others through the process of getting tested and starting treatment. After their experiences of losing loved ones who did not initiate treatment in time, the women become determined to prevent this from happening to others. Participant 001 seemed to derive self-worth and validation from helping others.

> *I have actually helped a lot of people, telling them to go to the hospital to get tested. Whatever you are suffering from, the headaches you are having, the malaria you are having, you don't know what it is. Do not lie that it is witchcraft. Go to the hospital and get tested, you will find out what is wrong. If you find that you are HIV positive, don't be worried. (P001).*

They share information about how they manage their own illness and bring a message of hope to others. Advocacy builds their self-esteem because people in the community look up to them and this helps to minimise the feeling that they are pariahs because of their diagnosis.

> *I usually tell them that positive living is not a life of worry. The main issue is hope and my main message to them is that one should get tested and know how you are because if you know that you are negative, it is a good thing and to also know that you are positive is also a good thing because you know how to take care of yourself. (P010).*

It seems that the use of their own success stories as testimony makes more impact on the individuals whom they reach out to, because they identify with the situation. Participant 004 takes comfort from motivating others to start treatment through recounting her own journey.

> *I gave them my example, I tell them how I got sick and got tested. And even when I was on ARVs I got pregnant and have a child who is HIV negative and healthy. (P004).*

In some cases, the wish to support other people gives them the impetus to disclose their status to continue being a good example. Participant 012 explained that her diagnosis helps her to support others who are initially ignorant about how to move forward to find out about ART after they learn about their status. Disclosing her status as a way of encouraging others is psychologically rewarding to her because she feels she had no secrets and that she is living as her authentic self.

> *I am very open and I tell them that I take ARV medication. For those who do not believe, I show them the medication I take. But some I just open up to them and tell them that they should not be deceived by the way I look because I take ARVs. I look at it positively that I know that I have HIV because I can encourage my friends to get tested to see how they are. (P012).*

Here we see how the women transform and experience personal growth by using their diagnosis to uplift others. They derive a sense of purpose by selflessly offering their time to guide others and to ensure that they start getting treatment while providing them with emotional support. Most important for them was the good feeling they get from being able to make a positive impact on others. Participant 005 expressed how content she feels when she offers her support to others.

> *I am happy that I am helping other people and giving them appropriate counselling. Even at home in the village some people find me and ask me how they can find their way to the hospital. I tell them where to go first, for VCT, and that after that they should use the results to know how their body is. Because some people can get sick and get tested but they may not have HIV. I feel very happy because and I don't find any problems with doing that. I tell them that if you have been found HIV positive after testing and*

> *you are worried, just let go of the worries and take care of yourself and eat well. (P005).*

As the above quotations demonstrate, supporting others brings the women feelings of positive wellbeing. The women are happy to encourage others and share their success stories of living with HIV. The women feel they have value by helping others and taking on the role of educating them about how they can take better care of their health. Seeing beyond themselves to the larger community helps them to focus less on themselves and their challenges. They employ various methods of coping, which involve using their inner psychological resources and getting support from the already established structures in the community. They utilise their diagnosis as a tool for supporting others and derive a renewed sense of wellbeing by employing multilevel strategies to cope. At the micro level, they use resilience, while at the macro level they seek support from the community.

Significant too is that by supporting others, it is likely that they are able to counteract the unspoken internalised and felt stigma associated with being HIV-positive. They are able to demonstrate their responsibility and worth by using their own experiences to help others. The following chapter provides further examples of how meaning and purpose are significant to the psychological challenges to living with HIV.

6.6 "IT'S THE BEGINNING OF A NEW LIFE": MEANING OF LIVING WITH HIV

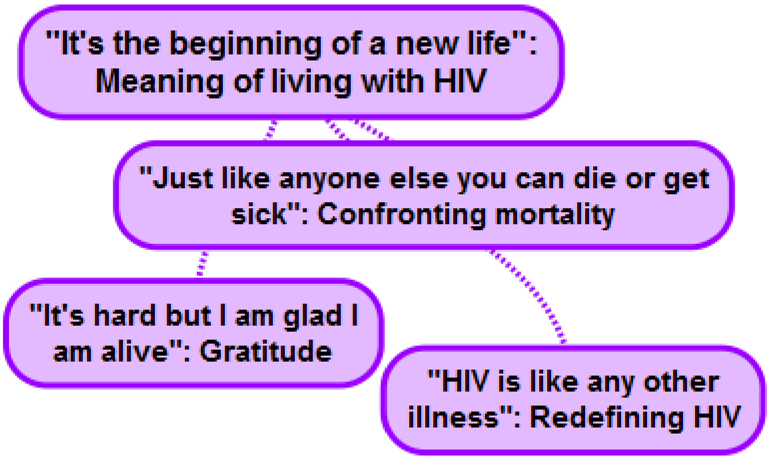

Figure 6.6: Abstracted theme contributing to the superordinate theme "It's the beginning of a new life": Meaning of living with HIV

The meaning attached to being diagnosed and living with HIV was captured in this final superordinate theme. Overall, the women described living with HIV in a balanced and realistic manner by looking at both the challenging and bearable aspects.

> *I look at it in two ways. The bad thing is that one's future is uncertain because what you were doing in the past cannot be the same as what you do when you have HIV. The other side is that if I had hesitated and never started taking ARVs and do what I wanted or if I had stayed angry and said to myself that I will not take the medication because my husband was the one who infected me, I would not have been here today. (P008).*

Three subthemes further describe the meaning of living with HIV. These are a) "It's hard but I am glad that I am alive": Gratitude, b) "HIV is like any other illness": Redefining HIV, and c) "Just like anyone else who can die or get sick": Confronting mortality (see Figure 6.6).

6.6.1 "It's hard but I am glad that I am alive": Gratitude

This subtheme regards the meaning the women attach to learning about their status. They feel that if they had delayed being tested, they could have learned about their diagnosis when their health was failing – hence their feelings of gratitude. Because HIV can exist in one's body without causing illness for a long time, unless one is tested in time, one may develop full-blown AIDS and this could be fatal. For Participant 001, early discovery of her diagnosis and staying positive about life and adhering to the medication makes her life normal.

> *It's hard but I am glad that I am alive. I can wake up and take the medication and be strong. I do not fall sick often and I am really grateful for that. When you take the medication properly, without missing some days, you don't get ill and you have a happy and strong life. You can do anything that a person who is HIV negative can do without any problems. (P001).*

Learning about the diagnosis saved them the danger of being incapacitated with illness if, for example, their immunity had been far too compromised to cope with the late initiation of the medication. Participant 002 felt that she still has her dignity because she did not have to experience debilitating illness before starting to take the medication.

> *I tell myself that I should just be grateful that I arrived at the right time. I was not propped up by people or admitted in the hospital. I walked on my own when going for testing. And they gave me the medication and I started taking the medication, not because I was very sick. (P002).*

Other participants who learned about their status when their health was already failing still expressed gratitude because they nevertheless started treatment in time and returned to good health. Participant 001 recollected getting very ill, to the point where her relatives lost hope and thought that she would die.

> *You would go to your relatives and they would see that I was getting better. My body was getting healthier and my hair started thickening and they would say, "Look at her, she is back from the grave." That was my name, "back from the grave". (P001).*

Although the women expressed feeling grateful about the diagnosis, they also acknowledged that at times, living with HIV feels like a burden, as if they have been tainted for life. The most difficult part is how to incorporate their medication in every aspect of their life. Participant 008, for example, pointed out that travelling is the biggest burden because it reminds her that she is dependent on medication in her life.

> *It is a burden; you have to have medication in your bag when travelling. One who has no HIV just leaves for their trip with their clothes, they don't even move around with a health book. For us, you have to carry medication and a health book so that if you run out of medication, you can be able to access medication there. (P008).*

Most adopt a new outlook in their lives and embrace the changes they have to make for the sake of their health. They view the diagnosis as the beginning of a new phase in their life. For them, the diagnosis makes it possible to start taking better care of themselves, without which they would have been sick frequently and would have deteriorated.

> *It's the beginning of a new life. To me it means that getting sick is not death or dying. When I come here at the clinic, I meet a lot of people who are also taking medication. It's a problem, yes, but it is not a big problem because we are eating and working. (P011).*

Adapting well to the medication without experiencing the adverse effects of the medication also makes them feel grateful. Participant 003 spoke about rediscovering her self-worth after she successfully initiated the therapy and using that as a driving force to soldier on.

> *I value my life more. I feel my life is very important and it makes me take care of my life more so that when my life ends, it should end for enough reasons. But not that I have not been able to take care of myself. That means I will leave a burden to my children. (P003).*

Feeling useful and still being productive also gives the women a reason to appreciate learning about their diagnosis. Participant 004 found meaning in her day-to-day activities.

> *I think HIV is not the end of my life. I can still do something useful in the eyes of people even though I am HIV positive. I can have a business and work hard and take care of my children. (P004).*

6.6.2 "HIV is like any other illness": Redefining HIV

This subtheme concerns how the women assign a new and more positive definition of HIV as an illness. The women also adapt new ways of thinking about their bodies as their physical appearance changes because of weight loss or the side effects of the medication. The changes in their physical appearance are a concern because this attracts unpleasant comments from those who knew them before their diagnosis. This makes them feel that their physical transformation gives their diagnosis away even before disclosing their status. In the case of Participant 001, her appearance attracted derogatory comments from her community after a bout of illness.

> *They would come to my home and say,"Your hair looks thin" and say "free Revlon" [hair relaxer]. My relatives would say those things. (P001).*

The side effects of the medication, especially when experienced for the first time, make the women doubt whether they will manage taking the medication for the rest of their lives and feel like their body is failing them. When the side effects eventually wear off, they regain their confidence and become more optimistic about their ability to manage the medication in the long term.

> *At first, when I just started on the medication, it was difficult for me to put my feet down. I would feel as if my feet were numb but then that stopped after some time. It was like I was in a pit. I was having nightmares, bad dreams. I was also feeling dizzy if I took the medication when I was not going to bed. I would also feel that when I was trying to get out of bed to visit the toilet in the middle of the night. (P004).*

The women drop their old understanding of HIV as a fatal illness and adopt a new perception of being diagnosed with HIV as just having any other ailment that requires treatment and proper management, which does not necessary spell death.

> *Being a woman living with HIV is not the end of one's life. I think about it that way. Even when I am living my life, I think that this is not the end of my life because one can fall over and die. That is not dying of HIV. (P003).*

Even though at first the women feel overwhelmed with the idea of taking medication for the rest of their lives, adherence becomes much easier knowing that they are simply managing an illness. To them, being diagnosed with HIV is no different from having any other chronic illness and with more and more people taking the medication, they feel less different from others.

> *Living with HIV is just like having any other illness. Like a headache, like malaria. You don't really prepare to have a headache, it just comes as God prepares it, that today this person will have a headache. (P003).*

6.6.3 "Just like anyone else who can die or get sick": Confronting mortality

This subtheme concerns how the women confronted the fear of impending mortality, which is common for people living with any chronic illness. To deal with the fear, most reason that there are many causes of death and HIV is just one of them. Participant 010 adopted this attitude after her diagnosis to forge ahead and chose not to be paralysed by fear and to proceed with her life plans.

> *I don't limit myself as to say I should not make this plan because I am HIV positive and I might die. I am not shaken by this illness. Because when we see in the world, the people who are dying are not all HIV positive.*

> *Everyone else is dying so I cannot stop making plans because I think I will die. (P010).*

On the negative side, some of the women explained that they feel that taking medication just buys them time and that they are waiting for death. The women expressed having moments where they are gripped with fear for their mortality because taking medication implies that they are trying to sustain their health, failing which means death.

> *Because now you are sort of waiting for a day. Even if you are taking medication, you are still waiting for a day that you may die. (P008).*

The availability of ARVs also contributes to how they think about living with HIV. They reason that if they adhere to the medication, and as long as the body has no illness and if they feel healthy, the disease has no threat to their life.

> *I look at the medication as any other pill that we get from the hospital; for example, like Paracetamol when we have malaria. (P002).*

Adjusting their attitudes makes them perceive living with HIV as a normal part of life. They perceive having HIV as something very common and because most people have it, all the morbid ideas associated with PLHIV in the earlier days of the pandemic are fading away.

> *People even say those who do not have AIDS are not in fashion. People are saying ARVs are the fashion now. (P001).*

6.7 CONCLUSION

The chapter presented the themes that described the actual experiences of living with HIV and the challenges the women experienced because of their HIV status. The themes described the financial and psychological struggles the women faced and the psychological resources they pulled together to overcome their challenges. These challenges include economic struggles, poor health, stigma, a lack of support, and uncooperative male partners. Despite this, they find support or less often, withdraw completely. Support comes in various forms, and it brings some risk of unplanned or inadvertent disclosure. For some, distraction helps, though if motivated by the fear of the danger of worry, may put them at risk of further worry. Significantly, meaning is obtained from supporting others, finding gratitude that they have survived, and redefining the illness as a chronic bit ordinary one. The meaning, behaviour change, religiosity and support of others may also serve to dispel internalised and felt stigma. The next chapter discusses these findings further by referring to the extant literature.

CHAPTER SEVEN:

DISCUSSION

> *Women in much of the world lack support for fundamental functions of a human life. They are less well-nourished than men, less healthy, more vulnerable to physical violence and sexual abuse. They are much less likely than men to be literate, and still less likely to have pre-professional or technical education.*
>
> - Nussbaum (2001) -

7.1 INTRODUCTION

The aim of the study was to investigate the lived experiences of being diagnosed and living with HIV of women attending an ART clinic in Malawi. The aims of the study were achieved through analysing semi-structured interviews, using the IPA approach, which informed all aspects of the study, from the formulation of the questions to the data collection. Fourteen main themes were identified (see Figure 7.1), which detailed thorough descriptions of the participants' personal worlds. The findings support the existing literature, as well as offer new insights. As is recommended in IPA, new literature, in addition to that explored in the literature review, may be used to explain the findings (Smith et al., 2009). Thus new literature is introduced in this chapter to highlight the findings, as some of the issues that emerged in relation to the women's experiences were not anticipated in the literature review phase.

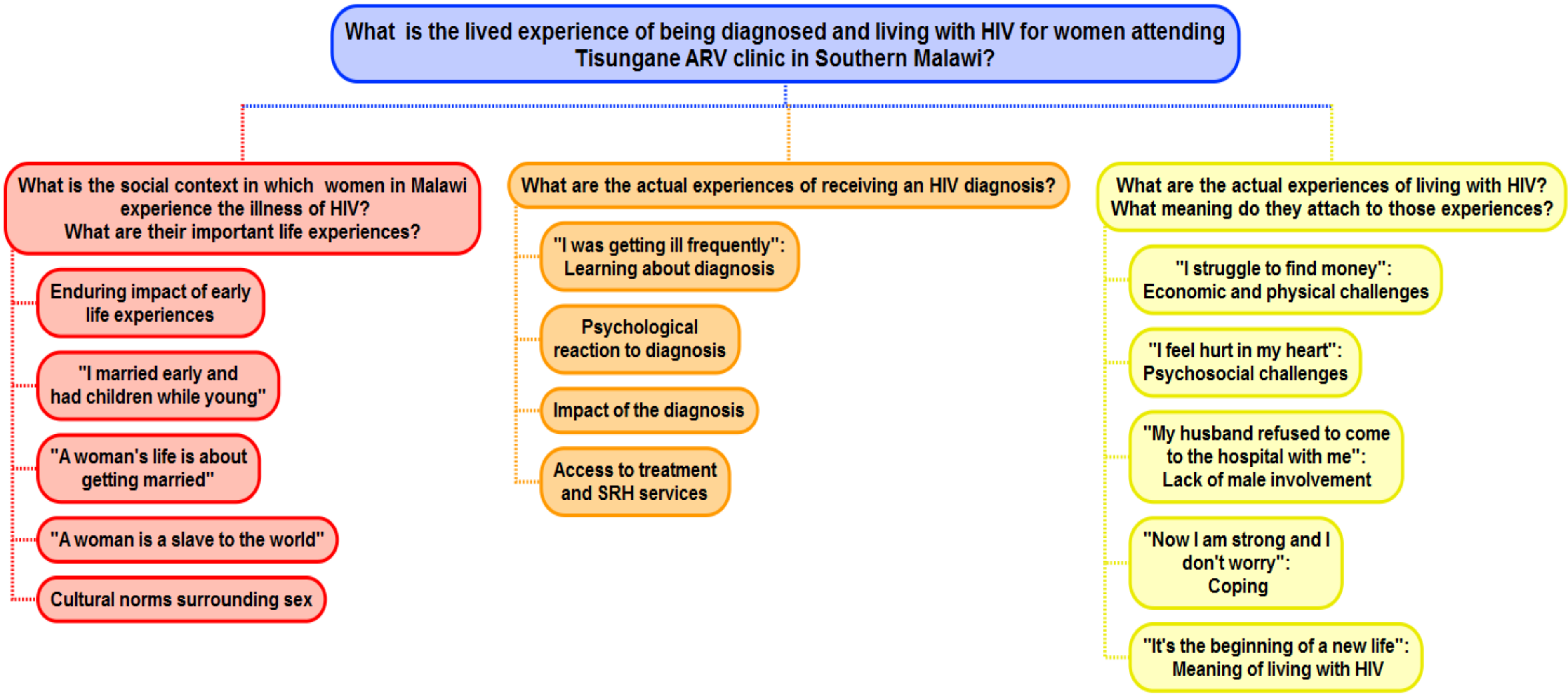

Figure 7.1: Summary of results showing superordinate themes

Based on the presented results in the previous three chapters, there are several conclusions that can be drawn. Firstly, biological factors alone are not responsible for the women's HIV status; instead, the intersections of early life pre-existing conditions of poverty, lack of educational opportunities, early marriages, and cultural factors rendered the women vulnerable to the infection in the first place. These challenges still accompany their diagnosis and make their experience of living with HIV more difficult. Significantly, advances in medical technology have not eradicated the sociocultural conditions that put women at risk and shape their experiences of living with HIV. Secondly, the women experience negative psychological reactions at the actual moment of diagnosis and the diagnosis impacts on their multiple identities as WLHIV in different ways. Without proper support, these psychological reactions to HIV infection pose a threat to their physical and mental health. This means that for HIV care to be fully impactful, it requires that psychosocial interventions are delivered alongside medical interventions. Thirdly, an HIV diagnosis on its own is not necessarily the worst event in the women's lives; instead, the experience of living with HIV presents multiple challenges that have a synergistic effect and the women have to employ various mechanisms to manage their health, cope with these challenges, and adopt a positive new meaning of living with the illness. This chapter proceeds by providing a summary of the findings for each of the research questions and discusses those findings in relation to the extant literature.

7.2 WHAT IS THE SOCIAL CONTEXT IN WHICH WOMEN IN MALAWI EXPERIENCE HIV, AND WHAT ARE THEIR PROMINENT LIFE EXPERIENCES?

7.2.1 Enduring impact of early life experiences

The present study provides additional evidence with respect to the intricate contextual factors surrounding the experience of living with HIV for women in Malawi. The women's stories reveal a childhood lacking in educational opportunities, early marriages, lack of economic empowerment, and disempowering cultural norms that relegate the role of women to mothers and wives, as the main factors that contribute to their vulnerability to HIV. Because of the dire poverty in Malawian communities, in the eyes of many families' education and empowering girls is not feasible, so the promise of marriage is seen as beneficial and is more promising. Prior studies have documented the same findings. Malawi ranks in the top ten list of countries with girls who enter into early marriages (Loaiza & Wong, 2012). Nearly half of young women aged 20 to 24 are married by the age of 18 (NSO, 2010). In further agreement with the findings, existing literature also shows that marrying young has a negative impact on schooling (Delprato, Akyeampong, Sabates, & Hernandez-Fernandez, 2015) and increases the risk of HIV (Clark, 2004).

The main risk factor for early marriages is household poverty, where girls are married off to relieve the responsibility of feeding and clothing. Despite their common occurrence, early marriages have a harmful impact on the health, psychological development, education, and economic wellbeing of young girls (Walker, 2012). Health-wise, girls experience early sexual debut, give birth to more children, and lose more children to neonatal and childhood diseases. Girls are also removed from school, which results in lower levels of literacy for women and a high dependency on men for their livelihood because of poverty (Walker, 2012). Similarly, the women in the study reported missing education opportunities because of their premature marriages – a situation which set them up for a future of poverty and low quality of life, both mentally and physically.

The 12 participants also explained that the more economically powerful their partners were, the more sexual partners their partners seemed to have. The women have no control over this because the men have the financial muscle and leaving the marriage means losing out on their only source of financial support. These findings are congruent with the literature on drivers of the HIV epidemic among women, which points out that HIV is driven by poverty and limits women's options, as well as driving gender inequalities where men are more financially empowered and women are dependent on the men, which leaves the women with no say in negotiating safe sex in marriages (Ghosh & Kalipeni, 2005). In this study, the women's economic dependency puts them at a disadvantage to negotiate safe sex and increases their risk of HIV infection. In the same vein, Jewkes (2009) also argues that, in a context of limited material resources, relationships are a mechanism through which girls access material goods such as cell phones, cosmetics, and often cash to gain the respect and admiration of other women. Poverty increases HIV risk because it creates economically dependent relationships that subordinate women (Masanjala, 2007). In general, poverty increases the vulnerability and risk to HIV infection because desperation drives women to commercial sex work (Amuyunzu-Nyamongo, Okeng'o, Wagura, & Mwenzwa, 2007). The findings of the current study have demonstrated that the women seek transactional relationships because of poverty and the dynamics of those relationships offer them no room for bargaining for protected sex. It can thus be argued that the women are more vulnerable to HIV infection because of poverty. Evidence shows that women are at a higher risk of infection by wealthy men who use their financial means to sexually exploit poor women. The men with resources are also at risk, because they are likely to have more women willing to engage in transactional relationships with them (Poulin, Dovel, & Watkins, 2016). Wealthy men, even by rural standards, carry a high prevalence of HIV. The study highlighted that men have been side-lined in policy documents with more resources of HIV prevention diverted to women and adolescent girls. However, the more money the men make, the more relationships with women the men have, thus increasing their HIV risk (Poulin et al., 2016). While the claim that men are also at risk is valid, the women interviewed in this study are at higher risk than the men because they described having no options in life, such that entering transactional relationships and marriage were their only way to attain basic necessities. Men often times make a conscious choice to pursue women, and take advantage of their economic desperation. Thus, resources should still be committed to economically empowering women, to end the cycle of dependency on men which leads to higher HIV risk.

There was a consensus among the women in this study that their families had low expectations of them as female children, and marriage, not education, was considered the only way out of poverty. The women in the study also felt that if they had the opportunity for an education, they would be more assertive in their relationships and perhaps this would make it easier for them to ask their partner to be faithful or to leave the relationship. This demonstrates that the women have an understanding of the impact of these limitations and, if given an opportunity in life, circumstances would be different for them. This suggests that empowering women through education would be beneficial to HIV prevention because empowered women would not stay in high-risk relationships. In agreement with this finding is a recent Malawian study with rural women that noted that women's empowerment increases their bargaining power for condom use in relationships and communication within marriage regarding HIV-related issues (Gerritzen, 2016). Further evidence supporting the positive effect of education comes from a study in four African cities which found that more educated people reported less risky sexual behaviours and respond better to health education programmes related to HIV (Glynn et al., 2004). Furthermore, countries with the highest rates of early marriages are also the countries with the highest rates of poverty and population growth. Girls living in rural areas of the developing world tend to marry earlier in life than their urban counterparts (44% versus 22%) (Loaiza & Wong, 2012), and education greatly reduces the probability that girls will marry before the age of 18.

It seems that as much as the women in this study had access to ARVs, which sustain their health and remove the threat of succumbing to a fatal illness, the very conditions that rendered them vulnerable to HIV infection in the first place continue to exist in their lives, namely poverty and lack of empowerment. What this means is that the imbalance of economic power between men and women forces them to remain in relationships that put them at risk and undermines the medical efforts in place to improve their lives. Availability of ARVs is of course primary and necessary, but addressing the underlying socio-economic inequalities that render women vulnerable in the first place provides a more comprehensive solution to improving women's quality of life. Indeed, the lesson is that governments, policy makes and researchers should not divert attention away from the HIV pandemic because of the life-saving advances in medical technology; the prevalence of HIV amongst women in Malawi has much to do with the socioeconomic and cultural conditions that have remained relatively unchanged.

7.2.2 Multiple sex partners

In this study, the women's most vividly and widely talked about experience was how their partners have multiple sex partners outside marriage and how the women persevere even when staying in a marriage characterised by infidelity increases their risk of HIV infection. This means that for the women, marriage is not only socially desirable but a means of survival for them and their children, but at the same time staying married is a risk factor for HIV infection. In agreement with this finding is a Nigerian study by Fagbamigbe, Adebayo, and Idemudia (2016). The study found that HIV prevalence was high among previously married women. This could be that for women who are in a marriage, tolerating infidelity becomes justifiable, while unmarried women may choose to leave the relationship when there is infidelity and seek a relationship elsewhere.

The women in the current study justified and normalised their partners' infidelities by citing that it is in the nature of men to have many partners and even implied that infidelity should be expected when one is married. Now this cultural norm is very interesting, because women are expected to be faithful because it is considered a natural feminine trait to be reserved and shy about matters concerning sex. The other side of this is that men are then expected to be sexually promiscuous, hence they cannot be held accountable. Perceiving men as blameless might be one of the reasons men continue to have several partners despite the fact that they are increasing their risk of HIV infection, and ascribe their behaviour to their masculinity.

Kaler (2003) made similar observations about the attitude towards extramarital affairs in Malawi in the reality of HIV. Men having extramarital affairs is a tolerated, if not a celebrated, practice in Malawi, especially in a country where masculinity is measured by sexual prowess demonstrated through multiple sexual partnerships outside marriage, which men boast about in their friendship circles (Kaler, 2003).

Further explaining why extramarital affairs are normalised in Malawian society, Izugbara and Undie (2008) contend that as young men, fragile masculinity, in need of constant protection and validation as powerful males, drives men to risky sexual practices. The ethnographic data from the study demonstrated that Malawian male youths are vulnerable to HIV because their sexual scripts reflect a perception of fragile masculinity that needs constant protection and drives them to assume a predatory stance towards women. The more women the young men sleep with, the more they gain respect and popularity among their peers. In these encounters, the preference is for sex workers because they feel power over them and can take charge of the sexual episode (Izugbara & Undie, 2008).

Similarly, in a synthesis of theoretical and empirical literature, Fleming, DiClemente, and Barrington (2016) identified three dimensions of masculine norms that shape men’s behaviours in sexual HIV-related practices: a) uncontrollable sex drive, b) capacity to perform sexually, and c) power over others. Men can exhibit risky sexual behaviours as long as they align with their masculine status that value men with a voracious sexual appetite. There is a belief that men are programmed to satisfy their insatiable sex appetite. It is also important for these men to perform sexually because the inability to perform might be associated with being homosexual; hence men have many female partners. Being associated with homosexuality is a problem for hegemonically masculine men because it makes them appear feminine, and this does not sit well with their status in the community. Indeed, hegemonic masculinity is by definition deeply homophobic. Multiple sex partners have to do with power over others, where sex partners are used as a strategy to gain status among other men (Fleming et al., 2016). It is these attitudes about the set differences between male and female sexuality that fuel the epidemic by exempting men from actively taking part in HIV prevention efforts within their own personal relationships. This may also explain why men refuse to use condoms because, as the findings in the current study reveal, condoms disrupt this notion of masculinity by interfering with erections, sexual performance and sexual pleasure. It seems that it is impossible for women to challenge this form of masculinity, which encourages men to have multiple partners.

Culturally, the women value themselves in relation to men and have internalised the belief that they are respected and recognised by society when they are married. With this mind-set, even in cases where the women are empowered, they would still be reluctant to leave the relationship because they value their place in society as a married woman and downplay the risk of staying in a relationship that increases their risk of infection. This means there is a need to address the deep-rooted cultural beliefs about the position of women in relation to men, which condone infidelity and sabotage HIV-prevention efforts.

Despite the attitudes that condone husbands' extramarital affairs, the women in this study who experienced infidelity in their marriages demonstrated agency by questioning their husbands, refusing to sleep with them, and imposing condom use to protect themselves. Schatz (2005) also describes similar strategies women employ to protect themselves from HIV risk. These include discussing the dangers of HIV with their husbands, divorcing men who do not adopt safer practices, publicly confronting husbands and mistresses, and utilising social networks to mediate marital problems (Schatz, 2005). As explained by the women in this study, these strategies are not very effective because there are no structures in place to support the women morally or financially when and if they choose to act upon the decision. The women's families encouraged them to stay married and they have no access to financial resources. This poses a dilemma for women who wish to protect themselves from infection if they suspect that their husbands are being unfaithful. What this illustrates, significantly, is that though the odds are stacked against these women, many show remarkable capacity to resist the conditions imposed on them, even when such resistance is largely futile.

One interesting finding was how the women explain that men are not afraid of extramarital affairs and unsafe sex despite knowing that they are HIV positive, and feel less at risk of succumbing to illness because they are on ARV medication. The confidence that their partners have seems to be misplaced as the men might inaccurately assess that sex partners are also on ARVs, and engage in unprotected sex and put their wives at risk.

These findings are consistent with recent results from a longitudinal survey conducted in rural Malawi, which investigated the social impact of ARV use and the consequences of readily available treatment (Kaler, Angotti, & Ramaiya, 2016). Through an analysis of observational journals, men's conversations exposed the reasons why they were reluctant to change their behaviours. ART makes people look healthier, and as such, it becomes difficult to detect the social danger of having a relationship with a particular person and prompts engagement in unprotected sexual relations with them. The availability of and knowledge about ARV medication may sometimes encourage risky sexual behaviour because these distort the risk assessment of danger because people look healthy despite their HIV status (Kaler et al., 2016). While access to ARVs has shifted the way people think about HIV/AIDS from fatalism and helplessness, in the face of an incurable disease, to hope, it has created difficulties for rural Malawians to accurately diagnose and determine who is a safe partner because people who are infected appear healthy (Conroy, Yeatman, & Dovel, 2013). More than trying to judge risk by how healthy people look, which has always been a problem with HIV because people infected with HIV look healthy for many before they become ill, is the assumption, perhaps, that ARVs reduce risk, resulting in an increase in sexually risky behaviours, which is very dangerous if the medication is not taken consistently or at all.

7.2.3 Forms of abuse

Several of the women in the study reported experiencing and enduring physical violence in their marriage, as well as other forms of abuse because of their HIV status. From the interviews, it seems that the women tolerated violence to keep their marriage intact as the marriage is their source of financial support. Enduring the violence seemed necessary because it is seen as the responsibility of the woman to ensure that the marriage works. Earlier studies conducted in South Africa (e.g., Dunkle et al., 2004; Jewkes et al., 2003) concluded that IPV is associated with HIV status, and gender inequalities were implicated as the main driver for violence towards WLHIV and that women in relationships with controlling partners were more likely to report violence.

These findings are also in agreement with the conclusions of a study by Chin (2013), as cited in the literature review, which reported that WLHIV experience physical, emotional, and sexual abuse from their partners. Similar findings linking women with HIV and experiencing violence were also recorded by Mkandawire-Valhmu et al. (2013) and Njie-Carr (2014). Chilemba et al. (2014) identified the emotional abuse that WLHIV experience, which included outing their status, labelling them as immoral, and them eventually being abandoned by their husbands. In short, the findings strengthen the evidence that HIV status in women is linked to experiencing violence.

What also emerged clearly in this study is that, for the WLHIV, it is not only the actual violence that they have to live with, but also the threat of being subjected to violence when they attempt to take charge of their health. It is very difficult for the women to exercise agency, whether it was enquiring about extramarital affairs or requesting that they go for an HIV test and adhere to medication, for fear of being subjected to violence by their partners. The violence, which often occurs as a form of control in the relationships, also highlights the disempowered position the women are in which sometimes affects their ability to be in full control of their health, and which puts them at risk of HIV infection in the first place.

7.2.4 Cultural drivers of HIV

Prevailing cultural beliefs are at play in the way women experience HIV. Most notable in the women's narratives was their subordinate role in the family, and the role of the head of the family and decision maker assigned to the men. Similar findings were discussed in the literature review, highlighting the lower status assigned to women in relation to men; for example, women are expected to be submissive and not take leading roles because their main role is that of mother and wife, while men are considered the providers and decision makers (Lindgren, Rankin, & Rankin, 2005). It was further discussed that these gender roles affect the ability of women to control many aspects of their lives, including protecting themselves from the risk of HIV infection (Arrehag et al., 2006). From the women's stories, cultural values cement their role as subordinate, and for the women it is difficult to break free from the subjugation because they are usually dependent on their cultural custodians, who are usually older family members, for their identity and sense of belonging in the community. As such, making independent decisions about their own health becomes challenging for them. Religious values have been used selectively to justify this narrative of subordination of women and to promote patriarchal values (Chitando, 2004). For example, according to the meaning of a "good wife" in Christian teachings, the woman is supposed to submit and surrender to her husband, which promotes docility and powerlessness that expose women to HIV risk. The women in the current study also alluded to Christian beliefs to justify their subordinate role to men and believed that the success of a marriage is solely their responsibility

The findings of the present study add to the body of knowledge on beliefs related to sexual practices that increase vulnerability to HIV, such as dry sex, herbal douching, and abstinence after childbirth. Similar cultural practices were reported by Maleche and Day (2011). The authors outlined several cultural practices across Africa that affect HIV responses. These include wife inheritance, dry sex, widows' and adolescents' sexual cleansing rituals, female genital mutilation (FGM), traditional treatments of vulva and vaginal warts and haemorrhoids, and traditional birth attendants (Maleche & Day, 2011). It is important to note that most of the traditional practices may have ceased after the aggressive behavioural change campaigns that took place from the early 1990s in Malawi (Kamwendo & Kamowa, 1999). Some of the sexual practices that are thought to have died out are the *Fisi* (hyena) system. With this system, when a girl reaches *menarche*, she is initiated upon her first menstruation to prepare her for her new role in the community of replenishing society. There is a belief that when a girl experiences her first menstruation, the blood is sacred and has mystical powers of sustaining human life, therefore proper rituals must be performed and all proscriptions observed so that nothing endangers her life and that of the community. The girls were given a man called a hyena, who usually came in the night to have sex with them. The belief behind this sex ritual is to end the menses, whereby the girl is given the strength of a man who ritually opens her womb (Longwe, 2006).

While some of these practices have ceased to take place, there is a lack of concrete evidence that these practices no longer exist in Malawi, with their impact on the girl child. Malawi has a culture of silence on topics that are seen as taboo, such as those related to issues that are sexual in nature. For example, the psychological damage and the impact that the *Fisi* practice has on young girls, and whether they are still protected from it, is not well known. In a study by Kamlongera (2007), an attempt was made to bring out the voice of a girl who had undergone the process of initiation to create awareness about the practice. Enquiries about the matter made people uncomfortable with the subject and there was a veil of silence over the issue. Without a deep understanding of how these practices are malignant to the wellbeing of young girls, there will be little effort in place to assist these women. In the current study, the women opened up about their own experiences about cultural norms surrounding sex and womanhood because they were provided with the right space to do so.

Some communities in Southern Malawi still perceive initiation rites as critical to young people’s transition into adulthood, arguing that they are not only taught about sex but also how to live respectfully in society (Skinner, Underwood, Schwandt, & Magombo, 2013). Lack of participation in these rites can result in the young person not being accepted as part of the community. However, the community members acknowledge the risk these initiations have for adolescent girls, who are propelled into sexual roles expected of adulthood without preparation for the realities of the threat of being infected with HIV.

These findings are worth noting because, in the early years, the spread of HIV in Malawi was aggravated by harmful cultural traditions, beliefs, and sexual practices which have been abolished after aggressive HIV campaigns. It seems, however, that the traditions have not been eradicated completely. Recently, a man in Southern Malawi confessed to sleeping with girls as young as 12 as a menstruation cleansing ritual (Butler, 2016). The man, who was HIV positive and never used protection in the sex rituals, reported to have been paid by the girls' families in the village to perform the sex ritual because they believed that it prevented bad things from happening to the girls' families (Butler, 2016). As the women in the study reported, the practices are often based on deep-rooted associations between sex, health, and illness, which continue to influence SRH and health-seeking behaviour. This may be because there is lack of access to proper medical information about health and, as a result, they use traditional knowledge to make decisions that affect their health.

It is argued that Anti-HIV projects should not clash with the local cultural practices because it is part of people's identity, but rather make the practices safe in a culturally acceptable way (Gausset, 2001). In the wake of the HIV pandemic, some of the cultural practices and beliefs have been renegotiated or completely discarded. For example, in polygamous societies, there is a demand for the new wife to get tested for HIV first (Banda & Kunkeyani, 2015). Similarly, in areas where people practise wife inheritance, HIV testing has become mandatory (Banda & Kunkeyani, 2015).

In short, the findings to the first research question (*What is the social context in which women experience the illness of HIV in Malawi, and what are the women's prominent experiences?*) provided rich descriptions and interpretations important for placing the women's actual experiences of diagnosis and experiences of living with HIV in their socio-cultural context. Women in Malawi have low socio-economic status and gender inequalities drive the HIV epidemic by: a) poor bargaining power for condom use and faithfulness, b) adverse cultural practices, and c) GBV (NSO, 2010).

Understanding the role of this social context in their lived experiences of WLHIV has implications for designing interventions that tackle the root causes of HIV infection beyond physiological vulnerability. This means that the interventions that are in place now, such as availability of ARV medication, condom distribution, and awareness campaigns, need to include multiple structural approaches, which challenge disempowering cultural practices, empower women, and promote the education of girls. While much about the social context is consistent with the existing literature on women in other African countries, the unique aspects of this research is that the women in this study describe how they are locked in a vicious cycle of conditions that sustain their vulnerability to HIV. To explain this further, the next part uses intersectionality to describe the interplay of these factors in the women's lives.

7.2.5 Intersectionality of gender inequalities, poverty, patriarchy, and culture

The results reveal the intersection of cultural norms, poverty, gender inequalities, and patriarchy in the life stories of the women from childhood to the time of their HIV infection. These factors work in unison against the efforts to make the women's lives better. Following the women's life stories, it can be noted that, from an early age, the women experience intersecting disadvantages and oppressions that socially locate them in a position of vulnerability to HIV infection. The women's narratives are not just anecdotes about 12 individuals, but reflect what is created at the intersection of the multiple forms of oppression and inequality, which mutually construct one another and lock the women into their subordinate positions.

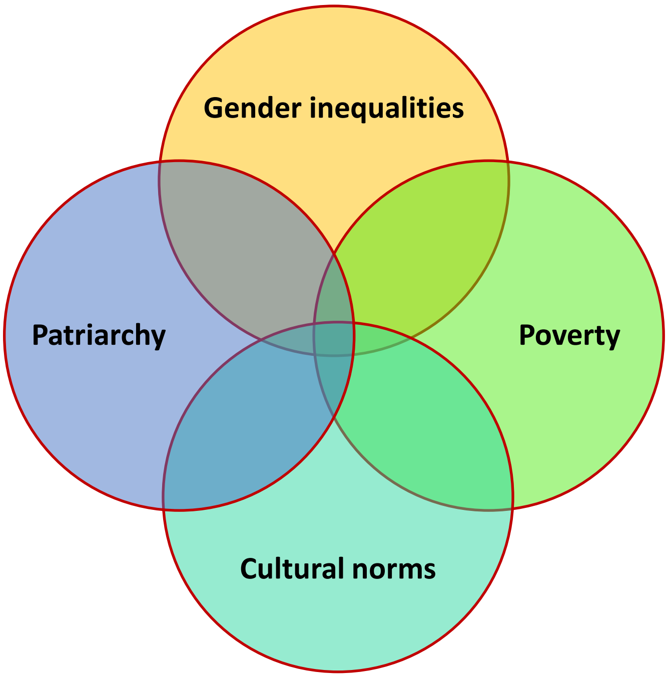

Figure 7.2: Experiences of living with HIV rooted in multiple forms of oppression

Patriarchy promotes male control over women in different aspects of their life, including their health decisions. Men are breadwinners who participate in the public sphere and women are confined to the domestic sphere, doing domestic chores and caring for the elderly, children, and the sick. Women do not have any power over their bodies; they are expected to yield to men's sexual demands, and therefore, may not succeed in controlling their fertility. Men also assert power and control over women using violence and financial abuse. Patriarchal values are woven into the marriage contract, where the man is automatically placed as the head of the family and this continues the cycle of subordinating and oppressing women by locking them in poverty. Household poverty has the largest impact on the girl child, which drives them into early marriages to relieve the economic burden on the family. As they get older, the women remarry or stay married for financial security. Culture justifies infidelity, polygamy, and behaviours that contribute to women's vulnerability to HIV, such as violence and the woman's low status, that render them powerless to exercise agency, such as negotiating safe sex. In their financially dependent position, attempting to assert their needs in matters pertaining to their health, contraceptive use becomes challenging and may end in violence, and other forms of abuse. In such a situation, it is not surprising that the women lack support from men when they wish to control their fertility or participate in HIV related services, which require the collaboration of a spouse.

In summary, this examination of the social context reveals that biological factors alone are not responsible for the vulnerability of women and girls to HIV, but the intersection of gender inequalities, patriarchal values, poverty, and culture norms, which exist from early life, subjugate women into a disempowered position, which puts them at risk. Tufts (2015) describes how identities such as gender, race and class, which are socially constructed, interact to create unique health experiences. These existing oppressive conditions assign multiple social identities to WLHIV, which expose them to multiple forms of social stigmatisation and discrimination, which influence their psychological reaction to the illness (Tufts, 2015).

7.3 WHAT ARE THE ACTUAL EXPERIENCES OF RECEIVING AN HIV DIAGNOSIS?

7.3.1 The experiences of diagnosis

Although the circumstances leading to the women's diagnosis were different, the common thread was that it was a stressful and traumatic event for the women and presented a threat to how the women would later adjust to living with HIV. It seems that the women lack support in terms of psychological counselling to prepare them for the life-changing news. The absence of a supportive environment is in itself traumatic for the women when they initially receive their diagnosis. The women's narratives also suggest that routine testing may not have occurred over the course of their life and, although they possess knowledge about HIV and testing, they are reluctant to be tested because they are afraid that it will arouse suspicion in the community and insinuate that they have been promiscuous.

Learning about their diagnosis after a child's illness was worrying (and tragic) because it suggests that they may not have been tested during routine antenatal care when pregnant, or, as in some cases, may have started the antenatal visits in the advanced stages of pregnancy. It is possible that the infection of a child born with HIV could have been prevented if the women had had access to information prior to conception. Lack of timeous access to information highlights how the women's underprivileged position in society disadvantages them from accessing health information in time.

Learning about the diagnosis through the illness of a child or husband meant that many women have to deal with their own diagnosis at the same time as deal with the illness or death of their children or husbands. This may distract them from the implications of their own diagnosis, thus denying them the opportunity of dealing with their own diagnosis in a healthy manner, as they are already burdened with worries about the child and/or husband's health, as women are usually the primary care givers in the communities.

In reacting to the diagnosis, the women reported shock, disbelief, anger, and anxiety. The shock and unexpectedness nature of their diagnosis is due to their not being in the stereotypical category of WLHIV, such as sex workers. Their main fear was facing stigma and they worried about keeping their diagnosis confidential. The reported emotional reactions documented in this study are synonymous with other findings in HIV diagnosis literature; for example, Lingen-Stallard et al.'s (2016) study cited in the literature review. Shortly after receiving the diagnosis, the women in this study explained that despite feeling overwhelmed with emotions, they received only medical counselling and no advice on how to manage what they were experiencing emotionally. In contrast to Hamela et al.'s (2013) study, cited in the literature review, these results go a step further to capture the personal stories surrounding the women's diagnosis and the manner in which they process the news of their diagnosis. This information, I hope, highlights the need for improving the quality of counselling support in ART clinics during diagnosis and follow-up support in the communities.

7.3.2 Impact of the diagnosis

It seems that the women's perceptions regarding motherhood changes after diagnosis. From what the women explained, having children in a marriage is one of the ways of securing financial support from the husband. Marriage and bearing children holds a special meaning to the women and is part of the identity of a socially acceptable woman in their communities. The diagnosis, however, changes the women's perceptions about intimate relationships and childbearing. The majority of the women in the study reported losing interest in marriage or relationships because the risks of being in a relationship outweighed the benefits. Those who were interested in relationships for companionship struggled with fears of reinfection and became uncomfortable about disclosing their status to their potential partners, risking rejection. In addition to protecting themselves from reinfection, internalised stigma may also be responsible for fear of pursuing relationships. A South African study documented similar findings and highlighted the complexities of love relationships for women after their diagnosis, especially the fear of disclosing their status to new relationship partners (Mkwanazi, Rochat, & Bland, 2015). Furthermore, it may also be that being single minimises vulnerability to abuse and violence from a partner, which they might be subjected to because of their status. For these women, celibacy seemed like a viable option as they would only be focusing on sustaining their own health and that of their children (Mkwanazi, Rochat, & Bland, 2015).

The interviews revealed that most of the women decide against having more children because, according to them, their HIV status is not conducive to pregnancy and childbearing. The women acknowledged motherhood as an integral part of their identities and that they have the same wishes of becoming a mother to a healthy child as most women do. Although motherhood is a form of cultural obligation, deciding not to have children may be a diversion to cultural expectations; the women felt the need to prioritise their health.

Some of the women in the study chose not to have children because they feared the stress that motherhood would add to their health. Access to ARVs and knowledge of PMTC programmes did not seem to influence the women to have more children. They based their decision on their perception of the relationship between HIV, childbearing, and quality of life. They have real anxieties about their own survival and worried about who would look after the children should they become sick. It appears as if they reason that having a child was hard work on its own, and with HIV it would add more to the challenge because of the need for extra financial and emotional resources. As women with limited social support, it would become difficult to care for their children; for example, in Malawi there are no provisions for material support for children with HIV or for mothers with children with HIV. Their decision to avoid having children makes sense in this context because childbearing is not just about physical health but also a peaceful state of mind. If they were constantly worried, it might become detrimental to their health. These findings are congruent with a study cited earlier (Saleem et al., 2015) which concluded that fears for the woman's health discourage women from having more children. These findings are, however, in contrast with a recent study conducted in South Africa that demonstrated that PLHIV desire to continue to have children for fear of the social stigma of being childless (Van Zyl & Visser, 2015).

In the current study, the desire for more children was not strong, even for women who did not have any children. For women who had children with HIV, motherhood proved to be an ambivalent experience filled with a pervasive sense of guilt, mainly because they felt responsible for infecting an innocent child. These findings concur with a study reviewed earlier (Sanders, 2008), where women reported feelings of ambivalence and worry over infecting their child. Lazarus et al. (2013) documented the same findings in their study conducted with South African women about their concerns regarding fertility.

There is also the stigma that WLHIV experience when they have a child as they are seen as irresponsible, and other people might feel that they should not have children at all. For the women, choosing not to have children may be one of the ways of controlling people's perception about them, that they have not been responsible because they are HIV positive. Women's decisions about childbearing are also influenced by their experiences of health workers at the clinic. The women reported a lack of adequate information and counselling about contraceptives, such that they sought information about family planning from peers. This is similar to what the literature suggests, that peer support plays a role in lives of WLHIV, in particular the successful retention of PMTCT programmes (Shroufi, Mafara, Saint-Sauveur, Taziwa, & Viñoles, 2013). In a Zimbabwean study with women attending a mother mentorship programme, the results showed that the women found mentor mothers more approachable than formal healthcare staff. Mentor mothers communicated effectively about the PMTCT programme and gave them advice from first-hand experience (Shroufi et al., 2013). In the study, several women pointed out that they were completely confident in having to rely on peers for information about family planning, which suggests that WLHIV open up to one another more than to health workers.

7.3.3 Impact of diagnosis on the multiple identities of WLHIV

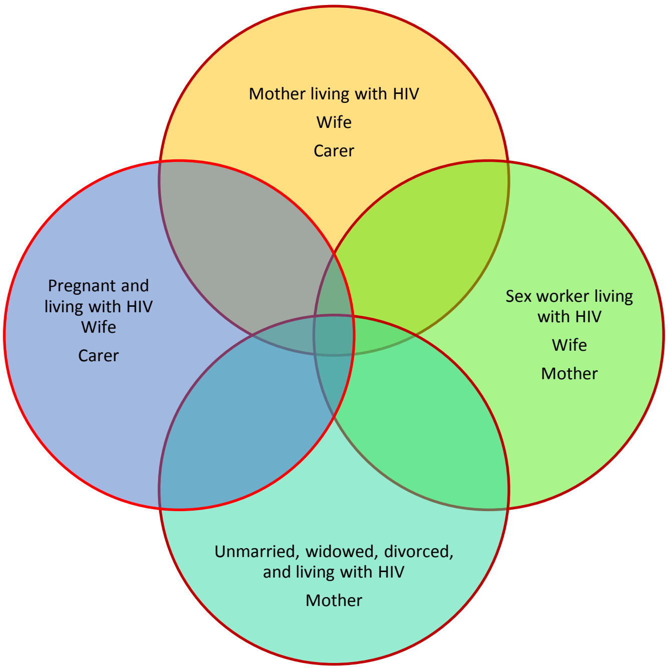

Figure 7.3: Multiple identities of WLHIV

Receiving an HIV diagnosis magnifies the women’s interlocking identities that undergo different challenging experiences. WLHIV are carers, mothers, wives, unmarried, sex workers, divorced, and pregnant, and each one of these identities carries a different social meaning in relation to their status. As mothers living with HIV, they have to deal with the stress of worrying about their children’s future, or breaking the news of their status to the child when they are older. Mothers who discovered that they had infected their children had to live with the guilt of having infected their children. The period of pregnancy is characterised by anxieties about their own health and that of the unborn child. Single, divorced, and widowed women not only live with the stigma of having no husband, but also have to confront the challenges of charting new relationships as they struggle to disclose their status for fear of rejection. Former commercial sex workers receive little sympathy after diagnosis, and face a future of blame for being HIV positive. Wives have the burden of care for their sick husbands, and these culminate in adding more stress to their lives, putting them at a risk of suffering from mental health issues. The actual moment of diagnosis itself arouses a myriad of psychological reactions that the women deal with in their private spheres. This suggests that receiving an HIV diagnosis is not only the beginning of a medical condition but also has a psychological impact in the women’s lives. An HIV diagnosis also affects women's multiple identities differently, and brings about multidimensional challenges that form a unique lived experience for each individual when these challenges overlap. As Law et al. (2013, p. 2) put it:

> An individual at the intersection of multiple identities and experiences could face different challenges and obstacles as a person living with or at risk of HIV, and it is important that their lived experiences are not left out of HIV research and advocacy solely because they do not fit, categorically, into one of the high-risk populations.

Another way of looking at this is that HIV has a collective phenomenology in that society sees and discusses it in certain ways in the Malawian social landscape. For example, the participants described that PLHIV are blamed for their infection and are perceived as promiscuous, hence they might not receive much empathy. Women have a phenomenology as subordinates who should only aspire to marry and have children. Women are also expected to be reserved in matters related to sex, thus being considered virtuous. Unlike men, women are poorer and have less access to resources because men are the decision makers in the households. Thus if one is a woman and an HIV-infected person, these two phenomenologies collide, so that there is a way in which society depicts a woman who also has HIV. This means that WLHIV can be subjected to various stigmas and oppression at the same time because one is a woman and also a PLHIV.

7.4 WHAT ARE THE ACTUAL EXPERIENCES OF LIVING WITH HIV?

7.4.1 Challenges of living with HIV

Living with HIV highlights already existing challenges such as poverty, lack of empowerment and the limited support resources available to women; the stigma, discrimination, and lack of support become magnified once the women disclose their HIV status. Due to low socio-economic status, most of the women in this study rely on menial labour to sustain their lives, hence being physically well enough to carry on being productive is very important to them. To ensure good health, they adhere to the medical regimen but also need optimal nutrition, which, as they narrated, is not easy to achieve. In this case, being poor directly interferes with the women's health in that, although they have access to medication, the quality nutrition required to support the therapy needs financial resources, which they lack. Thus, they may not always experience the full benefits of the medical interventions. Feeling physically weak makes them less productive in their work in subsistence farming, which reduces the amount of produce and, for some, the financial benefit when they sell the surplus. This finding is in agreement with Parker, Jacobsen, and Komwa's (2009) study which showed that, in HIV-affected households, agricultural productivity was affected because of reduced labour due to illness. Illness also affected the ability of those living with HIV to participate in agricultural markets, which required transporting goods and produce to faraway markets where they could get better prices for the goods (Parker et al., 2009). In this case, we see how one challenge sustains the other. Poverty renders it impossible for the women to take full control of their physical bodies and this affects their productivity and affects their livelihood.

The women also reported that being labelled HIV positive and openly blamed for bringing HIV into the family and community was a difficult challenge to surmount as it interfered with their community life. Their experience of stigma is that it starts from their immediate families and communities where they are supposed to be getting the support and extends to the wider society. Even after coping with the initial shock of the diagnosis, they find it harder to live with the aftermath of being known as a WLHIV in their communities. This finding suggests that the women are more afraid of experiencing stigma than having HIV. These results are congruent with the findings of studies cited in the literature review (Asiedu & Myers-Bowman, 2014; Colombini et al., 2014; Lekganyane & Du Plessis, 2012). WLHIV encounter stigma at interpersonal, community, and institutional levels (Fletcher et al., 2016). They also experience stigma in the medical environment and in their wider social circles.

Although support groups existed in the communities, the women generally felt that these were an inimical environment for them to release their personal and sensitive issues. This lack of "safe spaces" where the women could obtain social support made them rely on their own resources by seeking support, praying, and getting involved in community gatherings. These finding concur with the study reviewed earlier by Peterson (2010), which indicated that women lacked the resources needed to receive social support in their communities, although it is a vital component of coping with their diagnosis. This lack of an open source of support and reliance on individual resources may, in the long run, pose a great risk to their mental health. When one considers that they have to endure other challenges, proper psychosocial support is necessary to help them cope easier.

Managing chronic illness causes economic hardships in households (Jeon, Essue, Jan, Wells, & Whitworth, 2009). In the current study, the women reported living in conditions of poverty and being unable to support themselves financially, lacking empowerment because family resources tended to be controlled by the men in the household. Earlier studies point to similar economic difficulties where women lacked resources, such as transport to access HIV treatment services, because men have control over financial resources such as transport and money for food from their family, their community, and their own spouses (e.g., Nyirenda, Makwiza, Bongololo, & Theobald, 2006). As can be seen, poverty seems to be a recurring factor in making the lives of WLHIV difficult and seem to directly stifle efforts to maintain their health in different ways.

7.4.2 Disclosure of status

The women's narratives revealed that the main barrier to the disclosure of their status was fear of stigma, rejection from potential marriage partners and lack of support from partners. Anticipated social support from family and the community facilitated the decision to disclose their status. Some of the women in this study who disclosed their status experience stigma from the community and relatives and a lack of support from their husbands, while for some disclosure of their status gains them support from the community. In accordance with the present results, previous studies have demonstrated that fear of stigma was the main issue for non-disclosure in PLHIV (Osinde, Kakaire, & Kaye, 2012) and the negative consequences experienced by women who disclosed their status (Maeri et al., 2016). Osinde et al. (2012) interviewed PLHIV in Uganda about their disclosure of serostatus and concluded that non-disclosure was common because they feared stigma from the community. In cases where there was disclosure, there were differing experiences between men and women, with men receiving support from their spouses while women were blamed and experienced violence and the dissolution of the partnership (Maeri et al., 2016). Similarly, another study conducted in Ethiopia, which investigated the factors associated with HIV disclosure, found that disclosure was associated with fear of negative reactions from a partner, such as being accused of infidelity (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008). In the same study, lack of disclosure of one's status was found to limit one's ability to access support. These findings also corroborate a recent synthesis of studies on HIV disclosure (Adeoye-Agboola, Evans, Hewson, & Pappas, 2016). The review showed that non-disclosure was a mechanism of limiting stigma, and avoiding loss of relationships and support.

In some cases, disclosure of status had a positive effect of gaining the women social support in their communities. When family members learned about their status, they sometimes provided support to them. The results agree with a study where it was found that youths living with HIV who disclosed their status to friends and family members continued to socialise with them after the disclosure and they had higher levels of perceived support overall (Lee, Yamazaki, Harris, Harper, & Ellen, 2015). Disclosure of status allows one to receive more support from the community (Rodkjaer et al., 2014), and those with more support are less likely to suffer from depression (Yeji et al., 2014). In addition, it benefits women by motivating them into action to obtain support, develop social networks, and cope better with their illness (Medley et al., 2009).

The results seem to suggest that HIV support services encourage disclosure and the women believed that disclosure of status challenged stigma and enabled support. The actual experience with disclosure is that in some cases WLHIV are not supported and actually expose themselves to stigma. They are usually torn between disclosure and non-disclosure and often resort to partial disclosure; that is telling only those whom they trust, in this case the women told their close relatives first. Non-disclosure maintains stigma because negative beliefs about people with HIV go unchallenged, but it is also possible that disclosure risks reinforcing negative beliefs about PLHIV. Partial disclosure may, under these circumstances, be the best way of managing these conflicting circumstances.

7.4.3 Lack of male involvement

The findings also highlighted that the men rarely cooperate with the women’s efforts to adhere to health behaviours such as testing, adherence to medication, and the use of condoms. From the beginning, many of the men refuse to be tested and when they are tested, after the diagnosis, they refuse to comply with their medical prescriptions. Proposals made by women to go for HIV testing are bound to be lightning rods for dispute and controversy on the domestic front. Although knowledge of HIV status among couples brings about positive behavioural changes and is beneficial for high-prevalence environments (Delavande & Kohler, 2012; Fedor, Kohler, & Behrman, 2015), HIV testing is considered incompatible in marriage because it signifies a breach of trust and a measure used to confirm a partner’s infidelity (Conroy, 2014). HIV testing is usually acceptable before marriage but considered a problem in marriage because it goes against ideals of trust, love, and intimacy that couples strive for in a relationship. The current and former partners may have refuse to be tested because, by implication, they would be admitting to being unfaithful.

As quoted in the results section, talk about being tested arose when the women suspected that the men were having affairs, but their husbands reacted unfavourably. The findings are congruent with a study in Uganda which found that couples avoided HIV testing because they feared marriage dissolution and insinuations of infidelity associated with being tested (Matovu et al., 2014). Men perceive making a request for an HIV test as an accusation of unfaithfulness because it contradicts the values of trust in a committed relationship.

The results also suggest that, after men learn about their positive status, they are not inhibited regarding having affairs because the medication makes them more confident and reduces their fear of getting sick and succumbing to the infection. It could also be that they are not motivated to stay faithful because they reason that they are already infected and are confident that the drugs will protect their health, even cases of reinfection. Alternatively, they are resigned to a slow deterioration in their health and see no need to protect themselves.

Many of the women in this study also reported that they had no choice but to have unprotected sex with their partners because their partners did not want to use condoms. Mkandawire-Valhmu and Stevens' (2009) study echoed similar challenges among WLHIV in rural Malawi where women lacked agency in their relationships to impress the importance of condom use and this jeopardised their health maintenance efforts. Women failed to force their husbands to use condoms when they suspected they might be at risk. Similar findings were documented in an earlier Malawian study on condom use in marriages. The findings revealed that using condoms was frowned upon because marriage is viewed as a divine partnership and the condom was perceived as an intruder in the marriage sphere (Chimbiri, 2007). Condoms were thought to be intrusive even in cases where the wife had knowledge of the husband's extramarital affairs and the women attempted imposing condom use for their own protection (Chimbiri, 2007). Women then fear expressing their health needs and asserting themselves.

The women explained that men generally initiated ART later and had more problems adhering to the medication than women did because the women are usually the first to learn about the diagnosis. The Malawi Population-based HIV Impact Assessment (MPHIA) reported that nearly three-quarters of adults living with HIV (73.4%) are aware of their status and more women (77.1%) are aware of their status than men (67.1%) (MPHIA, 2016). This means that women start treatment much earlier than men, while the men may only start medication after a bout of illness. In a qualitative study by Camlin et al. (2016), men reported learning about their status by proxy, after their wives tested HIV positive. The men rarely sought medical attention when sick because they perceived seeking medical attention as something women and children do (Camlin et al., 2016).

In cases where men were taking the medication, they were inconsistent and had problems adhering to the regimen. This refusal of treatment has to do with notions of masculinity whereby admitting that they have an illness and need to seek treatment renders the men weak and this does fit into their scripts of masculinity. These present findings seem to be consistent with a Ugandan study with 26 men receiving ART which found that men who defined their masculinity in terms of strength, sexual virility, income generation, and capacity for hard work were likely to avoid HIV testing and treatment, because being labelled HIV positive reflected negatively on their masculine identity (Siu, Seeley, & Wight, 2013). On the other hand, men who defined their masculinity in terms of respectability endorsed by the wider society sought treatment because it corresponded with societal expectations as providers.

The results on lack of male involvement in other HIV services resonate with a host of studies cited in the literature review (e.g., Nyasulu & Nyasulu, 2011; Nyondo et al., 2014) which have documented that men are rarely involved in women’s health matters, most notably PMTCT. Men perceive antenatal clinics as places for women only to get HIV tests (Falnes et al., 2011). Subsequently, men refuse to comply with preventive behaviours such as condom use and refuse to be involved in breastfeeding decisions necessary for PMTCT to work. In this study, this manifested in the way the men simply refused to engage with the women in active conversations related to health, such as testing and status disclosure, contraceptive use, and child bearing.

The study goes a step further to providing detail of the roots of lack of male involvement. From the women’s perspective, it seems that the instability of marriage unions contributes to the lack of involvement of males in matters related to health. The women’s experiences highlight that marriage consists of cohabiting, which is a union that can end when the man neglects the family, or, in traditional marriages, where families agree by word of mouth that the marriage is valid and few are legally binding. The commitment is implied and not guaranteed and the men can come and go as they please, moving to another relationship when the previous one is not completely resolved. Women remarry out of desperation, sometimes entering polygamous unions, or do not expect to be in an established relationship. It may thus be difficult to convince and involve men to participate in, for example, PMTCT programmes when they are not fully committed to the relationship. Contraceptive use may also be inconsistent because the women may not see the motivation to use long-term contraceptives with the uncertainty that the marriage might end at any point.

It is important to understand that the context of these marriages is oppressive by nature, characterised by infidelity that goes unquestioned, financial neglect, and sometimes-physical violence. Suggesting the use of contraceptives might disrupt their marriage; they live with the fear of losing their financial support from the man. The women have no power of negotiation in the relationship to effect changes that may benefit their health. In such a psychologically disempowering environment, it is not impossible that, in this subordinate role, the women may not be able to fully assert themselves in matters pertaining to their health, including SRH issues or PMTCT. Improving the lives of WLHIV is thus not only about providing contraceptives and SRH services, but also about addressing the contextual issues that disempower the women to take control of their health.

7.4.4 Intersecting challenges

The various challenges the women experience work together to contribute to their quality of life negatively. While HIV infection brings its own risks to ones’ mental health, the complex circumstances surrounding their diagnosis, the stress from experiencing discrimination from work, stigma, violence, and poverty increases their risk to developing mental illness. Their main source of stress is the anxieties related to their own health, the health of the child and worries about how they manage the illness. Moreover, these threats exist in the context of a lack of emotional and financial support resources. Physical challenges experienced from the side effects of taking medication limit the amount and type of work they can be involved in to generate income. When they seek to empower themselves financially, they face stigma and are discriminated against in terms of employment because of their HIV status, which further exacerbates their lack of economic empowerment. The lack of empowerment renders them powerless to exercise agency in their relationships to involve the men in HIV-preventive behaviours such as contraception, support with PMTCT and use of, and adherence to, medication. What this means is that receiving an HIV diagnosis is not necessarily the worst event in the women’s life, but the interrelated challenges, which have a combined effect, that accompany the illness makes their lives much more difficult.

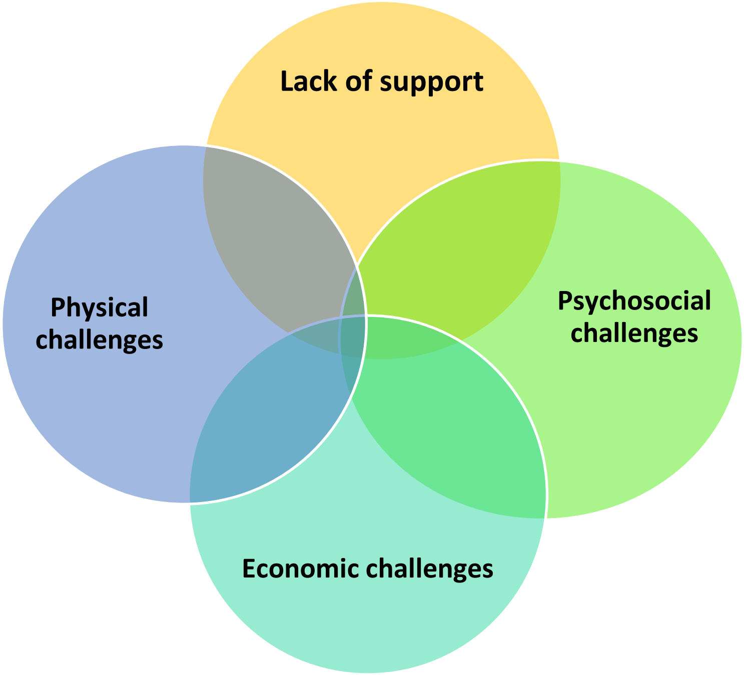

Figure 7.4: Multiple challenges faced by WLHIV

7.5 HOW DO THEY COPE WITH THESE CHALLENGES?

The manner in which women dealt with the challenges of living with HIV can be examined, and understood, in two ways. Firstly, as self-management of HIV as a chronic illness to maintain physical health; and secondly, as coping with the stress of living with HIV and finding meaning.

7.5.1 Managing HIV as a chronic illness

The women employ several strategies to manage the illness, which include learning how to deal with common body symptoms and monitoring their health. They actively seek information from the clinic to gain control of the illness and make the necessary lifestyle changes. These are similar strategies to the ones reported by Schulman-Green et al. (2012), discussed in the literature review. Although scarce financial resources frustrate their efforts, they still attempt to take control of the illness and seek help from family members. It thus seems that including financial support in efforts to assist WLHIV may improve how they manage the illness.

These findings build on the growing body of literature on self-management of chronic illnesses, in particular, HIV. Several studies thus far have investigated self-management in PLHIV (Martin, Kiwanuka, Kawuma, Zalwango, & Seeley, 2013; Russell et al., 2016;

Webel, Dolansky, Henry, & Salata, 2012). An in-depth study with 20 WLHIV by Martin et al. (2013) found that women manage the illness by monitoring their condition, managing disclosure, and managing to stay healthy. Through frequent visits to the clinic, the women obtained and adhered to ARV medication. Selective disclosure of their status to friends, relatives, and community members whom they trusted emerged as a one of the strategies used to manage stigma and its impact. To maintain their health, they paid attention to their diet and exercised (Martin et al., 2013). In another investigation with 20 women and 18 men visiting HIV facilities, Russell et al. (2016) found that PLHIV mobilised resources by establishing good relationships with workers, and acquired knowledge about HIV and ART, received counselling frequently, and followed the instructions given to them by the health workers. Their spiritual and social resources were religiosity and the belief that God was watching them (Russel et al., 2016). Similar management strategies were reported in a study in the USA with 46 WLHIV (Webel et al., 2012).

The findings of the current study are also congruent with Swendeman et al.’s (2009) review of chronic disease self-management literature discussed earlier which reported that WLHIV monitored their physical health and psychologically empowered themselves by engaging in supportive relationships. They developed positive social relationships with family and their peers and managed stigma (Swendeman et al., 2009).

What stands out from the experiences of women in this study is that in the management of their illness, the women’s relationship with health workers was not collaborative. In the Malawian setting, health workers are looked up to as experts, and while this is important for professional care, the health workers may operate on the assumption that they know what is good for the women and impose certain lifestyles, for example discouraging them not to have children, as alluded to earlier. A more person-oriented approach from the health workers, which requires working with the clients to identify their already existing strategies in the management of their illness and encouraging them, may be more favourable. Despite the minimal resources, the women in this study demonstrated that they could still manage their illness. They were able to attend medical appointments to deepen their knowledge; they attended social groups, and engaged in advocacy activities to promote positive living with HIV to others. They also reported contacting the clinic and learning more about their CD4 count to adhere to the medication, manage side effects, and monitor dietary requirements. Family members who initially accompanied the women to the ART clinic provided immediate support and assisted the women in dealing with the shock of the diagnosis. They also continued to maintain friendships and performed daily chores; for example, the women spoke of how they could still go to their gardens or their places of business for those who had small businesses; that is, carrying out their normal activities. This suggests that increasing resources for support and having a more organised support system for WLHIV has the potential of improving their current functioning

From the point of their diagnosis, the women managed to process their emotions by reflecting on how their diagnosis affected the various aspects of their lives and changed their perceptions to match the new reality. The women described a lack of supportive counselling required to deal with emotions after learning about their diagnosis and a sense of urgency on their part to move on with life, which made them side-line their emotions and focus on the practical aspects of their diagnosis. While not generalising from this sample of 12 women, this finding is important because it highlights that psychosocial support for WLHIV in Malawi may be the missing aspect in the HIV care continuum after the provision of ARVs and PMTCT services.

7.5.2 Coping with the stress of living with HIV and meaning attached to the experience of living with HIV

The diagnosis itself and the challenges that accompany the diagnosis, such as economic hardships, stigma, and discrimination, cause a significant amount of stress in their lives. Another cause of emotional distress was the challenges they encounter in their relationships because of their HIV status. To deal with the stress, the women employ emotion-focused coping and problem-focused coping strategies. The women in the study approach their diagnosis by either finding solutions to problems accompanying the diagnosis or attempting to deal with emotions associated with receiving the diagnosis. For example, in order to avoid feeling socially isolated, some of the women attend religious gatherings and seek support from friends in the community. They actively seek medical counselling from the hospital to empower themselves with knowledge. These strategies are similar to the ones reported in Mahmoudi et al.’s (2015) study cited in the literature review. These findings also concur with the those from a study conducted in Southern India where PLHIV empowered themselves with knowledge about their illness to increase their confidence in their ability to manage the illness, and this made them feel optimistic about their future (Kumar, Gruskin, Khosla, & Narasimhan, 2015). The emotion-focused strategies used include distracting themselves to avoid ruminating on their problems, praying, and encouraging others to improve their own feelings of wellbeing.

Attending religious activities and religious gatherings prove beneficial in helping the women cope with the stress of living with HIV. Religious gatherings in the community provide the women with the relief they need from the worries and stresses they experience. In contrast to religious settings, the clinic setting where they access counselling is very formal and too authoritative for the women to talk about their issues freely. Thus, the women turn to religious activities mainly because these religious groupings are more accepting of and welcoming to PLHIV. Religion comprises a large part of the women’s lives, which they turn to in their day-to-day. Religious gatherings have the advantage that they are associated with healing, trust, love, and confidentiality so they are a source of support for the women. These findings lend support to existing evidence which points to spirituality and religion as playing a major role in improving the quality of life of HIV-infected people (Szaflarski, 2013). A review of studies from the sub-Saharan region on the role of church groups in the lives of PLHIV found that church groups provide safe spaces for WLHIV because they are readily accessible to the women as already established community networks for vulnerable people (Campbell, Skovdal, & Gibbs, 2011). A study with women in the Democratic Republic of the Congo (DRC) also revealed that religion was used as a coping mechanism (Maman, Cathcart, Burkhardt, Omba, & Behets, 2009). The women in the current study reported utilising prayer to deal with the shock of the diagnosis and employed faith as ongoing support necessary for living positively with HIV. Some turned to church leaders for advice, the church supported them in the disclosure of their status, and they found that this gave them a positive outlook. Using religion and spirituality to cope has been associated with an increase in survival over a long period of time (Ironson, Kremer, & Lucette, 2016).

It is possible, too, that the involvement in religious activities serves another function, which is to counterbalance negative self-beliefs or internal stigma of being HIV-positive. In other words, their religiosity might also be about showing themselves and others that they are worthy people despite their HIV diagnosis. Something similar may happen with those who find purpose in using their own experiences and status to help infected or affected by HIV. Cognitive models of human distress emphasis the role of healthy and unhealthy self-schemas (see, Beck, Rush, Shaw & Emery, 1979). While some equilibrium may be obtained by emphasising alternative, healthy self-beliefs, the continued existence of the negative self-schemas would suggest that their mental health is precarious, vulnerable to events that make the negative more salient or that make the healthy alternatives unviable. It remains to be seen whether psychological therapy designed to address the negative cognitions associated with HIV infection would have long-term benefits.

Another coping mechanism the women use is seeking support from their peers who are also living with HIV. This mechanism seems beneficial to their wellbeing because the women do not feel judged, which minimises the feelings of stigma. This resonates with findings from a study with 340 individuals with HIV who used online support and found it both empowering and beneficial (Mo & Coulson, 2010). Similar findings emerged from a study conducted in Zimbabwe with HIV-infected children who attended support groups (Mupambireyi, Bernays, Dangarembize, & Cowan, 2014). The study found that support groups provided a safe space for children with HIV where they felt unjudged, gained confidence, and obtained useful information about their condition. In further congruence with the results is another study where the authors investigated the peer support experiences of PLHIV (Peterson, Rintamaki, Brashers, Goldsmith, & Neidig, 2012). They found that participants found it easy to receive and provide social support in already established social networks such as support groups. Similar findings from the studies of Cuca et al. (2016) and Goudge, Manderson, Ngoma, and Schneider (2009) echo what the current study found regarding social contact and having social relationships serve as a buffer to stigma for WLHIV.

With regard to mental health, the women’s narratives did not seem to suggest that they are experiencing serious mental health issues apart from the initial reactions to the diagnosis. They rely on their own support systems to strengthen their resilience but they could benefit from formal support. All in all, these coping strategies demonstrate that, despite the lack of both material and psychological support, the women in the study were proactive in seeking their own sources of support by mobilising themselves and pulling together their own resources to find information and manage their illness. In the developed world, most women are literate and able to access more information through the internet, for example, and may access more support through internet communities. It is not very easy for women such as those in this study to find support beyond the clinic setting. Identifying and understanding these modes of coping are crucial for beginning to build an understanding of how women stay resilient and how they can be supported.

According to Russell et al. (2016), PLHIV can use their illness as an opportunity for growth by charting new meaning in their life, appreciating life more, and adopting a new language for thinking and speaking about HIV. Central to the findings in the current study is the meaning the women develop to define living with HIV, how they adjust their attitudes, redefine the illness, and adopt a new way of looking at themselves. The women constructed a new meaning of HIV by engaging in cognitive reappraisal of HIV as an illness. The new information the women use in their reappraisal is the knowledge that ARV prolongs the life of those with the virus and death is thus no longer threatening. HIV attains the meaning of an illness that one can live with and continue with life normally. Lazarus and Folkman (1984, p. 31) define cognitive appraisal as "a process of categorising and encounter and its various facets with respect to its significance for wellbeing". Cognitive reappraisal means that the individual changes the initial appraisal and reinterprets the situation based on new information from the environment. A meta-analysis of literature on coping showed that positive reappraisal has been associated with better emotional and physical health outcomes among PLHIV (Moskowitz, Hult, Bussolari, & Acree, 2009), while disengagement forms of coping, such as use of alcohol, were associated with poorer outcomes.

Faith is used both as a coping mechanism and to make sense of the women's illness. This result seems to echo that of a study with African migrants and refugees living with HIV in New Zealand, which also found faith, spirituality, and religion to be tools that were used to construct new meaning after their diagnosis (Henrickson, Brown, Fouché, Poindexter, & Scott, 2013). It seems that finding the meaning of living with HIV is a positive step for the women, in that it motivates them to keep fighting and protects them from the hopelessness and anxieties that come with living with a chronic illness. To sum up, these findings on how women manage and cope with living with HIV are important for the development of psychosocial programmes for supporting WLHIV.

7.6 INTERSECTIONALITY AND LIVING WITH HIV

These findings demonstrate that there are various factors at play reported in the women's actual experiences of living with HIV, which interact to contribute to their health. Hence medical treatment, while necessary, needs to be supported by psychosocial interventions to make the experience of living with HIV bearable for the women. Living with HIV involves attending to multiple domains, the physical domain which entails management of the illness; the psychological domain, which entails coping with the stress of living with HIV; and an existential domain which requires developing a personal meaning attached to the illness. Management of the illness depends on material resources and easy access to treatment and services. While the women in this study seem to access services without any impediments and had easy access to medication, the lack of material support influences the nutritional aspects of their health regimen. Coping with stress involves employing strategies that enabled them to process their emotions and lessened the likelihood of developing mental health problems. The meaning they attach to living with an HIV diagnosis can give them a healthy philosophical outlook on life and helps them manage their health and live positively, using their diagnosis as a transformative event in their lives. These findings point to more holistic approaches to combating HIV, which acknowledge that various factors contribute to living with HIV as an illness and interventions should also take into consideration the psychosocial aspects of living with HIV.

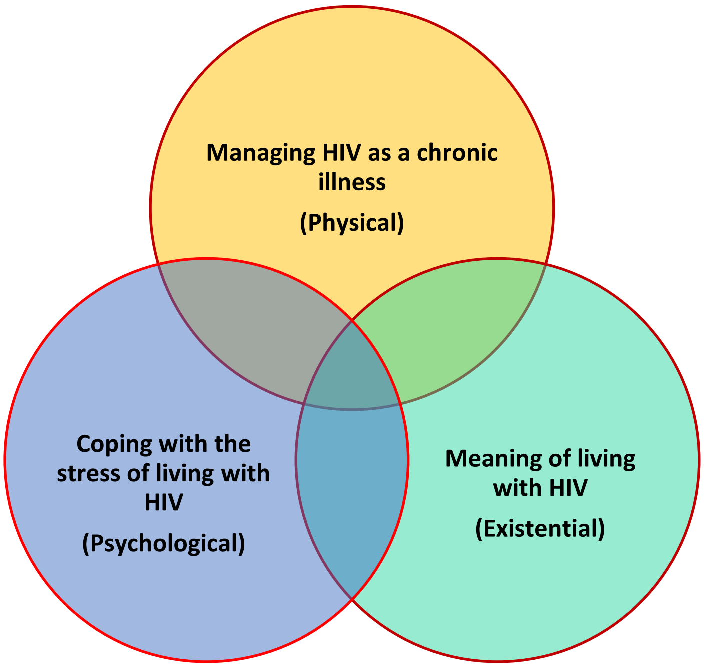

Figure 7.5: The experience of living with HIV involves managing the illness, coping, and meaning-making

In summary, while most of this study's results are similar to previous studies, the findings of this study are original in that they documented the experiences of Malawian WLHIV, which, as stated in the literature review chapter, had previously not been explored and there had been no similar prior published literature on the topic. The study captured the experience of being diagnosed and living with HIV in the women's socio-cultural context and demonstrated that various factors, other than biological ones alone, contribute to HIV risk. The common leitmotif shared by all 12 participants is that an HIV diagnosis is not in itself the worst event of their life. Instead, multiple factors, which pre-exist and co-occur, such as their living conditions of poverty, lack of educational opportunities and the subsequent lack of empowerment, domineering partners, and cultural norms that increased their vulnerability to HIV infection, proved to be more challenging. Information pertaining to how the women in the study cope with challenges and the stress of diagnosis and how they create meaning of their lived experiences demonstrate that there are psychosocial aspects of living with HIV that need to work alongside medical interventions. An intersectional understanding of their multiple adversities enables understanding of the context in which women experience the illness by highlighting the overlaps in the multiple disadvantages in their life story, the multiple identities that come with an HIV diagnosis, and the interlocking challenges they face as WLHIV. While these experiences might be common to women in other contexts in Africa, the 12 participants in the study addressed all the issues and demonstrated that WLHIV in Malawi experience multiple layers of oppression and disadvantage in their lives.

7.7 CONCLUSION

This chapter discussed the findings of the study in relation to the published literature and the implications for Malawian WLHIV. While there was a slight divergence from the established literature, most of the findings concur with previous studies, though never before with a samples of Malawian women who are HIV-positive and in receipt of ARV treatment. The new insights gained require further investigation before being able to be generalised to the wider population. The next chapter summarises and concludes the thesis.

CHAPTER EIGHT:

CONCLUSION AND RECOMMENDATIONS

8.1 INTRODUCTION

This chapter concludes the thesis and offers recommendations for future studies. The study aimed to document the lived experiences of women attending an ARV clinic in Southern Malawi in order to understand their socio-cultural context and prominent life experiences. The study also sought to understand their actual experiences of receiving an HIV-positive diagnosis, their experiences of living with HIV, and the meaning attached to those experiences. IPA methodology was deemed suitable to the nature of the research questions. This chapter begins with reflections on the method used in the research. The chapter proceeds to offer recommendations on how the lives of WLHIV in Malawi can be improved with regard to treatment and care. The chapter also discusses the possible areas of future research on the same topic. An explanation of what this study has contributed, the strengths of the study, and its limitations conclude the chapter.

8.2 METHODOLOGICAL CONSIDERATIONS AND CRITICAL REFLECTIONS

A major strength of this methodology was the use of an approach that allowed in-depth exploration of participants’ experiences. The rich and in-depth material was easy to capture because of the sample of size of 12 used in the study, which allowed intimate engagement with the data. Using IPA and adhering to its recommendation for a smaller sample size relative to quantitative designs made it possible to achieve the goals of researching lived experiences. The three phases of the interviews allowed for in-depth understanding and analysis of the data. The first interview, the biographical interview, served as a way of establishing rapport and preparing the women for more sensitive questions that were presented to them in the second and third phases of the data collection. The time gap between the interviews gave the women time to think about and reflect on their experiences before the next interview. This facilitated their expressing themselves more deeply. The sample size of 12 also ensured total engagement with the participants, and ensured that their voices were heard, thus meeting the idiographic commitment of IPA (Smith et al., 2009). The interviews were first individually analysed in detail as a mechanism of ensuring rigour and to facilitate a good level of interpretative engagement with the text. This was the first time the approach had been used in a study with WLHIV in Malawi, where most research on HIV uses the large sample sizes required of quantitative approaches. While the studies using large samples and quantitative approaches are very important as they provide generalizable findings, this study complements previous work done because it allows individual experiences to be heard. The IPA approach pushed the women's narratives beyond the descriptive into the realm of phenomenological meaning making. Using the IPA method for this research was very useful in bringing out issues that would have otherwise been missed using large-sample quantitative analyses. The systematic analysis of the data was facilitated by the use of the software QSR NVivo for qualitative data analysis. Time consuming as it was, the write-up process benefited from the investment made in learning how to use the programme to organise the data.

One-on-one interviews also proved to be optimal for investigating the women's issues relating to HIV in Malawi by providing a safe space for the women to have their voices heard. From my perspective as the researcher, it appears that the women in the study found it profoundly empowering to be consulted as "experts" on the subject of living with HIV, and to freely discuss issues that are considered taboo or too embarrassing to talk about in open fora. In addition, the women were given the opportunity to tell their own unique story; this story-telling process was perhaps a small step towards healing the trauma of an HIV diagnosis within the context of a life of adversity. As a Malawian female researcher, I am located historically in the social cultural context, hence it was easy to speak to the women and relate to their stories.

After each interview, I listened to the recordings to find out what the questions were that helped the women to open up and what phrases and probes opened up and closed up the space. This was an important aspect because the women were interviewed in a clinic setting where their role is that of listening to experts, as opposed to controlling the interaction situation. It seems that the women were treated differently in this instance, by being asked to narrate their experiences, because this showed that they were valued. The women are used to be spoken to, and treating them differently by recognising that they are experts in their life story made them feel respected.

I made several gestures to demonstrate respect for the 12 participants. During the interview, I ensured that if the woman was sitting on the floor, we would both sit on the floor and if I was offered a chair, I insisted that the woman also sat on a chair. I also ensured that I was the first to arrive for the interview and they would find me waiting for them. During the conversation, I did not interrupt them unnecessarily. Compensating them for their time also showed them that I appreciated their presence and considered their participation valuable and that they did not have to use their own resources to be involved in the research. These respectful gestures made them open up and explain intimate issues about their lives.

The process of ensuring trustworthiness, transparency, and credibility of the study was helped by the rigorous ethical scrutiny the study was subjected to by two institutions' ethical committees. The process of entering the field needed authorisation on three levels; at all stages, as a researcher, I put the participants' interests first and justified the benefit of the research to the understanding of HIV in Malawi. The decision to conduct the interviews, transcribe and translate the audio recordings myself without the use of research assistants, allowed for the process of understanding the data to begin immediately, in the field. By the time I was conducting the analysis and generating the themes, I had already developed an intricate understanding of the participants' lives.

During the course of the fieldwork, I developed a good working relationship with the women and appreciated their resilience and social consciousness. They acknowledged the difficulties of living with HIV but did not resign completely to their situation. The women's optimism gave me a glimmer of hope that the lives of WLHIV could be improved if they receive support. It is, however, important to note that the women interviewed in this study were all receiving treatment and were an important group, but it is also important to consider that there are other women outside the support of the clinic who might not yet be receiving treatment and may report different experiences.

I primarily regarded this research as generally involving women, as opposed to being specifically about WLHIV, an aspect which has made the research unique, because WLHIV in Malawi have been able to speak for themselves about their challenges as women. The language that is at our disposal when talking about WLHIV is victim-centred and medical, rarely reflecting that women have unique personal stories which shape their experiences and are capable of exercising agency over their lives. The interviews allowed a healthy space for the women to describe using their own words, what it is for them to live with HIV.

The research points to the multiple forms of oppression the women experience from a young age, the interconnected challenges, and the need for more structural approaches to deal with the issues they face. When one looks at these challenges and the manner in which they are interlinked, it is clear to see that the women wish to exercise agency in their lives, but they are constrained by these multiple disadvantages that exist in their communities. I therefore offer some recommendations, which might work towards improving the quality of life of WLHIV in Malawi.

8.3 RECOMMENDATIONS

The current research reported the lived experiences of WLHIV and the issues they have to surmount. The following sections offer recommendations that could potentially improve the lives of WLHIV.

8.3.1 Recommendation 1

Existing laws regarding the protection women in Malawi should be enacted. While there are a number of explicit laws to protect women, many of the participants in the study seemed to obtain no benefit from these legal frameworks. The government and other agencies, therefore, need to find ways of translating legal ideals into actual, effective protection. For example, from what the women in this study reported, GBV did not have any serious repercussions for the perpetrators. There should be more efforts and interventions to curb GBV in Malawi. At national level, the Malawi Constitution (1994), the National Gender Policy (2000-2005 and 2006-2011), the National Gender Programme, the Prevention against Domestic Violence Law, and the National Response to GBV Strategy (2008-2013) have laws against any form of abuse towards women. Other efforts include highlighting gender activities in the national budget and appointing gender focal point persons in all ministries and departments. However, the rhetoric of women's empowerment has done little to radically halt the scourge of GBV in the country, as the results demonstrate. Therefore, as seen here, the problem is not lack of legislation, but rather that the existing laws are not rigorously enforced. Education must be tailored to counteract the damaging compelling narrative put forward by cultural apologists and a patriarchal system that advances that women are less capable than men. Helping women does not mean ignoring men. Rather, a collaborative effort will ensure success of advancing women's empowerment. Institutions that protect women should be fully functional to support the women's personal efforts after they take an initiative to remove themselves from the abusive relationships as they strive to empower themselves. The female docility and subservience that is viewed, as the acceptable femininity culturally, is a fertile ground for all forms of violence targeted on girls and women. Because GBV happens in a marriage context, it is considered personal and hence it is regarded as difficult for the law or policies to intervene. There is a need to move beyond the cultural barriers, enact the laws of protecting women, and stop condoning all forms of abuse.

8.3.2 Recommendation 2

There is a need for more comprehensive psychosocial interventions such as financial support, housing, childcare, and components of counselling to address the multiple issues that WLHIV face, as reported by the 12 women in the study. Considering the multidimensional nature of the experiences the women in this study reported, no one-size, single intervention is likely to help, but rather, in accordance with the idea of intersectionality, multisectoral policies should be developed to provide a range of medical, psychological, economic, and social support to these women. The government should provide more financial and technical assistance for establishing and sustaining existing support groups in communities. Because most WLHIV live in abject poverty, material support should be included in the assistance to encourage participation in the groups. Micro loans should be offered to enable the women to empower themselves through small businesses. The existing social cash transfer programmes should continue to provide relief to women such as those interviewed in the study. A key policy priority should be to consider compulsory health literacy for men regarding their role of supporting women in HIV prevention and management.

In addition to being informative about the medical aspects of the illness, medical counselling provided by the clinics should address the personal issues that the women face that accompany HIV infection. This is useful to think about plans of developing local capacity in counselling, especially the training of health workers in order to provide the open space to women where they do not feel threatened to talk about their issues. There is also a need to rethink the current models of HIV counselling, which tend to be too formal and aim for culturally appropriate counselling that will enable PLHIV to open up easily. Because of the nature of the psychosocial issues the women are faced with, for example the stigma and rejection from family, systemic family counselling would be a viable solution.

8.3.3 Recommendation 3

It is the duty of the country to make it easy for women to make reproductive choices, and to provide educational opportunities and grants to those who are most vulnerable in order to create a friendlier and more responsible society. There is a need to improve SRH services in terms of counselling and access to specialised family planning services for WLHIV in the ART clinics to encourage the use of more effective contraceptives.

8.3.4 Recommendation 4

While the importance of cultural practices to the fabric of life and identity for many Malawians is acknowledged, this should not be allowed to deprive people of access to treatment and care, especially for women who may experience cultural prescripts as subjugating and oppressive. These prescripts sustain stigma and make them more vulnerable. If women are not empowered in their private spheres, the interventions are less likely to work. Lack of empowerment means that women have no capacity to define their course of life. Thus, there is a need to challenge the prevailing social and cultural values that sabotage these efforts to change women’s lives.

8.4 SUGGESTIONS FOR FUTURE RESEARCH

The study revealed some gaps in knowledge that might be useful to future research to further understand the experiences of living with HIV. There is a need for more research to develop and measure the effectiveness of policy interventions, and this should include both qualitative and quantitative research.

Replication of this study with men living with HIV would be useful in understanding the health behaviours of men, such as their lack of involvement or how they adapt to the illness – information that scantily featured in the narratives of the women. Such a study would explore in depth the issues that emerged from this study, for example reasons for non-compliance to medication by men.

To understand more about the lack of empowerment of women with HIV, a useful study would be with women living in urban areas who are empowered and have an income and more resources to manage their health. The women in this study came from low socio-economic backgrounds, living in peri-urban Malawi. Poverty is the number one factor that impacts on their decisions about marriage and relationships. It would be interesting to investigate how urban working-class women experience living with HIV.

Finally, the women in this study were all receiving ARV treatment. Their experiences may well be very different from those who are not receiving treatment. Further qualitative research to understand their experience to appreciate why they are not receiving treatment may also be revealing.

8.5 SIGNIFICANCE OF THE STUDY

Firstly, the study contributes to existing knowledge by stressing the complexity of women’s lives and exposing how living with HIV is a multi-layered experience related to structural and personal constraints, poverty, financial dependence, and cultural factors. Thus, the study has advanced the understanding of living with HIV beyond the biomedical discourse by demonstrating that women’s vulnerability to HIV is entrenched in contextual factors. The study has been able to provide those intricate personal factors that explain the roots of the challenges that WLHIV experience. This implies that changing the current status quo involves initiating more structural interventions such as challenging social power structures that subordinate women, improving girls’ access to education, helping women achieve economic empowerment, and addressing the root causes of stigma, discrimination, and GBV.

Secondly, the study can also lay claim to originality on the basis of it being the first study that investigated the lived experiences of WLHIV in Malawi using IPA to capture the nuances of women’s lives. The study is also one of few to place women as the subject of the research by using intensive three-part interviews conducted in the local language to gain in-depth access to their personal lives. Methodically, the use of three phases of interviewing has proved useful in generating biographical information necessary to place the phenomenon under study in its proper context.

As noted in the literature review chapter, there is little qualitative research on HIV-positive women in Malawi and even fewer opportunities for these women to express their own experiences. The research provided an opportunity for the women to tell their stories of personal humiliation, shame, and loss of dignity and begin the process of healing. Listening to women’s testimonies may not only helped transform their pain, but also empowered them. Thus, the research also served as an affiliative strategy to give a voice to the women and a space for them to narrate their stories, helping them to release the trauma of their diagnosis and make sense of their experiences.

The findings also highlight a gap in HIV care in Malawi where women lack counselling and support that addresses the psychosocial challenges they face due to their diagnosis, including adequate support for SRH issues. The experiences of living with HIV causes a significant amount of stress for women because of the care burden and responsibility to look after their children. Understanding the available resources of support will enable the development of culturally appropriate person-centred counselling for WLHIV.

Finally, implications for policy point to the importance of implementing interventions that draw from various disciplines to make an impact on the quality of life of WLHIV. In addition, the findings can inform the development of guidelines for addressing non-medical sequelae of HIV and behavioural change interventions for populations regarding biomedical interventions. The information from the study can also be used to develop public educational and HIV-awareness programmes.

8.6 STUDY STRENGTHS

This is the first study that explored the lived experiences of WLHIV in Malawi using IPA. The use of three interview phases allowed the women to talk about their background and thus captured the unique personal histories that shaped their experiences. The instruments used in the study were not adopted from other studies, but were developed specifically for the women in the study; thus, they were culturally sensitive, contextually relevant, and enabled the collection of accurate data.

8.7 LIMITATIONS OF THE WORK

The language used by the women during the interviews was extremely rich in idioms and metaphors specific to the Chichewa language. Those idioms might have been lost in translation and compromised the intensity of the meaning; nevertheless, great effort was made to ensure that the meaning of their experiences was adequately captured. The findings from this study are highly relevant to the context of Malawian women only. Despite the sample size of 12 and the geographical confinement of the study, it is likely that the findings, supported by other studies, are relatively common and reflect the challenges faced by many Malawian WLHIV.

8.8 CONCLUSION

The aim of study was to explore the experiences of WLHIV and is the first to explore the lived experiences of HIV in Malawi using the IPA approach. The main research question that guided the inquiry was: *What are the lived experiences of WLHIV attending Tisungane Clinic in Southern Malawi*? This thesis argued that being HIV positive alone is not the main challenge in the women’s lives; rather the social inequalities that sustain their vulnerable positions and the multidimensional disadvantages that accompany their HIV status were the main challenges. This has implications for more structural interventions to address the interlocking oppression that increases risk to HIV, and utilising multidisciplinary interventions to improve the lives of women with HIV in Malawi. The findings revealed that the issues of WLHIV should not be understood in isolation, but in relation to one another. This is the first study to bring together the life histories of women in Malawi with the aim of to understanding how the multiple disadvantages in their early life shape their experiences of living with HIV and subsequently the outcomes of their health. While there are limitations to the study, these monolingual women had the opportunity to be involved in the research as participants. Hopefully, other studies will follow suit.

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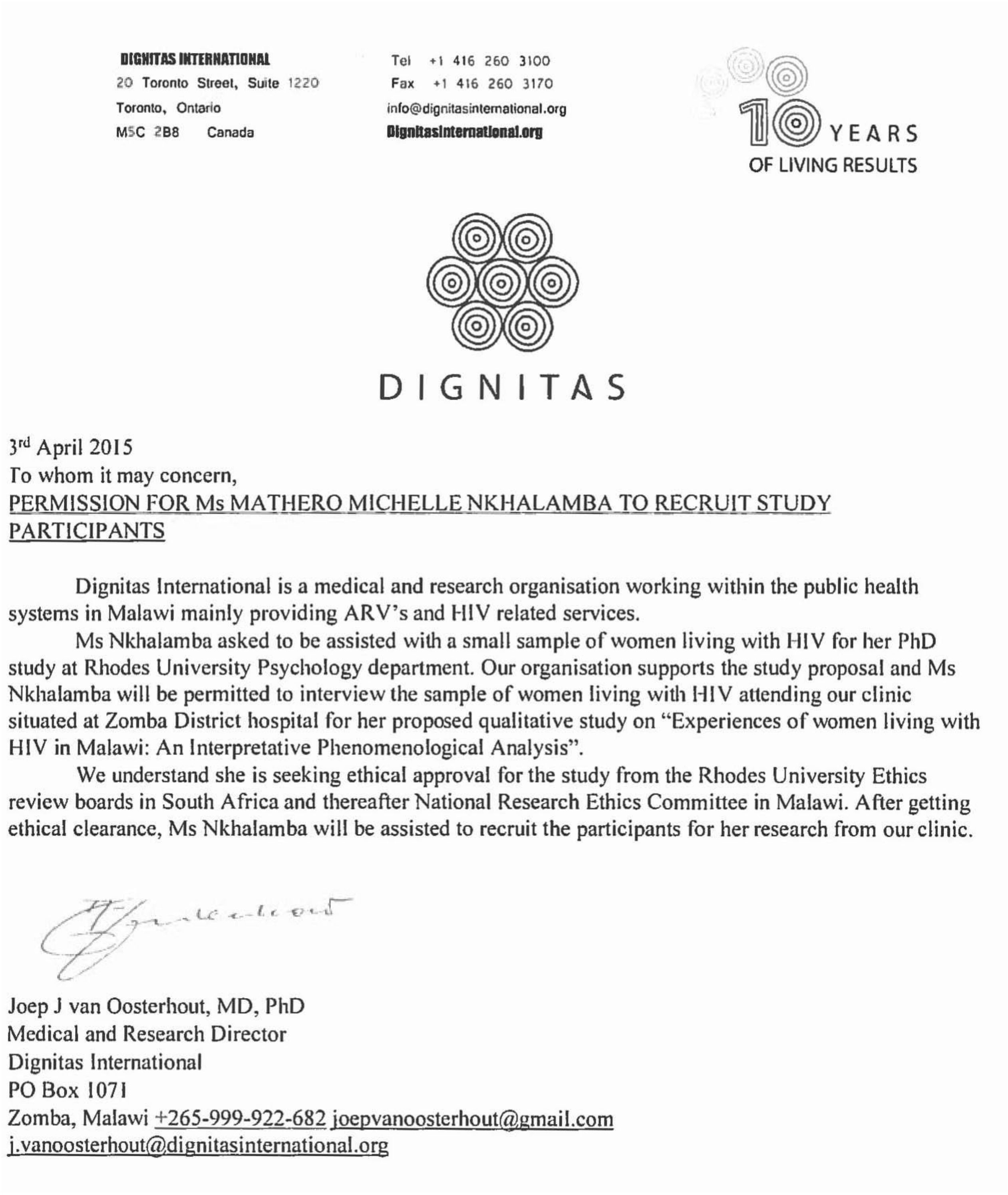
APPENDICES

APPENDIX 1: LETTER FROM DIGNITAS INTERNATIONAL ALLOWING ACCESS TO SAMPLE AT THE TISUNGANE CLINIC



DIGNITAS INTERNATIONAL
20 Toronto Street, Suite 1220
Toronto, Ontario
M5C 2B8 Canada

Tel +1 416 260 3100
Fax +1 416 260 3170
info@dignitasinternational.org
DignitasInternational.org

10 YEARS
OF LIVING RESULTS

DIGNITAS

3rd April 2015
To whom it may concern,

PERMISSION FOR Ms MATHERO MICHELLE NKHALAMBA TO RECRUIT STUDY PARTICIPANTS

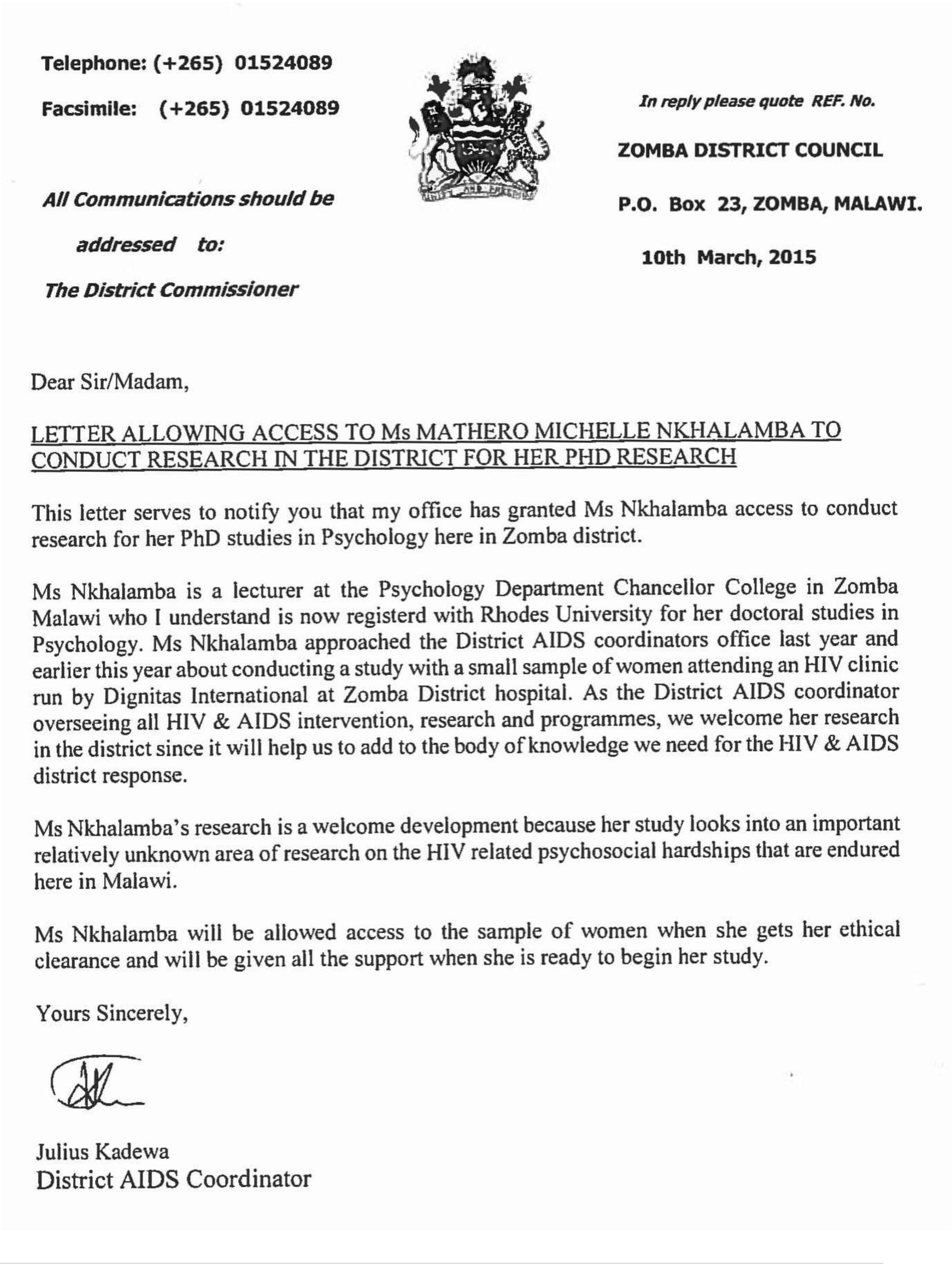
Dignitas International is a medical and research organisation working within the public health systems in Malawi mainly providing ARV's and HIV related services.

Ms Nkhalamba asked to be assisted with a small sample of women living with HIV for her PhD study at Rhodes University Psychology department. Our organisation supports the study proposal and Ms Nkhalamba will be permitted to interview the sample of women living with HIV attending our clinic situated at Zomba District hospital for her proposed qualitative study on "Experiences of women living with HIV in Malawi: An Interpretative Phenomenological Analysis".

We understand she is seeking ethical approval for the study from the Rhodes University Ethics review boards in South Africa and thereafter National Research Ethics Committee in Malawi. After getting ethical clearance, Ms Nkhalamba will be assisted to recruit the participants for her research from our clinic.

Joep J van Oosterhout, MD, PhD
Medical and Research Director
Dignitas International
PO Box 1071
Zomba, Malawi +265-999-922-682 joepvanoosterhout@gmail.com
j.vanoosterhout@dignitasinternational.org

APPENDIX 2: LETTER FROM ZOMBA DISTRICT COUNCIL ALLOWING RESEARCH



Telephone: (+265) 01524089
Facsimile: (+265) 01524089

All Communications should be addressed to:
The District Commissioner

In reply please quote REF. No.
ZOMBA DISTRICT COUNCIL
P.O. Box 23, ZOMBA, MALAWI.

10th March, 2015

Dear Sir/Madam,

LETTER ALLOWING ACCESS TO Ms MATHERO MICHELLE NKHALAMBA TO CONDUCT RESEARCH IN THE DISTRICT FOR HER PHD RESEARCH

This letter serves to notify you that my office has granted Ms Nkhalamba access to conduct research for her PhD studies in Psychology here in Zomba district.

Ms Nkhalamba is a lecturer at the Psychology Department Chancellor College in Zomba Malawi who I understand is now registerd with Rhodes University for her doctoral studies in Psychology. Ms Nkhalamba approached the District AIDS coordinators office last year and earlier this year about conducting a study with a small sample of women attending an HIV clinic run by Dignitas International at Zomba District hospital. As the District AIDS coordinator overseeing all HIV & AIDS intervention, research and programmes, we welcome her research in the district since it will help us to add to the body of knowledge we need for the HIV & AIDS district response.

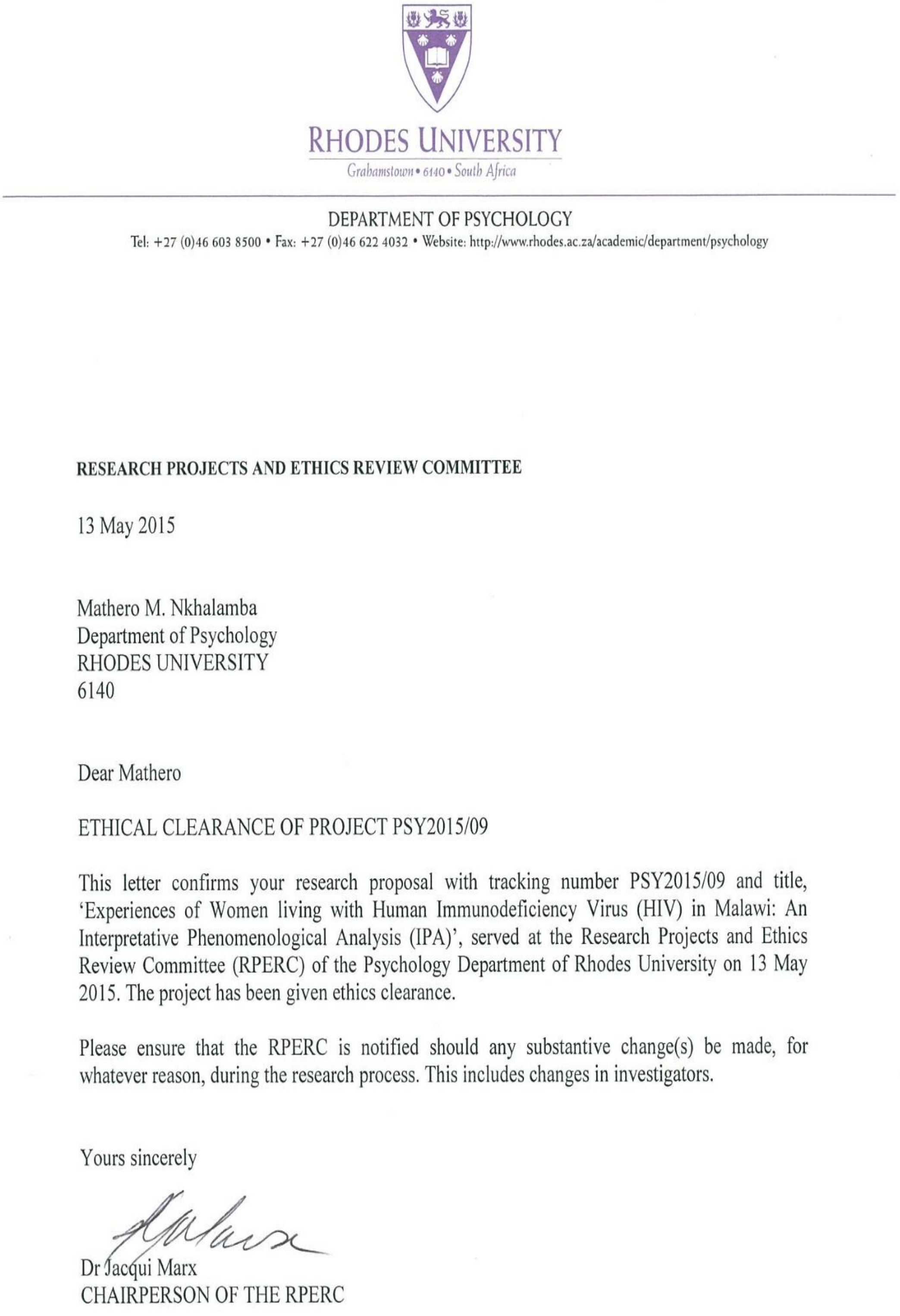
Ms Nkhalamba's research is a welcome development because her study looks into an important relatively unknown area of research on the HIV related psychosocial hardships that are endured here in Malawi.

Ms Nkhalamba will be allowed access to the sample of women when she gets her ethical clearance and will be given all the support when she is ready to begin her study.

Yours Sincerely,

Julius Kadewa
District AIDS Coordinator

APPENDIX 3: ETHICS APPROVAL FROM RHODES UNIVERSITY, PSYCHOLOGY DEPARTMENT



RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

DEPARTMENT OF PSYCHOLOGY
Tel: +27 (0)46 603 8500 • Fax: +27 (0)46 622 4032 • Website: http://www.rhodes.ac.za/academic/department/psychology

RESEARCH PROJECTS AND ETHICS REVIEW COMMITTEE

13 May 2015

Mathero M. Nkhalamba
Department of Psychology
RHODES UNIVERSITY
6140

Dear Mathero

ETHICAL CLEARANCE OF PROJECT PSY2015/09

This letter confirms your research proposal with tracking number PSY2015/09 and title, 'Experiences of Women living with Human Immunodeficiency Virus (HIV) in Malawi: An Interpretative Phenomenological Analysis (IPA)', served at the Research Projects and Ethics Review Committee (RPERC) of the Psychology Department of Rhodes University on 13 May 2015. The project has been given ethics clearance.

Please ensure that the RPERC is notified should any substantive change(s) be made, for whatever reason, during the research process. This includes changes in investigators.

Yours sincerely

Dr Jacqui Marx
CHAIRPERSON OF THE RPERC

APPENDIX 4: ETHICS APPROVAL FROM MALAWI NATIONAL RESEARCH ETHICS COUNCIL

NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY

Lingadzi House
Robert Mugabe Crescent
P/Bag B303
City Centre
Lilongwe

Tel: +265 1 771 550
+265 1 774 189
+265 1 774 869
Fax: +265 1772 431
Email:directorgeneral@ncst.mw
Website:http://www.ncst.mw

Ref No: NCST/RTT/2/6 **18TH June 2015**

Faculty of Humanities Department of Psychology

Rhodes University

P.O Box 94

Grahamstown 6140

Dear Mathero Michelle Nkhalamba

RE: RESEARCH ETHICS APPROVAL OF PROTOCOL NO.P.05/15/40: EXPERIENCES OF WOMEN LIVING WITH HIV ATTENDING TISUNGANE HIV CLINIC IN SOUTHERN MALAWI: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS.

Having satisfied all the ethical, scientific and regulatory requirements, procedures and guidelines for the conduct of research in the social sciences sector in Malawi, I am pleased to inform you that the above referred research study has officially been approved. You may now proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this letter. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research in the Social Sciences and Humanities in a format that is available at the secretariat. Once the study is finished, you are required to furnish the Committee and the Commission with a final report of the study.

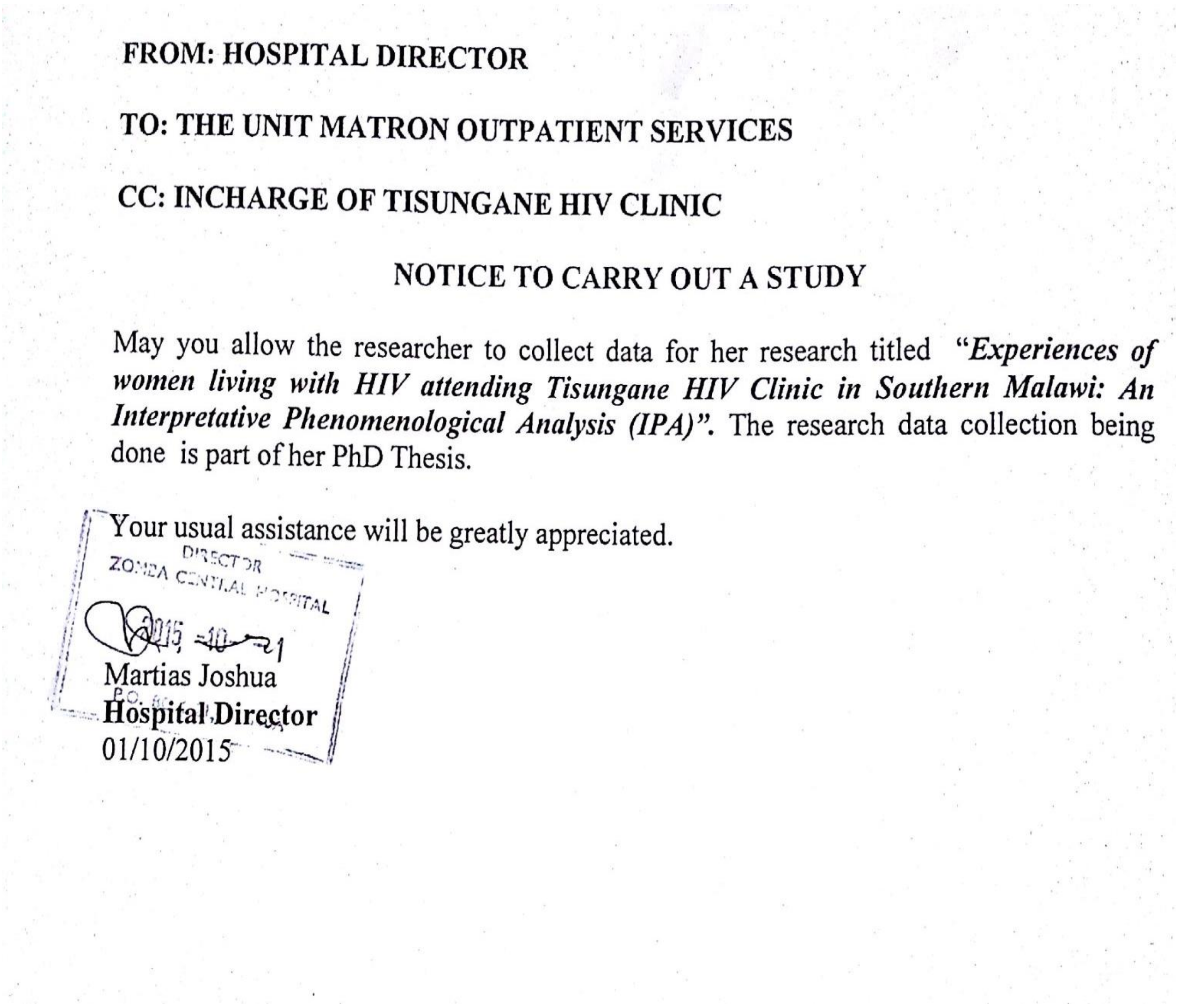
Wishing you a successful implementation of your study.

Yours Sincerely

Martina Chimzimu

NCRSH ADMINISTRATOR AND RESEARCH OFFICER HEALTH, SOCIAL SCIENCES AND HUMANITIES
For: CHAIRMAN OF NCRSH

APPENDIX 5: PERMISSION TO CONDUCT RESEARCH AT ZOMBA CENTRAL HOSPITAL



FROM: HOSPITAL DIRECTOR

TO: THE UNIT MATRON OUTPATIENT SERVICES

CC: INCHARGE OF TISUNGANE HIV CLINIC

NOTICE TO CARRY OUT A STUDY

May you allow the researcher to collect data for her research titled ***"Experiences of women living with HIV attending Tisungane HIV Clinic in Southern Malawi: An Interpretative Phenomenological Analysis (IPA)".*** The research data collection being done is part of her PhD Thesis.

Your usual assistance will be greatly appreciated.

DIRECTOR
ZOMBA CENTRAL HOSPITAL
2015 -10- 21

Martias Joshua
Hospital Director
01/10/2015

APPENDIX 6: MEDICAL COUNCIL CERTIFICATE

CERTIFICATE OF REGISTRATION

REGISTRATION NO. MCM/CLIN-PSY/0009 **CERTIFICATE NO: 109**

This is to certify that

MATHERO MICHELLE NKHALAMBA

is this 12th day of December 2012, registered on the

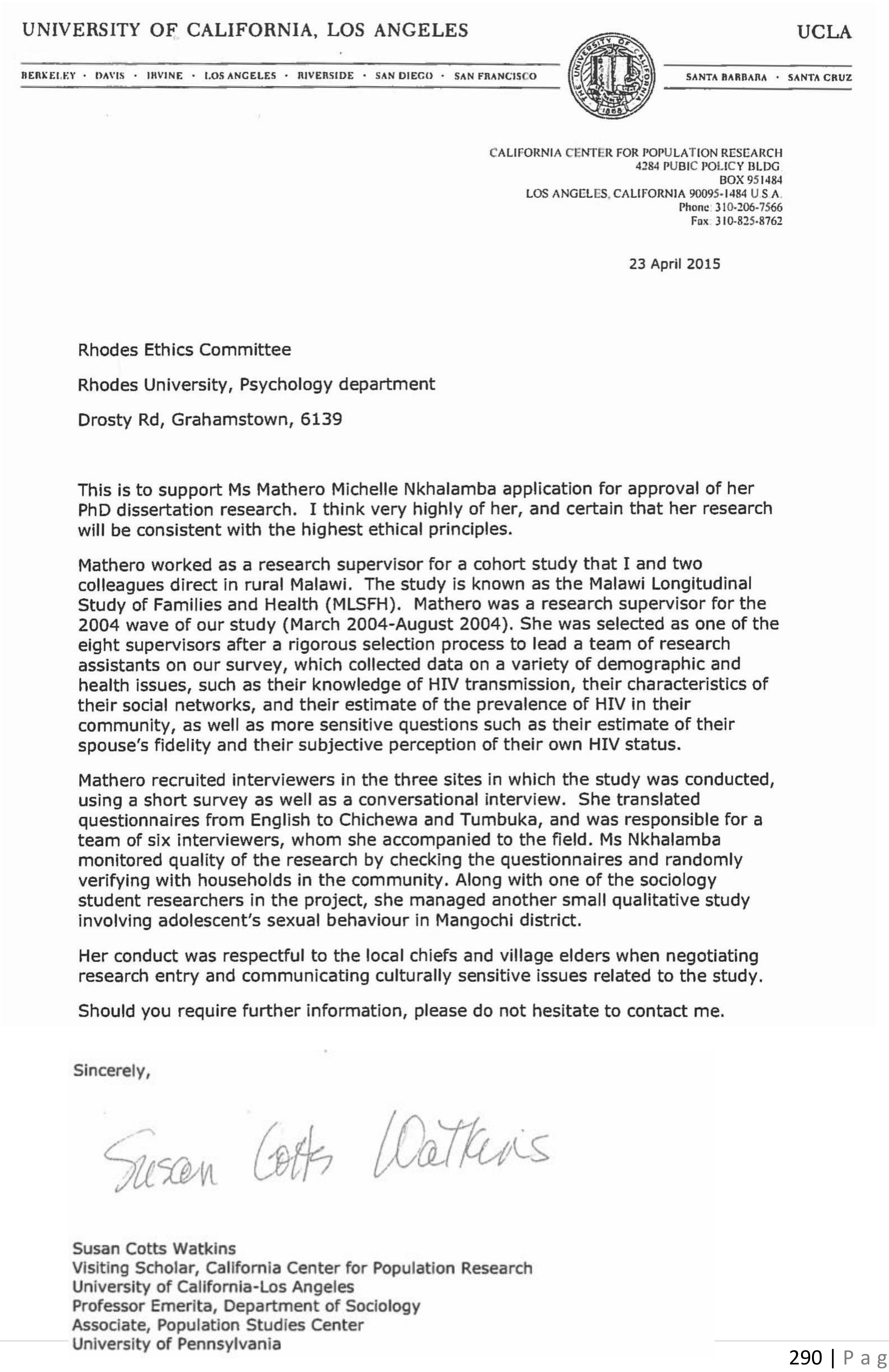
Register of **CLINICAL PSYCHOLOGISTS**
kept by the Medical Council of Malawi in accordance with the provisions of the Medical Practitioners and Dentists Act, 1987, and the Regulations made thereunder.

Chairman

Registrar

I certify this to be a true copy of the original hereof
03/03/15
VUYOKAZI GONTSHI
FACULTY LIBRARIAN
Commissioner of Oaths, Cacadu District
Rhodes University, Drostdy Road Grahamstown 6139

APPENDIX 7: RESEARCH EXPERIENCE REFERENCE LETTER



UNIVERSITY OF CALIFORNIA, LOS ANGELES UCLA

BERKELEY · DAVIS · IRVINE · LOS ANGELES · RIVERSIDE · SAN DIEGO · SAN FRANCISCO SANTA BARBARA · SANTA CRUZ

CALIFORNIA CENTER FOR POPULATION RESEARCH
4284 PUBIC POLICY BLDG
BOX 951484
LOS ANGELES, CALIFORNIA 90095-1484 U.S.A.
Phone: 310-206-7566
Fax: 310-825-8762

23 April 2015

Rhodes Ethics Committee

Rhodes University, Psychology department

Drosty Rd, Grahamstown, 6139

This is to support Ms Mathero Michelle Nkhalamba application for approval of her PhD dissertation research. I think very highly of her, and certain that her research will be consistent with the highest ethical principles.

Mathero worked as a research supervisor for a cohort study that I and two colleagues direct in rural Malawi. The study is known as the Malawi Longitudinal Study of Families and Health (MLSFH). Mathero was a research supervisor for the 2004 wave of our study (March 2004-August 2004). She was selected as one of the eight supervisors after a rigorous selection process to lead a team of research assistants on our survey, which collected data on a variety of demographic and health issues, such as their knowledge of HIV transmission, their characteristics of their social networks, and their estimate of the prevalence of HIV in their community, as well as more sensitive questions such as their estimate of their spouse's fidelity and their subjective perception of their own HIV status.

Mathero recruited interviewers in the three sites in which the study was conducted, using a short survey as well as a conversational interview. She translated questionnaires from English to Chichewa and Tumbuka, and was responsible for a team of six interviewers, whom she accompanied to the field. Ms Nkhalamba monitored quality of the research by checking the questionnaires and randomly verifying with households in the community. Along with one of the sociology student researchers in the project, she managed another small qualitative study involving adolescent's sexual behaviour in Mangochi district.

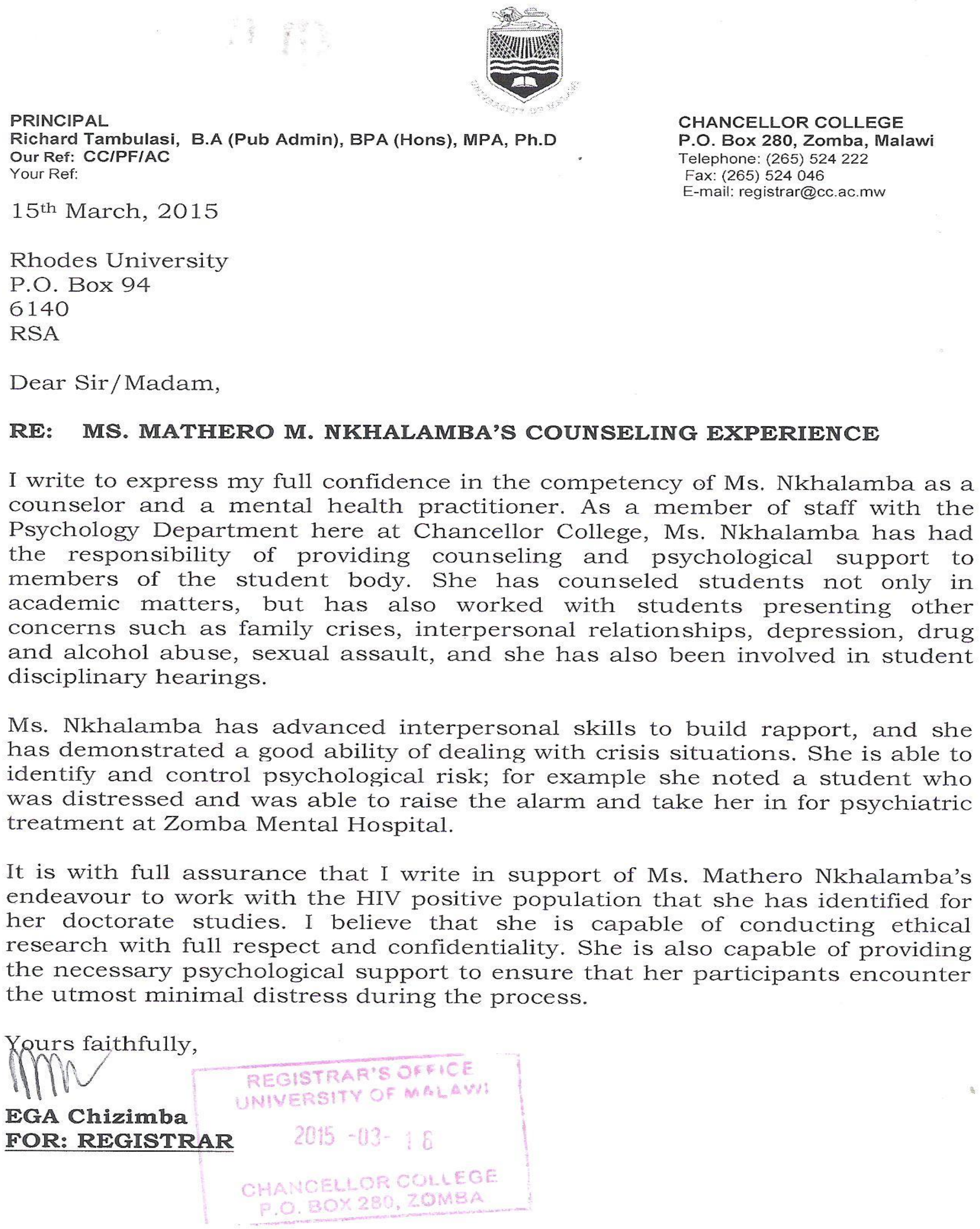
Her conduct was respectful to the local chiefs and village elders when negotiating research entry and communicating culturally sensitive issues related to the study.

Should you require further information, please do not hesitate to contact me.

Sincerely,

Susan Cotts Watkins

Susan Cotts Watkins
Visiting Scholar, California Center for Population Research
University of California-Los Angeles
Professor Emerita, Department of Sociology
Associate, Population Studies Center
University of Pennsylvania



PRINCIPAL
Richard Tambulasi, B.A (Pub Admin), BPA (Hons), MPA, Ph.D
Our Ref: CC/PF/AC
Your Ref:

CHANCELLOR COLLEGE
P.O. Box 280, Zomba, Malawi
Telephone: (265) 524 222
Fax: (265) 524 046
E-mail: registrar@cc.ac.mw

15th March, 2015

Rhodes University
P.O. Box 94
6140
RSA

Dear Sir/Madam,

RE: MS. MATHERO M. NKHALAMBA'S COUNSELING EXPERIENCE

I write to express my full confidence in the competency of Ms. Nkhalamba as a counselor and a mental health practitioner. As a member of staff with the Psychology Department here at Chancellor College, Ms. Nkhalamba has had the responsibility of providing counseling and psychological support to members of the student body. She has counseled students not only in academic matters, but has also worked with students presenting other concerns such as family crises, interpersonal relationships, depression, drug and alcohol abuse, sexual assault, and she has also been involved in student disciplinary hearings.

Ms. Nkhalamba has advanced interpersonal skills to build rapport, and she has demonstrated a good ability of dealing with crisis situations. She is able to identify and control psychological risk; for example she noted a student who was distressed and was able to raise the alarm and take her in for psychiatric treatment at Zomba Mental Hospital.

It is with full assurance that I write in support of Ms. Mathero Nkhalamba's endeavour to work with the HIV positive population that she has identified for her doctorate studies. I believe that she is capable of conducting ethical research with full respect and confidentiality. She is also capable of providing the necessary psychological support to ensure that her participants encounter the utmost minimal distress during the process.

Yours faithfully,

EGA Chizimba
FOR: REGISTRAR

REGISTRAR'S OFFICE
UNIVERSITY OF MALAWI
2015 -03- 18
CHANCELLOR COLLEGE
P.O. BOX 280, ZOMBA

APPENDIX 8: COUNSELLING EXPERIENCE REFERENCE LETTER

APPENDIX 9: CONSENT FORM: ENGLISH VERSION

PARTICIPANT AGREEMENT/CONSENT FORM ENGLISH VERSION

Title of Study: Experiences of Women living with HIV attending Tisungane HIV clinic in Southern Malawi: An Interpretative Phenomenological Analysis

Institution: Rhodes University

Investigators: Mathero Michelle Nkhalamba, Supervisor: Prof. Charles Young

1.	I confirm that I have read and understood the information about the study which is being conducted as part of a PhD in Psychology, as provided in the information sheet	☐
2.	I have been given the opportunity to ask questions about the study and my participation.	☐
3.	I have been given information on whom I can contact if I have questions or concerns about the study.	☐
4.	I voluntarily agree to participate in the study investigating the experiences of women living with HIV in Malawi	☐
5.	I understand that I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn. I have also been assured that my withdrawal will not affect my receiving treatment at this clinic.	☐
6.	The procedures regarding confidentiality and privacy have been clearly explained to me. I understand that quotations that will be used in the publications will not be attached to my name.	☐
7.	I agree to the interview being audio recorded.	☐
8.	The use of the data in research, publications, sharing and archiving has been explained to me.	☐
9.	I, along with the Researcher, agree to sign and date this informed consent form.	☐

________________________ ____________________ __________

Participant’s name/thumb [print] Participant’s signature Date

________________________ ____________________ __________

Researcher’s name [print] Researcher’s signature Date

APPENDIX 10: CONSENT FORM: CHICHEWA VERSION

PARTICIPANT AGREEMENT/ CONSENT FORM CHICHEWA VERSION

MGWIRIZANO WA AKAFUKUFUKU NDI OTENGA NAWO MBALI

Title of Study: Experiences of Women living with HIV attending Tisungane HIV clinic in Southern Malawi: An Interpretative Phenomenological Analysis

Institution: Rhodes University

Investigators: Mathero Michelle Nkhalamba, Supervisor: Prof. Charles Young

1.	Ndikutsimikiza kuti ndawerenga ndipo ndamvetsetsa ndondomeko za kafukufukuyu, zimene zaperekedwa mchikalata cha ndondomeko, ndiponso kuti kafukufuku ndi gawo la maphunziro a PhD	☐
2.	Ndapatsidwa mwayi ofunsa mafunso omwe ndingakhala nawo okhudzana ndi kafukufuyu ndi kutenga nawo mbali kwanga.	☐
3.	Ndawuzidwa amene ndingakumane nawo patakhala mafunso kapena zondikhudza pa kafukukukuyi.	
4.	Ndavomera mwakufuna kwanga kutenga nawo mbali mu kafukufukyu.amene akufufuza za azimayi amene ali ndi HIV	☐
5.	Ndamvetsetsa kuti ndikhoza kusiya kutenganawo mbali mukafukufukuyu nthawi ina iliyonse popanda kupereka zifukwa ndipo kuti sindidzaimbidwa mlandu chifukwa chosiya kutenganawo mbali olo kapena ndidzafunsidwa chifukwa chimene ndasiyira kutenga nawo mbali. Ndatsimikizidwanso kuti kusiya kutenga nawo mbali sikudzakhudzana ndi chithandizo chimene ndimalandira mu kiliniki	☐
6.	Ndondomeko yokhudzana ndi chinsinsi yafotokozeredwa momveka kwa ine. Ndamvetsetsa kuti zonenedwa zamukafukufukuyu panthawi yowulutsa sizidza sonyeza dzina langa.	☐
7.	Ndavomera kuti zokambirana zathu zidzajambulidwe.	☐
8.	Kagwiritsidwe ntchito ka zokambirana ndi zotsatira za kafukufuku, ndi kasungidwe kake za fotokozeredwa kwa ine.	☐
9.	Ine, ndi ofufuzawa, tagwirizana kuti tiyika chidindo/sayini ndi tsiku pachikalata cha chilolezochi.	☐

Mgwirizano wa otenga nawo mbali

_______________________________ ______________________ ___________

Dzina la otenga nawo mbali [Dinda] Sayini ya otenga nawo mbali Tsiku

_______________________________ ______________________ __________

Dzina la ogwira mu kafukufuku [Dinda] Sayini ya Ogwira mu kafukufuku Tsiku

APPENDIX 11: FEEDBACK FORM: ENGLISH VERSION

FEEDBACK FORM: ENGLISH VERSION

Title of Study: Experiences of women living with HIV attending Tisungane HIV clinic in Southern Malawi: An Interpretive Phenomenological Analysis (IPA)

Institution: Rhodes University

Investigators: Mathero Michelle Nkhalamba, Supervisor: Prof. Charles Young

Thank you for agreeing to participate in this study! The general purpose of this research is to understand the lived experiences of women who are living with HIV. We invited women who are have been living with HIV for over one year and attending the Tisungane HIV clinic. In this study, you were asked to describe the challenges you encountered after receiving an HIV diagnosis and how you cope with the challenges including other issues that concern you. The results of the study will help in understanding how organizations and government can support women living with HIV in Malawi.

What if I want to know more?

If you have further questions about the study, please contact:

Mathero Michelle Nkhalamba, Rhodes University, Department of Psychology, P.O Box 94, Grahamstown, 6140. South Africa email:mnkhalamba@gmail.com Tel: 0994391472

Prof. Charles Young, Rhodes University, Department of Psychology, P.O Box 94, Grahamstown, 6140. South Africa +27(0)46603-8541 email:cyoung@ru.ac.za

Dignitas International Malawi, P.O Box 1071, Zomba, +265(0)1525 420

National Commission for Science and Technology, National Health Sciences Research Committee Lingadzi House, City Centre, Private Bag B303, Lilongwe, Malawi. +2651771550 email: director general@ncst.mW

APPENDIX 12: FEEDBACK FORM: CHICHEWA VERSION

FEEDBACK FORM: CHICHEWA VERSION

Title of Study: Experiences of women living with HIV attending Tisungane clinic in Southern Malawi: An Interpretive Phenomenological Analysis (IPA)

Institution: Rhodes University

Investigators: Mathero Michelle Nkhalamba, Supervisor: Prof. Charles Young

Zikomo povomera kutenga nawo mbali mu kafukufukuyu! Cholinga cha kafukufukuyi ndikufuna kumvetsetsa kakhalidwe ka azimayi amene anapezeka ndi kachilombo ka HIV komanso zomwe amakumana nazo pa moyo wawo wa tsiku ndi tsiku.

Tikuyitana azimayi amene, apezeka, ndipo akhala ndi kachilombo ka HIV kupyolera chaka chimodzi.Mukafukufukuyu, munapemphedwa kuti mufotokoze zovuta zimene mwakumana nazo kuchokera pamene munapezeka ndi kachilombo ka HIV, ndimmene mumakwanitsa kukhala ndi zovutazo, ndi mavuto ena okhukudzani. Zotsatira zakafukufukuyu zithandizani kuti tidziwe ndi kumvetsa momwe ma mabungwe ndi boma linga perekere thandizo loyenera kwa azimayi amene ali ndi kachilombo ka HIV mudziko lino.

Nanga nditafuna kudziwa zambiri?

Ngati muli ndi mafunso ena okhudzana ndi kafukufukuyu, chonde imbirani:

Mathero Michelle Nkhalamba, Rhodes University, Department of Psychology, P.O Box 94, Grahamstown, 6140. South Africa email:mnkhalamba@gmail.com 0994391472

Prof. Charles Young, Rhodes University, Department of Psychology, P.O Box 94, Grahamstown, 6140. South Africa +27(0)46603-8541 email:cyoung@ru.ac.za

Dignitas International Malawi, P.O Box 1071, Zomba, +265(0)1525 420

National Commission for Science and Technology, National Health Sciences Research Committee Lingadzi House, City Centre, Private Bag B303, Lilongwe, Malawi. +2651771550 email: director general@ncst.mw

APPENDIX 13: INFORMATION SHEET: ENGLISH VERSION

INFORMATION SHEET

Title of Study: Experiences of Women living with HIV attending Tisungane Clinic in Southern Malawi: An Interpretative Phenomenological Analysis

Institution: Rhodes University

Investigators: Mathero Michelle Nkhalamba, Supervisor: Prof. Charles Young

Why is this study being done?

This research is being conducted as part of the requirements for a PhD degree at Rhodes University. The purpose of this research study is to explore the experiences that women go through upon receiving an HIV diagnosis and how they cope thereafter.

What will happen today if I take part in this study?

If you agree to take part, you will be asked to talk about your life describe how you felt when you received the news of your HIV diagnosis the challenges you are facing and your current life situation. I will record your answers on paper and on a digital recorder.

How will my privacy be protected?

All information gathered will be treated as confidential and records of the interviews will be kept securely on password protected computers. No personal identification information such as names will be used in any reports arising out of this research. Although your quotations will be used, you will not be identified in any publication about this study.

How many subjects will take part in this study?

If you decide to take part, you will be one of the approximately 15 women in this research study.

How long will the study last?

Today, the interview will last about 60-90 minutes.

Are there any reasons you should not take part?

You do not have to take part in this study if you feel uncomfortable to talk about your HIV diagnosis and experiences of living with HIV. You may also choose to not take part if you are not comfortable discussing your HIV status.

What are the possible risks or discomforts?

Some of the questions that I will ask you may make you feel upset or uncomfortable and there is a chance that you will feel worried that I will tell other people what you share with me in the interview. Please be assured that I will not record your full name or other identifying information, so that your confidentiality is secure. The information obtained from these interviews will only be used by the researcher.

Are there benefits to taking part in the study?

If you take part in this study, you will have the chance to share your opinions and experience which might help in improving support given to women living with HIV. The information collected in the study will be used to know about the challenges women living with HIV face and how we can help researchers and policy-makers understand how best to improve care for women in Malawi.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you. It will not affect any care that you seek at this clinic, now or in the near future.

What are the costs of taking part in this study? Will I be paid for taking part in this study?

There are no costs to you for taking part in this study. You will not be paid for taking part in the study. However, you will be given an allowance towards transport and meals.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may change your mind at any time. No matter what decision you take, there will be no penalty to you in any way.

Who can answer my questions about the study?

You can talk to the researcher about any questions or concerns you have about this study.

What if you have questions about your rights as a participant?

This research has been reviewed and approved by and the Rhodes University, National Health Science Research Ethics Committee in Malawi. If you have any questions or concerns regarding your rights as a research participant, you can use the details in the feedback form to contact the relevant authorities.

Giving consent to participate in the study

You may keep this information sheet if you wish. You have the right to decline to participate in the study, or to withdraw from it at any point without penalty. If you do wish to participate in this study, you should tell the researcher now. If you do not agree to quotes or other results arising from your participation in the study being included, even anonymously, in any reports about the study, please tell the researcher now. If you have any questions, you may ask them now.

APPENDIX 14: INFORMATION SHEET: CHICHEWA VERSION

INFORMATION SHEET: CHICHEWA VERSION

ZOYENERA KUDZIWA ZOKHUDZANA NDI KAFUKUFUKUYI

Title of Study: Experiences of Women living with HIV attending Tisungane HIV clinic in Southern Malawi: An Interpretative Phenomenological Analysis

Chifukwa chani kafukufukuyu akupangidwa?

Kafukufukuyu akupangidwa ngati gawo lamaphunziro azau Dokotola ku Rhodes University. Cholinga cha kafukufukuyu ndi kufufuza zimene azimayi amakumana nazo akadziwa kuti ali ndi kachilombo ka HIV ndimmene amakhalira kupita patsogolo.

Kodi chichitike ndichani lero ngati nditenge nawo mbali mu kafukufukuyu?

Ngati muvomere kutenga nawo mbali mudzapemphedwa kuti mukambe za moyo wanu, kufotokoza za mmene mudamvera mutamva kuti muli ndi kachilombo ka HIV, mavuto amene mukukumana nawo ndi mmene mukukhalira panopa. Ndilemba mayankho anu komaso ndijambula mawu anu.

Kodi chinsinsi changa chidzatetezedwa bwanji?

Zokambirana zonse zimene zitengedwe zidzasungidwa mwachinsinsi ndipo zojambula za zokambirana zidzasungidwa mu makina a kompyuta amene adzatetezedwe kuti munthu wina asathe kuwona zomwe zili pa makinawa. Palibe zokuzindikiritsani, ngati dzina, zimene zidzagwiritsidwe ncthito mu zowulutsa za kafukufukuyu. Ngakhale zolembedwa za mau anu zidzagwiritsidwe ncthito, simudzatchulidwa mu zoulutsa zakafukufukuyu.

Kodi ndi anthu angati amene atenge nawo mbali mukafukufukuyu?

Ngati mupange chiganizo chotenga nawo mbali, mudzakhala mmodzi mwa azimayi pafupifupi khumi ndi asanu (15) amene atenge nawo mbali mu kafukufukuyi.

Kodi Kafukufukuyu atenga nthawi yayitali bwanji?

Lero, zokambirana zitenga pafupifupi mphindi pakati pa makumi asanu ndi imodzi ndi makumi anayi. (60-90 Minutes)

Kodi pali zifukwa zina zimene simungatengere nawo mbali?

Simukuyenera kutenga nawo mbali mu kafukufukuyu ngati mukusowa mtendere ndi kufotokoza za mmene mudapezekera ndi HIV komanso ndi mmene mwakhalira ndi ka chilombo ka HIV. Mukhozanso kusankha kusatenga nawo mbali ngati simuli omasuka kufotokoza za kupezeka kwanu ndi kachilombo ka HIV.

Kodi pali zovuta kapena zosowetsa mtendere zanji ndikatenga nawo mbali mu kafukufukuyi?

Mafunso ena amene nditakufunseni akhoza kukukhumudwitsani kapena kukusowetsani mtendere komanso pali mpata oti mwina mukhoza kuda nkhawa kuti ndikhoza kukafotokozera ena zimene takambirana mukafukufukuyu. Chonde, mukutsimikiziridwa kuti sindidzalemba dzina lanu kapena zokuzindikiritsani kuti chinsinsi chanu chisungidwe. Zokambirana zimene zitengedwe mukafukufukuyu zidzagwiritsidwa ncthito ndi okhawo amene akufufuza mu kafukufukuyu.

Kodi pali phindu pakutenga nawo mbali mu kafukufukuyu?

Ngati mutenge nawo mbali mukafukufukuyu, mukhala ndi mpata ofotokoza maganizo anu ndi pa zimene mwakumana nazo, zimene zingathandize umoyo wa azimayi amene ali ndi kachilombo ka HIV. Zokambirana zimene zitengedwe mu kafukufukuyu zidzagwiritsidwa ntchito kudziwa za mavuto amene azimayi amene ali ndi kachilombo ka HIV amakumana nawo ndi mmene zingathandizire afufuzi ndi opanga malamulo kumvetsetsa mmene anga pititsire patsogolo kasamalidwe ka azimayiwa Mmalawi.

Pali zisankho zina zanji zimene ndingakhale nazo ngati sinditenga nawo mbali mu kafukufukuyu?

Muli omasuka kusankha kusatenga nawo mbali mu akafukufuyu. Ngati mwaganiza kusatenga nawo mbali mukafukufukuyu, sipadzakhala mulandu wina uliwonse kwa inu. Sizidzakhudza chithandizo chimene mumalandira pa chipatala chino.

Pali zolipira zanji potenga nawo mbali mukafukufukuyu? Ndidzalipiridwa potenga nawo mbali mukafukufukuyu?

Palibe zolipira potenga nawo mbali mukafukufukuyu. Simudzalipiridwa mukatenga nawo mbali mukafukufukuyu. Koma, mudzapatsidwa kangachepe ya mayendedwe ndi chakudya.

Kodi Ufulu wanga ndi chani ngati nditatenga nawo mbali mu kafukufukuyu?

Kutenga nawo mbali mukafukufukuyu ndi chisankho chanu. Mukhoza kusankha kutenga nawo mbali kapena kusatenga nawo mbali mu kafukufukuyu. Ngati mwapanga chiganizo choti mutenga nawo mbali mukafukufukuyu, mukhoza kusintha maganizo anu pa nthawi ina iliyonse. Chiganizo chimene mutapange, sipadzakhala mlandu kwa inu munjira ina iriyonse.

Ndani angayankhe mafunso anga okhudzana ndi kafukufuku?

Mukhoza kuyankhula ndi afufuzi pa mafunso ena aliwonse amene mungakhale nawo okhudzana ndi kafukufuku.

Nanga nditakhala ndi mafunso okhudzana ndi ufulu wanga ngati otenga nawo mbali?

Kafukufukuyu wawonedwa ndi kutsimikiziridwa ndi a Rhodes University ku South Africa ndi bungwe la National Health Science Research Ethics Committee kuno ku Malawi. Ngati muli ndi mafunso okhudzana ndi ufulu wanu ngati otenga nawo mbali mu kafukufuku, mukhoza kugwiritsa ntchito manambala ali mu chikalata chofotokozera mwachidule za kafukufukuyu, kuti mulumikizane ndi mabugwe oyenera.

Kupereka chilolezo chotengera nawo mbali mukafukufuku.

Mukhoza kusunga chikalatachi mutafuna.Muli ndi ufulu okana kutenga nawo mbali mukafukufukuyu, kapenanso osiya panthawi ina iriyonse popanda mulandu. Ngati simukufuna kutenga nawo mbali mukafukufukuyu, muwafotokozere afufuzi panopa.Ngati simukugwirizana ndi zoti zokamba zanu kapena zotsatira zina zokhudzana ndi kutenga nawo mbali kwanu mu kafukufukuyu, zidzaikidwe, ngakhale mwachinsinsi, mu zotulutsidwa za kafukufukuyu, chonde awuzeni afufuzi panopa. Ngati muli ndi mafunso aliwonse, mukhoza kufunsa panopa.

APPENDIX 15: INTERVIEW TOPIC GUIDE: ENGLISH VERSION

INTERVIEW TOPIC GUIDE ENGLISH VERSION

Title: Experiences of Women living with HIV attending Tisungane HIV clinic in Southern Malawi: An Interpretative Phenomenological Analysis

Institution: Rhodes University

Investigators: Mathero Michelle Nkhalamba, Supervisor: Prof. Charles Young

Participant ID NO |__|__|__|__| Date |__|__/__|__/__|__|

My name is Mathero Nkhalamba. Thank you very much for showing interest in participating in the study.

I am expecting to hear you views about the questions that I will ask you. There is no right or wrong answer I will take every answer that you give as regards to what you have been experiencing.

Before we start can you express verbally to the audio recording that you have signed a letter agreeing to take part in the study.

As I mentioned earlier, I want to assure you that what we discuss here is confidential and your identity will not be revealed or linked to what has been discussed in this interview.

Warm up [demographic]

Can I ask some details about you and your job or what you do for a living?

Job Title/Occupation _____________________________

Highest Educational Qualification attained ___ __   Year of graduation____________

Are you originally from this area/district?   ☐ Yes   ☐ No (if No) ....

How old are you?   ……………………………………………

Do you have any children?   ☐ Yes ☐ No

(If yes) How many children do you have? …………………………………

Are you married? ………………………………

Tell me about your medical situation……………………

First interview: Life history interview	
1. **Birth and family origin:** • Do you remember anything about your first year of life? • What is your earliest memory?	***Possible probe topics:*** • Are there any family stories told about you as a baby? • What characteristics do you remember most about your parents and grandparents?
2. **Cultural setting and traditions:** • What is the ethnic or cultural background of your parents? • What are some early memories of	***Possible probe topics:*** • What family or cultural celebrations, traditions, or rituals were important in your life? • Was religion important in your family?

cultural influences?	
3. Social factors: • Did you feel nurtured as a child? Tell me about your childhood? • What social pressures have you experienced as an adult?	***Possible probe topics***: • What were some of your struggles as a child? • Did you get along with your family members? • What pressures did you feel as a child and where did they come from? • How was discipline handled in your family? • How would you describe your relationship with your family (friends, neighbours and community).
4. Education: • What is your first memory of attending school? • How far did you go with your formal education?	***Possible probe topics:*** • What factors influenced the level of education that you have?
5. Love and work: • Do you remember the first time you had a serious relationship?	***Possible probe topics:*** • How would you describe your courtship? • What has been the best and worst parts of your relationship?
6. Inner life and spiritual awareness: • What primary beliefs guide your life?	***Possible probe topics:*** • How does your spiritual values and beliefs affect how you live your life? • Do you feel you are in control of your life?
7. Major life themes: • What has been the most important learning experience in your life? • How do you feel about yourself and the age you are at now?	***Possible probe topics:*** • How have you overcome or learned from your difficulties. • How do you handle disappointment? • What has been your greatest accomplishment?
8. Closure questions: • Is there anything we have left out of your life story?	

Second interview	
1. **HIV diagnosis:** I would like to know more about how you learnt about your diagnosis. • What was it like for you before your diagnosis? • Do you know how you contracted the virus?	***Possible probe topics***: • How did you find out that you were positive? • What kind of emotions did your diagnosis evoke in you? • Were you surprised by the diagnosis? • How did you deal with the news? • Have you disclosed your diagnosis to community and friends?
2. Impact of the diagnosis: • How has your HIV status impacted your life? (socially, financially, lifestyle).	***Possible probe topics:*** • How has the diagnosis impacted your day to day life? • How has the diagnosis impacted the interaction with your family and community? • How did the people around you react to your diagnosis?
3. Living with HIV: • What changes have you made since being diagnosed with HIV?	***Possible probe topics*:** • What routine do you do to take care of your health?

	- How do you manage living with HIV?
4. **Adherence:** - Tell me about your experience of taking ARV drugs.	***Possible probe topics:*** - When did you start attending the clinic?
5. **Challenges:** - Can you explain the challenges you have experienced because of being diagnosed with HIV? - What challenges have you and your family faced as a result of your HIV positive status? (social, financial, leisure activities).	***Possible probe topics:*** - How do you cope with those challenges?
6. **Disclosure:** - How did you disclose your status? - How did you disclose to your family? - Have you disclosed your status to your partner?	***Possible probe topics:*** - How would you describe the reaction of your family and friends after hearing the results? - Did you have the test with your partner? - Were you already married? How is he coping? - Do you think your family is closer now than before your disclosure?
7. **Family and relationships:** - What is your relationship like with family members? - What is your relationship life with your husband? - How did the relationships change with the diagnosis?	***Possible probe topics*:** - Do you feel they have accepted you? - How did your family receive the news? - How did the community treat you?
8. **SRH services:** What is your experience of family planning services?	***Possible probe topics*:** - Do you experience pressure to have children? - Do you have access to reproductive health services? - Have you been on Option B+? What was your experience?
9. **HIV Stigma and acceptance:** - Have you experienced stigma because of your HIV status? - Has your family, community accepted your status?	***Possible probe topics:*** - What did you think of HIV positive people before you were diagnosed with HIV? - What do you think of HIV people now that you know your status?
10. **Access to treatment and support:** - Do you have access to the treatment you need? - What services have been offered to you? **Coping:** How do you cope with living with HIV?	***Possible probe topics:*** - What kind of support do you have (e.g. family, friends, and support groups). - How were you coping in the past?

Third interview *(In this interview we will be referring to most of the issues you spoke about during our last conversation*)	
1. Are there things from the last time we spoke that you would like to explain in more detail?	***Possible probe topics:*** - Is there something you have remembered since that time? Do you need to clarify anything?
2. What does living with HIV mean to you?	***Possible probe topics:*** - As someone living with HIV, how do you see yourself? Is there anything you would like to share about living with HIV?
3. From what you have explained about having HIV, what do you think about your future?	***Possible probe topics***: - What are you planning for your future? - What do you see for yourself in the next 5 to 15 years?
4. Looking back, how differently would you have dealt with the situation after you had your diagnosis.	***Possible probe topics*:** - How do you feel you handled the news?
5. What worries you most about being HIV positive?	***Possible probe topics*:** - What do you do when you feel worried?
6. How do you feel about taking medication and adhering to it throughout your life time?	***Possible probe topics*:** - Are there any challenges as regards to adhering to medication?
7. What do you think about the reaction of your family to your diagnosis?	***Possible probe topics*:** - How comfortable do you feel with your family and community about your diagnosis?
8. Can you suggest what could be done to make sure that you are coping better with the challenges you face.	***Possible probe topics:*** - Are there any support groups that you attend?
9. What do you think about stigma against people living with HIV?	***Possible probe topics:*** - What can be done to prevent people living with HIV being stigmatised?

APPENDIX 16: INTERVIEW TOPIC GUIDE: CHICHEWA VERSION

INTERVIEW TOPIC GUIDE: CHICHEWA VERSION

Title: Experiences of Women living with HIV attending Tisungane HIV Clinic in Southern Malawi: An Interpretative Phenomenological Analysis

Otenga mbali ID NO |__|__|__|__| Date |__|__/__|__/__|__|

Zikomo kwambiri powonetsa chidwi chotenga nawo mbali mu kafukufukuyu.

Ndikuyembekeza kumva maganizo anu pa mafunso amene ndikufunseni. Palibe yankho lokhoza kapena lolakwa. Nditenga yankho lililonse limene mundipatse kukhudzana ndi zimene mwakumana nazo.

Tisanayambe, munga fotokoze mu mau anu pa cho jambula mau kuti mwa sayina chikalata chovomereza za kutenga nawo mbali kwani mu kafukufukuyu.

Monga momwe ndinafotokozera payamba, ndifuna ndikutsimikizireni kuti zokambirana zanthu zikhala za chinsinsi ndipo zokuzindikiritsani sizidza perekedwa kapena kukulumikizani ku zimene takambirana mu zokambiranazi.

Warm up [demographic]

Ndingakudziweni komanso ndingadziwe za ntchito yomwe mumagwira yomwe mumapeza ndalama ya chisamaliro tsiku ndi tsiku?

Mumagwira ntchito yanji ____________________________

Mapepala asukulu pamene munalekezera___ __ chaka chomalizira sukulu____________

Mumachokera ku Zomba kuno/Boma? ☐ Eya ☐ Ayi (ngati ayi)

Muli ndi zaka zingati? ……………………………………………

Muli ndi ana? ☐ Eya ☐ Ayi

(Ngati eya) Muli ndi ana angati? …………………………………

Kodi ndinu okwatiwa? ………………………………
Mungandiwuze za umoyo wanu?……………………

Ndime yoyamba ya kucheza	
1. **Kobabwila ndi mbili ya banja:** - Kodi mukukumbukura chinachirichonse za chaka choyamba cha moyo wanu? - Mukukumbukira chani pa mbili ya banja lanu?	***Kufusitsitsa:*** - Pali nkhani zimene banja lanu limakambako za mmene munali ang'ono? - Mumakumbukira zinthu ngati chiyani za makolo anu ndi agogo anu?
2. **Chikhalidwe ndi Miyambo:** - Makolo anu ndi achikhalidwe, kapena tinene kuti mtundu wanji? - Pali zomwe mumakumbukira za chikhalidwe chanu muli ang'ono.	***Kufusitsitsa:*** - Ndi zikodwelero , madyelero ndi miyambo yanji yokudzana ndi chikhalidwe chanu yomwe inali yofunikira pa moyo wanu mukukula? - Chipembedzo chinali chofunikira mbanja mwanu?
3. **Za chikhalidwe**: - Mmene munali angóno ankakuyanganirani bwino? - Tandiuzani za kuubwana wanu. - Mmene mwakulamu, pali zinthu zomwe mumawona kuti mumapanga chifukwa cha anthu ena?	***Kufusitsitsa:*** - Kodi mumakumana ndi zovuta zanji muli a n'gono? - Mumagwirizana bwino bwino ndi anthu a mbanja lanu? - Kodi pali zinthu zomwe mumapanga chifukwa cha ena muli ang'ono ndipo zimazchokera kuti?? - Kodi mwambo mbanja mwanu unkayendetsedwa bwanji? - Mumakhala bwanji ndi anthu ambanja mwanu (anzanu, oyandikana nawo ndi anthu

	ammudzimo?)
4. **Maphunziro:** • Kodi mumakumbukira chani za nthawi yomwe munkayamba sukulu? • Sukulu munalekezera pati?	***Kufusitsitsa:*** • Ndizifukwa zanji zomwe zinapangitsa kuti mu lekeze sukulu pamene munalekezerapo?
5. **Chikondi ndi Ntchito**: • Mungakumbukire nthawi yomwe munakhala ndi chibwenzi choyamba chokhazikika?	***Kufusitsitsa:*** • Munganenepo chani za ubwenzi wanuwu? • Ndichiyani chimene chinali chabwino kwambiri ndi zovuta pa ubwenzi wanuwo?
6. **Moyo wauzimu**: • Mungafotokoze chikhulupiliro chomwe chimatsogolera ndikuunikira moyo wanu?	***Kufusitsitsa:*** • Moyo wanu wa uzimu umathandiza bwanji pa moyo wanu wa tsiku ndi tsiku? • Muli ndi chikhulupiliro kuti mumayendetsa mwanokha moyo wanu?
7. **Zazikulu zochitika pa moyo wanu:** • Pali zomwe munakumana nazo zomwe munatengapo phunziro la moyo wanu? • Mukuwuwona bwanji moyo wanu ndi zaka zomwe muli nazo pakali pano?	***Kufusitsitsa:*** • Munathana bwanji kapena kuphunzirapo chani pa zovuta zomwe munakumana nazo? • Mukakumana ndi zokhumudwitsa, mumatani? • Kodi chani chomwe munapangako chachikulu ndi chabwino kwambiri pa moyo wanu?
8. **Funso lotseka**: • Pali china chomwe tasiya pa nkhani ya moyo wanu?	

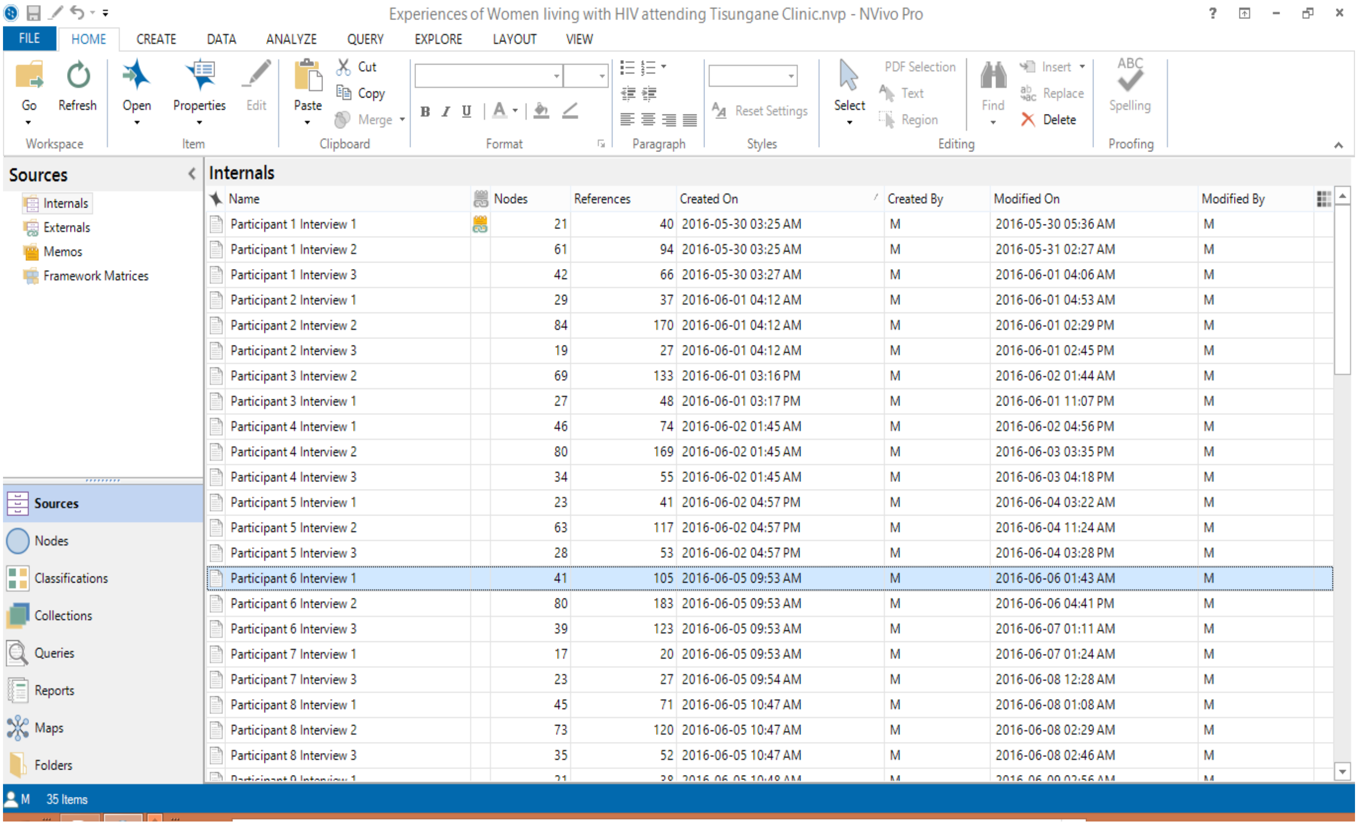
Ndime yachiwiri yocheza	
1. **Kupezeka ndi HIV:** Ndikufuna ndidziwe zambiri za nthawi imene munadziwa koyamba kuti muli ndi HIV. • Kodi zinthu zinali bwanji musanadziwe za zotsatirazi? • Mukudziwa momwe munatengera HIV?	***Kufusitsitsa:*** • Munadziwa mu njira yanji kuti muli ndi HIV? • Munamva bwanji muntima mwanu mutamva zotsatirazi? • Kodi munali odabwa ndi zotsatirazi? • Muna panga chani mutamva zoti uthengawu? • Kodi munawazuwa anthu a mmudzi mwanu ndi anzanu za zotsatirazi?
2. **Magwero/Zochitika atakupezani ndi HIV**: • Kupezeka ndi HIV kwasintha bwanji moyo wanu monga ku mbali ya (moyo wanu ndi anzanu, zachuma/ndalama zanu/ umoyo wanu watsiku ndi tsiku).	***Kufusitsitsa:*** • Kodi zotsatirazi zasintha bwanji moyo wanu watsiku ndi tsiku. • Kodi zotsatirazi zasintha bwanji moyo wanu ndi banja lanu ndi anthu mmudzi/malo amene mumakhala? • Kodi anthu amene mumakhala nawo atamva zotsatirazi analandira bwanji uthengawo ndipo anasintha bwanji?
3. **Moyo wokhala ndi HIV:** Mwasintha moyo wanu mwantundu wanji chipezekereni ndi kachilombo ka HIV.	***Kufusisitsa:*** • Mumapanga zinthu zanji kuti musamalire umoyo wanu? • Mumakwanitsa bwanji kukhala ndi HIV?
4. **Kumwa mankhwala**: • Mungandifotokozere zimene mwakumana nazo pamene mukumwa ma ARVs.	***Kufusitsitsa:*** • Munayamba liti kubwera kuchipatala kuno?
5. **Zovuta**: • Mungandifotokozere zovuta zomwe mwakumananazo chifukwa chopezeka ndi HIV? • Mungandifotokozere zovuta zimene inu ndi banja lanu mwakumana nazo chifukwa cha zotsatira zoti muli ndi kachilombo ka HIV?	***Kufusitsitsa:*** • Mavuto amenewa mumathana nawo bwanji?

(ndi anthu okhala nawo, zachuma ndi zomwe mu machita kuti muzisangalatse).	
6. Kubwera poyela/kufotokozera anthu kuti muli ndi HIV? • Munafotokoza bwanji za mmene mulili? • Munawafotokozera bwanji abale anu? • Munawafotokozeara bwanji amuna anu/chibwenzi chanu?	***Kufusitsitsa:*** • Mungandiwuze chimene chinachitika anzanu ndi abale anu atamva zotsatirazi? • Kodi munakayezetsa limodzi ndi amuna/chibwenzi chanu? • Kodi munali muli pa banja kale? Amuna/chibwenzi chanu akukhala bwanji ndi nkhaniyi? • Chiwawuzireni za zotsatirazi, mukuganiza kuti mgwirizano wanu, ndi anthu akubanja kwanu uli bwino kuyerekeza ndi kale?
7. Banja ndi ma ubale ena: • Mungandifotokozere mmene mumakhalira ndi abale anu abanja limodzi? • Mumakhala motani ndi amuna anu/chibwenzi chanu? • Ma ubale amenewa, anasintha bwanji mutapezeka ndi kachilombo ka HIV?	***Kufusitsitsa:*** • Munganene kuti anavomeleza mmene mulili? • A kubanja kwanu, anawulandila uthengawu motani?
8. Zakulera ndi uchembere wabwino • Mungandifotokozera zimene mumakumana nazo mukamafuna chithandizo pa za kulera.	***Kufusitsitsa:*** • Munayamba mwauzidwapo mowirikiza kuti mu beleke ana? • Kodi mumapeza chithandizo cha zakulera? • Munakhala po pa Option B+, mankhwala opatsa azimayi amene ali ndi HIV komanso ali oyembekezera kuti asapatsire mwana osabadwayo HIV? • Mungandi fotokozere mmene zinayendera, zomwe munakumana nazo polandila thandizo limeneli ?
9. Kusankhidwa Kamba kokhala ndi HIV ndi kuvomerezedwa: • Munayamba mwa salidwako chifukwa chakuti muli ndi HIV? • Kodi banja lanu ndi anthu amene mumakhala nawo anavomeleza zakuti muli ndi HIV?	***Kufusitsitsa:*** • Musanadziwe kuti muli ndi HIV, anthu amene ali ndi HIV mumawawona bwanji? • Panopa mmene munadziwa kuti muli ndi HIV, anthu amene ali ndi HIV mumawawona bwanji?
10. Kulandira chithandizo cha mwankhwala: • Kodi mumapeza chithandinzo cha mankhwala choyenelera? • Mungandifotokozere za chithandizo chomwe mumalandira. • **Kukhala mosakwinyilira ndi HIV**: Kodi mumakhala bwanji mmoyo wanu ndi HIV?	***Kufusitsitsa:*** • Mumalandira chilimbikitso/chithandizo chotani kuchokera kwa (banja lanu, abale anu, ma gulu olimbikitsa anthu amene ali ndi HIV?). • Mbuyomu mumakhala bwanji?

Ndime yachitatu ya kucheza *(Tikamba zomwe tinacheza mbuyomu)*	
1. Pali zina zomwe mukufuna kuwonjezera kapena kufotokozera pa zomwe munakamba nthawi yatha yomwe tinacheza?	***Kufusitsitsa:*** • Pali zina zomwe mwakumbukirapo zomwe mungafuna kukamba. Kapena pali zina zomwe mungafune kuyikapo ndemanga?

2. Mungandifotokozere tanthauzo lanu la kukhala ndi HIV?	***Kufusitsitsa:*** - Ngati munthu/mzimayi okuti muli ndi HIV, mumadziwona bwanji/mumadziganizira bwanji: Mungafotokoze zambiri zokhala munthu opezeka ndi HIV?
3. Kuchokera pa zomwe mwandifotokozera zokhala ndi HIV, mumaganiza bwanji za tsogolo lanu?	***Kufusitsitsa:*** - Mukukonzekera chiyani za tsogolo lanu? - Zaka khumi ndi khumi ndi zisanu zikubwerazi, mukudziwona muli pati?
4. Mukayang'ana mbuyomu, kodi pali njira yina yomwe munakapanga mutamva kuti muli ndi kachilombo ka HIV/pamene munalandira zotsatira zanu?	***Kufusitsitsa:*** - Mmene mukuwonera panopa, nkhani yi munayilandira bwanji ndipo munathana nayo bwanji?
5. Kodi chinthu chimene chimakudandawulitsani kwambiri mukaganiza kuti muli ndi HIV ndi chiyani?	***Kufusitsitsa:*** - Mumapanga chiyani mukakhala ndi madandaulo amenewa?
6. Pa nkhani yokuti muzimwa mankhwala moyo wanu onse, mumamva bwanji kapena mumaganiza bwanji za nkhani imeneyi?	***Kufusitsitsa:*** - Pali zovuta zina zokhudzana ndi kumwa mankwalawa mosa dumphitsa?
7. Mumaganiza bwanji kapena mumamva bwanji za mmene aku banja lanu ana panga atamva kuti muli ndi HIV?	***Kufusitsitsa:*** - Muli omasuka bwanji ngati munthu oti ali ndi HIV ndi banja lanu ndi anthu omwe mumakhala nawo?
8. Mukuwona kuti chingachitike ndi chiyani kuti zovuta zomwe mumakumana nazo muzi thana nazo munjira yokuthandizani?	***Kufusitsitsa:*** - Kodi mumakhala nawo mu magulu ena ali wonse okulimbikitsani?
9. Maganizo anu ndiotani pa nkhani yosankha/kusala anthu amene ali ndi HIV?	***Kufusitsitsa:*** - Mungandifotokozere zomwe mukuwona kuti zitha kuthandiza kuti anthu amene ali ndi HIV asamasankhidwe komanso kuti mchitidwe osala anthu amene ali ndi HIV usapitilire.

APPENDIX 17: QSR NVIVO ANALYSIS



Internals

Name	Nodes	References	Created On	Created By	Modified On	Modified By
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Participant 1 Interview 2	61	94	2016-05-30 03:25 AM	M	2016-05-31 02:27 AM	M
Participant 1 Interview 3	42	66	2016-05-30 03:27 AM	M	2016-06-01 04:06 AM	M
Participant 2 Interview 1	29	37	2016-06-01 04:12 AM	M	2016-06-01 04:53 AM	M
Participant 2 Interview 2	84	170	2016-06-01 04:12 AM	M	2016-06-01 02:29 PM	M
Participant 2 Interview 3	19	27	2016-06-01 04:12 AM	M	2016-06-01 02:45 PM	M
Participant 3 Interview 2	69	133	2016-06-01 03:16 PM	M	2016-06-02 01:44 AM	M
Participant 3 Interview 1	27	48	2016-06-01 03:17 PM	M	2016-06-01 11:07 PM	M
Participant 4 Interview 1	46	74	2016-06-02 01:45 AM	M	2016-06-02 04:56 PM	M
Participant 4 Interview 2	80	169	2016-06-02 01:45 AM	M	2016-06-03 03:35 PM	M
Participant 4 Interview 3	34	55	2016-06-02 01:45 AM	M	2016-06-03 04:18 PM	M
Participant 5 Interview 1	23	41	2016-06-02 04:57 PM	M	2016-06-04 03:22 AM	M
Participant 5 Interview 2	63	117	2016-06-02 04:57 PM	M	2016-06-04 11:24 AM	M
Participant 5 Interview 3	28	53	2016-06-02 04:57 PM	M	2016-06-04 03:28 PM	M
Participant 6 Interview 1	41	105	2016-06-05 09:53 AM	M	2016-06-06 01:43 AM	M
Participant 6 Interview 2	80	183	2016-06-05 09:53 AM	M	2016-06-06 04:41 PM	M
Participant 6 Interview 3	39	123	2016-06-05 09:53 AM	M	2016-06-07 01:11 AM	M
Participant 7 Interview 1	17	20	2016-06-05 09:53 AM	M	2016-06-07 01:24 AM	M
Participant 7 Interview 3	23	27	2016-06-05 09:54 AM	M	2016-06-08 12:28 AM	M
Participant 8 Interview 1	45	71	2016-06-05 10:47 AM	M	2016-06-08 01:08 AM	M
Participant 8 Interview 2	73	120	2016-06-05 10:47 AM	M	2016-06-08 02:29 AM	M
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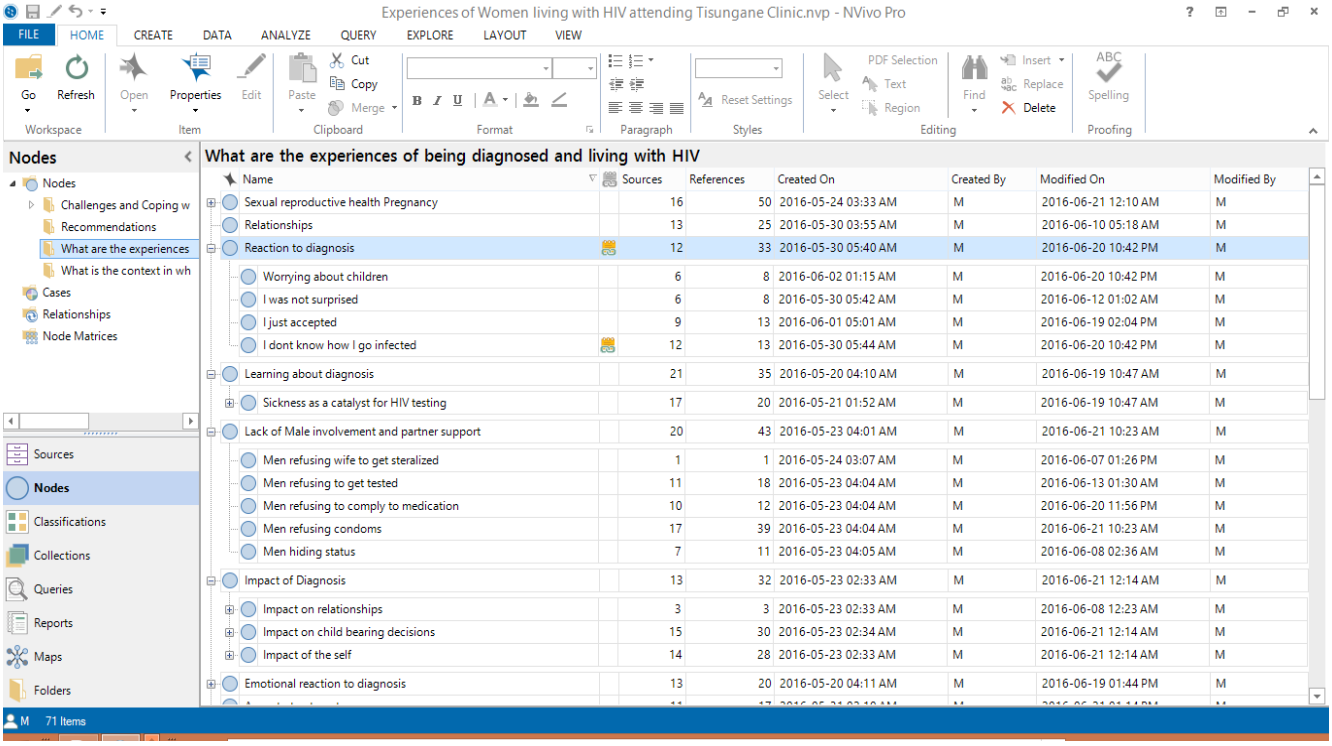

What are the experiences of being diagnosed and living with HIV

Name	Sources	References	Created On	Created By	Modified On	Modified By
Sexual reproductive health Pregnancy	16	50	2016-05-24 03:33 AM	M	2016-06-21 12:10 AM	M
Relationships	13	25	2016-05-30 03:55 AM	M	2016-06-10 05:18 AM	M
Reaction to diagnosis	12	33	2016-05-30 05:40 AM	M	2016-06-20 10:42 PM	M
Worrying about children	6	8	2016-06-02 01:15 AM	M	2016-06-20 10:42 PM	M
I was not surprised	6	8	2016-05-30 05:42 AM	M	2016-06-12 01:02 AM	M
I just accepted	9	13	2016-06-01 05:01 AM	M	2016-06-19 02:04 PM	M
I dont know how I go infected	12	13	2016-05-30 05:44 AM	M	2016-06-20 10:42 PM	M
Learning about diagnosis	21	35	2016-05-20 04:10 AM	M	2016-06-19 10:47 AM	M
Sickness as a catalyst for HIV testing	17	20	2016-05-21 01:52 AM	M	2016-06-19 10:47 AM	M
Lack of Male involvement and partner support	20	43	2016-05-23 04:01 AM	M	2016-06-21 10:23 AM	M
Men refusing wife to get steralized	1	1	2016-05-24 03:07 AM	M	2016-06-07 01:26 PM	M
Men refusing to get tested	11	18	2016-05-23 04:04 AM	M	2016-06-13 01:30 AM	M
Men refusing to comply to medication	10	12	2016-05-23 04:04 AM	M	2016-06-20 11:56 PM	M
Men refusing condoms	17	39	2016-05-23 04:04 AM	M	2016-06-21 10:23 AM	M
Men hiding status	7	11	2016-05-23 04:05 AM	M	2016-06-08 02:36 AM	M
Impact of Diagnosis	13	32	2016-05-23 02:33 AM	M	2016-06-21 12:14 AM	M
Impact on relationships	3	3	2016-05-23 02:33 AM	M	2016-06-08 12:23 AM	M
Impact on child bearing decisions	15	30	2016-05-23 02:34 AM	M	2016-06-21 12:14 AM	M
Impact of the self	14	28	2016-05-23 02:33 AM	M	2016-06-21 12:14 AM	M
Emotional reaction to diagnosis	13	20	2016-05-20 04:11 AM	M	2016-06-19 01:44 PM	M