

**LIVED EXPERIENCES OF ADULTS WITH HIV/AIDS ON ANTI-
RETROVIRAL THERAPY (ART) IN A SELECTED COMPOUND OF
LUSAKA DISTRICT, ZAMBIA**

By

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**A Dissertation Submitted to the University of Zambia in Collaboration with the Zimbabwe
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Master of Science in Counseling**

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DECLARATION

I, **Phyllis M. Nyirenda**, do hereby solemnly declare that this dissertation represents my work and that it has never been previously submitted for a degree at this or any other University.

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Student

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Signature

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Date

APPROVAL

Phyllis M. Nyirenda, has been approved as a partial fulfillment of the requirements for the award of the Degree of Master of Science in Counselling of the University of Zambia in Association with the Zimbabwe open University

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DEDICATION

This work is dedicated to the precious memory of my late parents, Mr. Joseph Tillys Nyirenda and Mrs. Doreen Mulumo Mundia and my late Aunty, Mrs. Cecilia Nomai Mulumo Kalaluka. My beloved parents and Aunty, I wish you were still alive to see how your inspiration, direction, counsel and belief in me has led to a firm foundation for me. It is further dedicated to my husband Brian, and my children whose support and encouragement in the course of this study will forever inspire me.

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ABSTRACT

The study examined the lived experiences of adults with HIV and AIDS on Anti-Retroviral therapy in selected compounds of Lusaka. The study addressed the question, “What are the contextually lived experiences of adults with HIV and AIDS on ARVs?” The objectives of the study were threefold; firstly, explore the lived experiences of adults with HIV and AIDS on ARVs therapy; secondly, to establish factors that might have led to current lived experiences among individuals living with HIV and AIDS on ARV therapy and thirdly, to ascertain coping strategies being used in the management of lived experiences of adults with HIV and AIDS on ARVs therapy. An interpretive phenomenological design supported by qualitative approaches was used in the study. A sample of 12 adults between the age of 26-53 living with HIV and AIDS on ART was purposively selected from the population in a selected compound of Lusaka in Zambia. The research instruments used in the study was interview guides and observation and checklists. In data processing, qualitative technique of thematic analysis was used to analyze the data. The study revealed that adults living with HIV/AIDS on ART experienced physical changes such as reduced sexual behaviour; enhanced body structure; frequent fatigue and other physical illness. The study also noted that the outlook on their illness and their lives both in the past and present tended to be negative. They depicted fear, pain, sadness and anxiety in their lived experiences. Further, the study showed that there were anxious about their own death due to illness which included knowing their own HIV status and severe health problems. It was noted during the study that the respondents also experienced psychological related issues such as anger, uncertainty, guilt, confusion and depression. Respondents also lived a life of always taking ART as a fundamental part of their everyday life. The respondents had good experiences of HIV treatment at their clinics and some commended some support network groups for their support in terms of emotional and material support. The study recommended regular support financially for the adults living with HIV and AIDS on ART in order for them to meet the cost of transport to and from the clinics and as well as support to help with regard to social, material, spiritual and psychological need as they live with their condition.

KEY WORDS: Lived Experiences, Adults, HIV/AIDS, Antiretroviral Therapy

ACROYNMS

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
AHF	AIDS Health Foundation
CDC	Centre for Disease Control
CICT	Client Initiated Counseling and Testing
COVID 19	Corona Virus Disease 19
DREAMS	Determined, Resilient, Empowered, AIDS free, Mentored and Safe
HIV	Human Immunodeficiency Virus
MOH	Ministry of Health
PeP	Post-Exposure Prophylaxis
PreP	Pre-Exposure Prophylaxis
UNAIDS	United Nations Programme on HIV/AIDS
UNZA-ZOU	University of Zambia – Zimbabwe Open University
VMMC	Voluntary Medical Male Circumcision
WHO	World Health Organization

DEFINITIONS OF KEY TERMS OF THE STUDY

- Human Immunodeficiency Virus (HIV):** The virus that causes AIDS by infecting human lymphocytes called T-lymphocytes.
- Acquired Immune Deficiency Syndrome (AIDS):** A collection of illness resulting from infection with human immunodeficiency virus.
- Lived experiences:** It refers to the experiences, which describes the first- hand accounts, impressions and experiences faced by the people living with HIV/AIDS during day to day life as elicited through in psychosocial, and financial experiences of HIV/AIDS.
- Adults living with HIV/AIDS:** It refers to the people living with HIV/AIDS above 18 years of age and diagnosed as a case of HIV as per as the records and who are attending selected at centers for treatment in clinics or hospitals.
- Anti-Retroviral Therapy:** These are medications that are used to treat HIV. The drugs do not kill or cure the virus, but they can only prevent the growth of the virus.
- Stigma:** A mark of disgrace associated with a particular circumstance, quality or person.
- Medical adherence:** The degree to which the person's behaviour corresponds with the agreed recommendation from a health care provider.

CHAPTER ONE: INTRODUCTION

1.1 OVERVIEW

The chapter covers background, statement of the problem, purpose of the study, objectives, research questions, significance of the study, delimitation, limitations, theoretical framework, definitions of operational terms and ends with a summary.

1.2 BACKGROUND

Acquired Immuno-Deficiency Syndrome (AIDS), is a disease caused by human immunodeficiency virus (HIV). According to Croft (1992), it was epidemically, discovered in the United States of America in 1981, and later on traced in various parts of the world including African countries. Fox, et al (2010), states that the human immunodeficiency virus (HIV) targets cells in the immune system, the body's defense mechanisms against illness and weakens the body's ability to fight against infections and some types of cancer. Thus, virus destroys white blood cells in the immune system called CD4 cells and replicates itself inside these cells. Fox et al (2010), adds that as the virus destroys and impairs the function of immune cells, infected individuals generally become immune-deficient. The body becomes increasingly unable to fight infections and diseases, hence vulnerable to opportunistic infections and cancers.

According to Pilcher et al (2004), HIV is spread only in certain body fluids from a person who is infected with HIV to another. These fluids include; blood, semen, pre-seminal fluids, rectal fluids, vaginal fluids and breast milk. HIV transmission is only possible if the fluids come in contact with a mucous membrane or damaged tissue or are directly injected into the blood stream from a needle or syringe. Pilcher et al (2004), adds that HIV can also be spread from a woman with HIV to her child during pregnancy, childbirth or breast feeding. HIV can also be transmitted by sharing needles or other sharp objects. The UNAIDS (2020), reports that globally, approximately there were 76 million people who had been infected with HIV since the start of the epidemic, and goes on to say that there were approximately 38 million people currently living with HIV in 2019 up from 30.7 million in 2010. This, therefore, shows a result of continuing new infections and people living longer with HIV. The UNAIDS (2020), states further that of the people living with HIV in 2018, 36.2 million were adults and 1.8 million were children under the age of 15.

The HIV and AIDS disease has changed the quality of lifestyles for people living with HIV and AIDS. According to UNAIDS (2006), empirical evidence shows that as HIV disease progresses, quality of life deteriorates. In addition, people living with HIV and AIDS face physical, psychological and social problems. Bogart et al (2000), states that HIV has a significant physical impact on people living with HIV. When HIV attacks the immune system, it makes it harder for one to fight off infections that can make a person sick. As the virus weakens the natural defenses, a person might develop some opportunistic infections. But if a person starts antiretroviral therapy early, he or she may not have these problems. Furthermore, Antiretroviral drugs, however can also have side effects on the individual hence, some of which have psychosocial consequences such as lipodystrophy. It also leads to long term physical side effects such as cardiovascular diseases and hepatitis. Bonuck (1993), states that psychosocial issues also affect people living with HIV and AIDS. Bonuck (1993), adds that after being diagnosed, people confronted with their HIV-positive status are highly stressed and uncertain despite the availability of antiretroviral drugs. Hence, their lives may be devastated by the need to deal with the new medical, personal and social situation on how they will manage stigma associated with HIV and AIDS. Holzemer (2009), adds that research in most cultures finds that adults living with HIV and AIDS face psychological problems such as stigma. The stigma makes it more difficult for people living with HIV to cope and manage their illness and makes it difficult for them to fight the AIDS epidemic as a whole.

According to the UNAIDS Report (2012), HIV is a global threat that cannot be ignored because of the persistence of new cases despite the knowledge of modes of transmission, methods of prevention and resources available. The UNAIDS Report (2012), adds that the global effect of HIV and AIDS in particular, has the potential to impact negatively on societies because of the associated high-adult mortality rates in some countries, especially in sub-Saharan Africa. Furthermore, despite the progress made in the response to HIV and AIDS during the last decade, the HIV pandemic remains one of the most serious challenges and the leading cause of death and disability in the world.

According to the Report on Global AIDS Epidemic (2006), HIV and AIDS became a pandemic when the Centre for Disease Control (CDC) reported five cases of rare lung infection pneumocystis carina pneumonia in young homosexual men in Los Angeles, which heralded a

pandemic of AIDS. In 1983, a retrovirus later named the human immunodeficiency virus or HIV. HIV and AIDS is a major public health concern and cause of death in many parts of the world. UNAIDS (2020), notes that the number of people living with HIV in Asia and the Pacific region was estimated 5.8 million in 2019. The region's annual number of new HIV infections has been declining by 12% since 2010. However, trends vary from country to country, and the decline in the region may obscure increases in some countries. In Western and Central Europe and North America estimated 2.2 million people living with HIV in this region. However, high coverage of ART plays a key role in the reduction of AIDS-related deaths in the region since 2010 and the number of AIDS related deaths decreased by 40%. It could also be noted that 4 in 5 people living with HIV (81%) were on treatment, while 2 in 3 people living with HIV 67% were virally suppressed.

UNAIDS (2020), reports further that in Latin America an estimated 2.1 million were people living with HIV between 2010 and 2019, while new HIV infections increased by 21%. In addition, HIV related deaths fell by 8% in the region overall. Furthermore, in 2019, 40% of new infections in Latin America occurred in Brazil, which has the greatest number of people living with the disease (920,000) in the region. UNAIDS (2019), reports that Eastern Europe and Central Asia had an estimated 1.7 million people living with HIV, including 170,000 newly infected persons in 2019. In addition, new infections in the region increased by 72% and AIDS-related deaths increased by 24% between 2010 and 2019. Hence, 99% of the infections in the region are among key populations and their sexual partners, including 48% of infections occurring among people who inject drugs.

The WHO (2016), reports that Sub-Saharan Africa has over 25.6 million people living with HIV. This accounts for two-thirds of the recent overall world HIV infections and more than 70 percent of all related deaths. Eastern and Southern Africa has an estimated 20.7 million people living with HIV. The report adds that two-thirds of children living with HIV (67%) are found in this region. However, despite the significant impact of new infections in the region, death have been declining by 38% since 2010. Almost all of the region's nations have generalized HIV epidemics, that is, their national HIV prevalence is greater than 1%. The WHO (2019), reports further that South Africa has the highest number of people living with HIV in the world with estimates of about 7.5 million, while Swaziland has the highest prevalence of HIV in the world.

In addition, The WHO (2019), reports that Western and Central Africa had an estimated 4.9 million people living with HIV. However, new HIV infections among adults declined by 25% between 2010 and 2019. In addition, women and girls were accounting for 58% of the estimated 240,000 new infections in the region. According to UNAIDS (2018), the life expectancy in many parts of Africa was declining, largely as a result of HIV AND AIDS epidemic with life expectancy in some countries reaching as low as thirty-four (34) years.

The UNAIDS (2018), adds that there were a number of initiatives that had been launched in various parts of the continent that were aimed at educating the public on HIV and AIDS. Among these were the combination prevention programmes, considered to be the most effective initiatives, such as the abstinence, be faithful, use a condom campaign, Post Exposure Prophylaxis (PEP), Pre-Exposure Prophylaxis (Prep) and the Desmond Tutu HIV Foundation Outreach Program, which was a non-profit organization founded to provide treatment for and conduct HIV and AIDS research.

In Zambia, the first HIV case was reported in 1984 and by 1991 the Zambia National AIDS program had recorded fifteen thousand (15,000) cases and accounted for 14% of the total death (MOH, 2014). It was this statistical data that led to Zambia to declare HIV as an epidemic and a major public health concern. The current estimates from the Joint United Nations program on HIV and AIDS (2018), state that HIV prevalence among adults was at 12.0%, 14.6% among females, 9.3% among males, despite free Antiretroviral Therapy and related services available.

The HIV, has continued to be a burden among many Zambians and indeed remains high and disproportionately affecting more females than males. According to Bond et al (2003), the metaphors around HIV and AIDS are riddled with accusations against women for their sexual deviance, their temptation, their love of money and for spreading HIV. However, HIV is perceived as a disease of women which was spread by them, hence, more women are more vulnerable to name calling, gossip, poverty exacerbated by brutal practices such as property grabbing, widowhood and less income generating power. Bond et al (2003), adds that women are more likely to be blamed for bringing HIV into the home, resulting in them being chased from their home or sent back to their close relatives or abandoned when sick.

According to the MOH National HIV and AIDS Policy (2002), HIV and AIDS researchers and analysts believed that over the course of an epidemic, about equal numbers of men and women

would become infected but the multi-Centre study. The study revealed prevalence rate of 32% among females and 25.5% in males in Ndola. However, this imbalance in the sex ratio may occur because women are more prone to infection than men, hence, lack control over their lives. For example, women are taught from early childhood to be obedient and submissive to males, more especially males who command power such as father, uncle, husband, brother or guardian.

In relation to sexual relations, a woman is expected to please her male partner, even at the expense of her own pleasure and well-being. Bond et al (2003), states that the dominance of male interests and lack of self-assertiveness on the part of women puts them at risk. Women are taught to never refuse having sex with their husbands, regardless of the number of partners the husband may have or his non-willingness to use condoms, even if he is suspected of having HIV or a sexually transmitted disease (STI).

According to the MOH National HIV and AIDS Policy (2002), research has shown that women were two to four times more vulnerable to HIV infection than men during unprotected sex because of the larger surface areas exposed to contact. Similarly, women were more vulnerable to other sexually transmitted diseases, the presence of which greatly enhances the risk of HIV infection. Some sexually transmitted diseases present recognizable symptoms in men are often asymptomatic in women and, therefore remain untreated.

Although HIV is a manageable disease today, it is still a pressing health concern with different consideration by sex, gender, racial, ethnic groups, age, socio-economic status and geographic location. According to Kimchi (1991), several studies indicate that people living with HIV and on ARTs experience disparate health concerns such as access to care, availability of treatment, quality of care, delayed diagnosis and stigma. However, less information seemed to be available on what lived experiences of adults with HIV and on ARTs were in various spheres of life such as: medical; psychological and socio-ecological environments in Zambian compounds or villages. It is against this background that the study was undertaken in a selected compound of Lusaka in Zambia.

1.3 STATEMENT OF THE PROBLEM

Although the Zambian government has been providing free therapy for people with HIV and AIDS (MOH, 2014, WHO, 2014), and has tried to overcome some of the challenges associated

with the condition including stigma and suffering, less is known of the lived experiences of persons with HIV and AIDS on Anti-Retroviral therapy (ART) in Zambian compounds from a medication, sociopsychological and socio-economic point of view. Hence, the question still is, what are the lived experiences of adults living with HIV and AIDS on Anti-Retroviral therapy in Zambian compounds? The study, therefore, was an attempt to investigate the lived experiences of adults living with HIV and AIDS and were on Anti-Retroviral therapy in a selected compound of Lusaka in Zambia.

1.4 PURPOSE

The purpose of the study was to investigate the lived experiences of adults with HIV and AIDS and are on Anti-Retroviral therapy in selected compounds of Lusaka in Zambia.

1.5 OBJECTIVES

- i. To establish the lived experiences of adults with HIV and AIDS on ARVs therapy in the study site.
- ii. To explore factors that might have led to current lived experiences among individuals living with HIV and AIDS on ARV therapy in the study site.
- iii. To ascertain coping strategies adults with HIV and AIDS and ARVs therapy were using to manage their lived experiences study site

1.6 RESEARCH QUESTIONS

- i. How are the contextually lived experiences of adults living with HIV and AIDS who are on ARVs therapy in the study site?
- ii. What factors have led to current lived experiences among individuals living with HIV and AIDS and are on ARVs therapy in the study site?
- iii. What are the coping strategies used to manage lived experiences of adults with HIV and AIDS on ARVs in the study?

1.7 SIGNIFICANCE

The study has established the information on lived experiences of adults with HIV and AIDS on ARVs. The findings of the study will be useful to counsellors in educational and health institutions, counselors, teachers, policy makers; clients themselves and other, stakeholders. The study has also contributed to the existing body of knowledge on lived experiences of adults

living with HIV AND AIDS on Anti-Retroviral therapy, and can be used as a reference material for future studies. It is also hoped that reflections on the human experiences of those living with HIV and AIDS infections would influence the meaning of a humanistically and holistically counselor's perspective to society.

1.8 LIMITATIONS

Price and Murnan (2004), states that limitations are those characteristics of design that impact or influence the interpretations of the findings from the study. They are the short comings, conditions that cannot be controlled by the researcher that place restrictions on the conclusion of particular study. The study was limited to (12) respondents living with HIV and AIDS on ART in Lusaka District of Zambia. Findings of the study may not be generalized for they represent only views of the sampled population. Consequently, the findings do not represent the views of the entire population of adults living with HIV and AIDS on ART in Zambia.

1.9 DELIMITATIONS

The study was confined to adults living with HIV and AIDS on Antiretroviral therapy who were willing to share their experience. The study focused on those living in the study compound in Lusaka in Zambia because of the high population and that Lusaka has the highest prevalence rate of Adults living with HIV and AIDS which was about 16% this is According to Zambia Population Based HIV Impact Assessment report of (2019), hence, the researcher thought it was worthwhile to conduct the study in one of the compounds in Lusaka.

1.10 THEORETICAL FRAMEWORK

The study was guided by a phase theory of reaction to HIV infection by Nicholas. The phase theory of reaction to HIV infection can be summarized in three stages. Nicholas (1985), notes that these stages include, crisis, transitional and deficiency. The reactions to each phase can be described as exemplified below. Using the phase theory of reaction to HIV infection, this study recognizes that adults living with HIV and AIDS go through the crisis stage which Nicholas (1985) notes was the crisis phase that involves periods of anxiety and denial, with shock, guilt, anger, sadness bargaining and acceptance. It was noted that adults living with HIV infection may experience anxiety at the time of detection, onset, or progression of HIV infection, ranging across the full spectrum of anxiety disorders. According to Bravo et al (2010), a previous study

found that anxiety symptoms were common in HIV patients, but the prevalence of syndromal anxiety disorders is similar to that in the general population. Bravo et al (2010), add that, recent studies have revealed that, several people experienced feelings of anger related to HIV infection and that this was as a resultant negative social reaction. In addition, once a persons' HIV positive status is confirmed, he or she has to make life-changing decisions such as whether to inform their close relatives and friends of their positive status, they have to decide about undergoing treatment and how to continue with their daily routine activates and decide about the future sexual relations. Hence, because of their decision, they may become isolated with reduced social support, may refuse treatment, or even develop psychiatric illness such as anxiety and depression.

According to Nicholas (1985), transitional phase is the second stage that people go through. However, this study recognizes that adults living with HIV and AIDS go through a transitional phase which begins when denial is no longer the dominant emotion, but is suppressed by period of anger, guilt, self-pity and anxiety. According to Aggarwal (2008), a study was conducted to ascertain the individual early reactions to the diagnosis of HIV. The results showed that people diagnosed with HIV commonly go through an initial stage of denial in which they do not acknowledge having the disease or deny its likely consequences. Nicholas (1985), adds that patients attempt to find meaning in their HIV status "Why me?" which is aggravated by social rejections, loss of self-esteem, changes in identity and personal values. Furthermore, the adults and patients may become frankly paranoid, viewing the illness as the work of malevolent forces or people and displaying a suspicious, angry and hostile attitude towards others. At this stage, the person is in great need of psychological counseling because of the great threat of social withdrawal.

Nicholas (1985), states that the final phase is the deficiency stage, once the deficiency is met, the person achieves and becomes comfortable with a new identity and accepts the limits imposed by his or her disease on his/her life. Nicholas (1985), adds that the people them feel less victimized by life, become less ego-centric and find satisfaction in altruistic and community activates. This study, therefore, recognizes that adults living with HIV and AIDS on ART can achieve much with their lives and become comfortable with a new identity and accepts the limits imposed by the disease on their lives. The phase theory of reactive to HIV and AIDS was formed

appropriate to this study as it helps to explore the lived experiences of adults living with HIV and AIDS on ART in selected compounds of Lusaka.

1.11 CHAPTER SUMMARY

Chapter one provided an introduction to the study. It discussed the background, statement of the problem, purpose of the study and objectives. Further, research questions were identified, followed by significance, limitations, delimitation and theoretical frameworks. The chapter has ended with the chapter and a summary. The next chapter dealt with the review of related literature.

CHAPTER TWO: LITERATURE REVIEW

2.1 OVERVIEW

This chapter reviewed literature related to lived experiences of adults with HIV and AIDS on Anti-Retroviral Therapy. The review was discussed under the following subheadings: exploring the lived experiences of adults with HIV and AIDS on Anti-Retroviral Therapy in terms of physical, psychological and social aspect of their experiences. To establish factors leading to current lived experiences among individuals living with HIV and AIDS on ARV therapy, and the coping strategies being used to manage lived experiences of adults with HIV and AIDS on ARV therapy. The chapter ends with the knowledge gaps in the current literature and the relevance of this study.

2.2 LIVED EXPERIENCES OF ADULTS WITH HIV AND AIDS ON ART

2.2.1 Physical Illness related Issues

According to Aggleton et al (1989), physical problems related to HIV and AIDS infection may or may not display the symptoms associated with the disease in the early stage when the infection involves human immune system. Hence, many symptoms become apparent and result in limited human function, such as opportunistic infections and cancer. O'Brien et al (1993), conducted a three-year longitudinal project designed to identify a data base of the physical and psychological issues related to 133 participants living with HIV on Art. The authors used both structured and open-ended questions as both the quantitative and qualitative research tool. Findings showed that 55% of the group experienced physical symptoms before the diagnosis of HIV infection was made. These symptoms included such conditions as flu-like symptoms, lymphadenopathy, upper respiratory tract infection, oral infection and pneumonia. In addition, O'Brian, et al (1993), adds that fatigue, impaired mobility and nutritional disturbances were the most common problems that limited the participants' ability to perform many activities and affected these people in terms of what they were expected to do or able to do.

2.2.2 Psychological Related issues

Adults living with HIV and AIDS may not be considered the same as living with other infections. According to Deribew et al (2010), HIV and AIDS imposes a significant psychological burden to people living with the condition. Usually people living with HIV and

AIDS suffer from depression and anxiety as they adjust to the diagnosis of their being infected and face the difficulties of living with chronic life-threatening illnesses. However, many researchers documented feelings of fear after blood testing and that of the results being found to be positive. McClain et al (1992), identified stress amongst 36 people living with HIV and AIDS who are on Art. Findings showed that people living with HIV and AIDS who participated in the study experienced feelings of fear related to death and dying. Hence, these feelings were perceived as the major stressor. Kermode (1995), points out that fears of suffering in the future were also common experiences of people living with the HIV infection.

Firn (1995), adds that HIV infection also affects the interpersonal relationships of an individual. In his study, Firn (1995), investigated the psychological distress of people living with HIV and were experiencing fear of rejection from their significant others as well as fear of disruption of relationships with others. In addition, adults living with HIV and AIDS perceived the feeling of fear as a significant emotional distress. Furthermore, Firn (1995), reported that the emotional and psychological anxieties felt by these people were related to three factors, being unprepared for being told that they were HIV positive, being admitted to hospital for the first time with others who had HIV and AIDS, and the lack of information associated with their illness.

Maj (1990), states that experiences of uncertainty related to living with HIV is also one of the reasons, hence he used self-measurement to identify feelings of uncertainty amongst people living with HIV and AIDS. The results from the study showed that the feelings of uncertainty were an actual sense of anxiety, especially at the onset of the early symptoms of HIV related illnesses. Chuang et al (1989), adds that the symptoms raised on awareness of an uncertain future and signaled a decline in health and physical functioning of those living with HIV and AIDS. Coward (1994), reported also that these people living with HIV and AIDS experienced living uncertainty. Their experience was described as an inability to predict periods of their own illness and how long each would continue. Thiangthan et al (2009), stated that in his investigation on HIV positive pregnant women, it was observed that two patterns emerged. He gives the patterns as that of suffering, and that of hope. He adds that Suffering was caused by fear of condemnation from their spouses, and by fear of disappointing their larger families and friends.

According to Miller et al (1988), people living with HIV and AIDS felt guilty following HIV testing. The guilty feelings were related to self-devaluation with beliefs about having engaged in behaviours that resulted in infection. However, Miller et al (1988), adds that the concern about having possibly infected others prior to or after testing HIV positive was also included. Furthermore, Bennett (1990), also noted that in his study, people living with HIV and AIDS experienced a feeling of guilt when they perceived that their significant others had to care for them.

People living with HIV and AIDS experience low self-esteem. According to the study of O'Brien et al (1993), the self-esteem of people living with HIV and AIDS decreased when they experienced being rejected by the others. O'Brien (1993) adds that when there were changes in their self-image as a result of a disruption in their relationship with their significant others. A study by Turner et al (1993), found that the level of self-esteem was positively associated with all types of social support such as emotional, informational and practical support provided to people living with HIV and AIDS. Similarly, a study by Lang (1991), found out that high level of self-esteem of people living with HIV and AIDS might have been as a result of gained support from others or from the support groups available to them. Lang (1991), adds that the majority of people living with HIV and AIDS have moderate to high level of self-esteem which may limit their ability or access to social relationship. However, the findings support that if people living with HIV and AIDS were better supported and cared, their negative psychological consequences would have been prevented or at least reduced.

Several researchers have reported that people living with HIV had implicated experiences of grief, loss and changes to an individual. Martin et al (1993), conducted a study tracking the effects of bereavement among homosexual-bisexual American men. Martin et al (1993), discovered that bereavement reactions to AIDS-related deaths were most pronounced amongst people who were living with HIV and AIDS. The experiences of loss were associated with the limited social activities and job performance. Martin et al (1993), adds further that the precedence of illness or the death of someone living with HIV and AIDS was also a factor that was influencing the loss. However, bereavement coping challenges can be difficult for people living with HIV and AIDS, hence it can often be accompanied by depression, on illness that can

affect mind, mood, body and behaviour. It was found out that if left untreated, depression can increase the risk of suicide, deteriorate in relationship among others.

According to Deribew et al (2010), the risk of committing suicide is significantly high among people living with HIV and AIDS in order to lessen the shame and grief of loved ones. Many other studies were conducted to investigate suicidal thoughts and attempts related to HIV infection. The WHO (2010), observed that several studies have reported rates of suicidal thoughts and attempt among people with HIV and AIDS. In most of these studies, depression and HIV and AIDS featured prominently as important risk factors for suicide. For instance, Deribew et al (2010), studied the prevalence of suicide among people living with HIV in New York by reviewing the data from the large cohort show that was between 2000 to 2015. Deribew et al (2010) found out that the rates of suicide were almost always much higher among people living with HIV than that of 2015. to the general population. Rabkin et al (1993), adds that the desire to die most likely occurred during the course of infection rather than attempting suicide in response to the diagnosis of HIV infection. Mazurk et al (1988), found out that most of those people infected with HIV infection talked of killing themselves at some time in the future, but few carried out their threats when the time came. Belkin et al (1992), states that the common factors influencing the suicidal thoughts included the experiences of physical symptoms particularly being discriminated or isolated from others especially when they disclose their status.

According to Parker (2000), reported changes in human sexuality related to HIV had a bigger bearing on people living with HIV and AIDS. Dating, sexual exploration and negotiating relationships are complicated for people living with HIV and AIDS. However, engaging in sexual activity since becoming HIV positive requires adults to consider the implications of HIV transmission to their partners, which involves abstaining or delaying sexual activity, negotiating condom use to prevent transmission or evaluating the risk of not engaging in safer sex practices. Marhefka et al (2011), reveals that adults living with HIV may avoid or delay sexual activity because of their fear of transmitting HIV. This is in contrast to the findings of a Canadian study by Fernet et al (2007), who found that many adults discussed being afraid of engaging in sexual activity after being diagnosed with HIV as they felt a sense of responsibility in protecting other people because they did not want to transmit it to anyone else.

For adults living with HIV who do engage in sexual activity, there is a relationship noted in the literature between condom use and the responsibility which was also related to HIV disclosure that having sex without a condom was acceptable if they had disclosed their HIV status with their partners. In complementing findings, Rice et al (2006), found that disclosing one's HIV status changed the dynamic of responsibility to their partners. Adults felt that HIV disclosure shifted the responsibility for condom use where some adults felt HIV disclosure was not necessary if they were practicing safer sex through condom use. This is similar to the findings of the Canadian study by Fernet et al (2011), who found that adults felt disclosure was not needed if they were using condoms in order to practice safer sex. However, in the earlier Canadian study by Fernet et al (2011), the adults talked about their sense of responsibility in protecting other people, but feared negotiating condom use with a partner because of disclosure and rejection. Fielden et al (2006), found similar results in their Canadian study where adults were afraid to disclose their HIV status to girlfriends or boyfriends because of fear of rejection.

In addition, Marhefka et al (2011), also found that women living with HIV took more risks with regards to sexual behaviour in order to fit in with their HIV-negative people. In the Canadian study by Fernet et al (2011), it was found that the sexually active adults used condoms at less once. Since they found out their HIV status. However, similar to findings from Koenig et al (2010), found that over half of adults who used condoms during their first sexual relationship, after diagnosis, engaged in a barrier to intimacy and a reminder that they were living with HIV. According to Fernet et al (2011), their findings illustrate a change in risk perception, with regards to unprotected sex, especially when their viral load was undetectable and their partners did not become infected after practicing unprotected sex in the past. According to Deribew et al (2010), HIV and AIDS imposes a significant psychological burden to people living with HIV and AIDS. People living with HIV and AIDS often suffer from depression and anxiety as they adjust to the diagnosis of being infected and face the difficulties of living with chronic life-threatening illness, for such as shortened life expectancy, complicated therapeutic regimes, stigmatization and loss of social support, family or friends. Deribew et al (2010), adds that the risk of committing suicide is significantly high among people living with HIV and AIDS to lessening the shame and grief of loved ones. HIV and AIDS influence the psychological coping not only to people with HIV and AIDS but also those close to them. However, following the death of someone from

AIDS, family and friends may experience bereavement and loss. Furthermore, bereavement coping challenges can be difficult for people living with HIV and AIDS hence it can often be accompanied by depression, an illness that can affect mind, mood, body and behavior. In addition, if left untreated, depression can increase the risk of suicide, deteriorate in relationship among others. Pada et al (2002), states that self-esteem for people living with HIV and AIDS is often threatened early in the process of living with rejection by friends, acquaintance and loved ones and quickly lead to loss of confidence and social identity and thus to reduced feelings of warmth or belonging.

According to Selnes et al (2005), people living with HIV and AIDS usually have auditory hallucinations and are much more common than visual ones, and schizophrenic which is frequently hearing voices. However, AIDS dementia is common among people living with HIV who have lost their memories and are unable to recognize other people and the close relatives within their surroundings. Selnes et al (2005), in study on memory loss in people living with HIV and AIDS for the assignment and strategies for coping, stated that although the incidence of HIV- related dementia has decrease significantly in the era of contemporary ART, the prevalence of memory loss and symptoms remains steady in people living with HIV and AIDS.

2.2.3 Social Related Issues

A number of negative responses to people living with HIV and AIDS has been discussed. According to Andrews et al (1993), people living with HIV and AIDS experienced negative social reactions after disclosing their HIV status and this caused people living with HIV to develop a variety of psychological distresses, which included feelings of being ashamed, loneliness, depression and loss of self-respect. Shultz (1998), purported that a deficiency of social interaction, or missing something in one's life, can result in an individual feeling lonely. According to Eliason (1993), there are two powerful social stigma related to the social reactions towards people living with HIV and AIDS. These situations include fear of contracting HIV and homophobia. Eliason (1993), adds that the fear of contracting HIV and AIDS is a stigma that most people believe will lead to inevitable death. Northcott et al (1991), conducted a survey of public opinion regarding HIV and AIDS policies. Because of the public's fear of contracting AIDS, they agreed opinion was that health care workers should be screened for HIV and AIDS to protect the public while the patients in the hospital should be screened routinely for HIV and AIDS disease in order for them not to infect health care workers Furthermore, Macks (1988),

notes that adults living with HIV and AIDS were consistently ranked low from the perspective of physicians when comparing their willingness to treat HIV and AIDS related ailments with their willingness to treat other illnesses.

2.3 FACTORS LEADING TO CURRENT LIVED EXPERIENCES

2.3.1 Stigma

The UNAIDS (2003), defined stigma as a process of devaluation of people living with or associated with HIV and AIDS. Herek (1990), states that HIV and AIDS related stigma is used to refer to prejudice, discounting, discrediting and discrimination directed at people perceived to live with HIV and AIDS, as well as the individuals, groups and communities with which they are associated. Badahdah (2010), adds that this stigma makes it more difficult for people living with HIV and AIDS to cope with and manage their illness and also make it difficult to fight the HIV and AIDS epidemic as a whole. However, HIV stigma contributes significantly and independently to the perception of quality of life of people living with HIV and AIDS.

According to Moon (2008), stigma remains the single most important barrier to public action. It is the main reason why too many people are afraid to see a doctor to determine whether they have the disease or seek treatment if so. Hence the factors have helped make HIV and AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily about the available prescriptions. Holzemer et al (2009), reported six main factors related to the stigma of HIV and AIDS namely; negative self-perception, social isolation, verbal abuse, healthcare neglect, fear of contagion and work place stigma.

According to Brown et al (2003), people living with HIV and AIDS experience enacted and felt stigma. Felt stigma also known as internal stigma or self-stigmatization, refers to shame, blame and the expectation that persons will discriminate against people living with HIV and AIDS. Brown et al (2003), adds that felt or internal stigma refers to real or imagined fear of societal attitudes and potential for persons to discriminate due to undesirable attribute towards HIV and AIDS.

In a Canadian study by Flicker et al (2005), adults living with HIV felt lonely, stigmatized sad and depressed and these feelings negatively influenced their ability to access social support

systems. In addition, a study by Hosek et al (2008), found that adults would self-isolate and dissociate themselves from their friends soon after diagnosis in order to avoid rejection due to HIV stigma similarly, Rao et al (2007), found that adults would isolate themselves and hide their HIV status from their friends or family members because of stigmatizing comments about people living with HIV and AIDS. The UNAIDS (2017), cites fear of stigma and discrimination as the main reason why people are reluctant to get tested, disclose their HIV status and take antiretroviral drugs. One study found that participants who reported high levels of stigma were over four times more likely to report poor access to care. This state of affairs contributes significantly to the expansion of the global HIV epidemic and higher number of AIDS related death.

Verbal stigma is also one of the stigma that people living with HIV and AIDS face. Fetene et al (2013), states that in a study, participants reported that if one is suspected of being HIV positive and on Art, he/she was given names that imply that his/her days of staying alive were numbered. However, Fetene et al (2013), adds that the tendency of labelling people living with HIV or name calling is part of gossip and accounts for most of the stigmatizing behaviours from the community. The participants argued that labelling is conceptualized as society's symbolic punishment for those who were considered to have violated sexual moralities.

Katz et al (2013), points out that self-stigma and fear of a negative community reaction can hinder efforts to address the HIV epidemic by continuing the wall of silence and shame, surrounding the virus. However, negative self judgement resulting in shame, worthlessness and blame represents an important but neglected aspect of living with HIV. Katz et al (2013), adds that self-stigma affects a person's ability to live positively, limits meaningful self-agency, quality of life, adherence to treatment and access to health care services.

According to Dugue et al (2011), large numbers of people continue to experience various forms of stigma and discrimination in community interactions with friends and neighbours, thus, exhibiting high rates of discrimination compared with other categories of people. However, Dugue et al (2011), adds that many people living with HIV were reluctant to let their friends or neighbours know of their HIV status, although there were frequent instances of respondents' HIV positive status being disclosed to friends and neighbours without respondents' consent. Furthermore, Deacon (2005), states that in the study respondents expressed fear of being HIV

positive and being on Art. Their fear was based on the observation that community members tend to associate HIV positive status with engagement in immoral behaviours. However, the participants, particularly women, attributed social stigma to community members' perception that all HIV positive people were prostitutes or engaged in sex carelessly and that being on medication means that one was about to die.

According to Grossman (2013), the fear of stigma experienced by people on Art result in non-adherence to medication through a number of ways. Firstly, because of stigma, a substantial number of respondents revealed that they fear of being identified by people who knew them, including health staff at nearby health facilities. Consequently, a person living with HIV may feel compelled to go to a different community, district or even region to access services for fear of being known or identified by those who know him or her.

According to Herman (2005), stigma marks people as different and as disgraced, denying individuals' dignity, respect and the right to fully participate in their community work or activities. It may impede access to education, work or even the much needed health care. However, many people living with HIV respond to stigma in many ways. Such as acceptance, concealing the identity of ARVs, preemptive disclosure and spiritual devotion.

According to Makowe et al (2008), most people living with HIV and AIDS on Art accept the condition of being HIV positive and consider HIV and AIDS as no longer fatal and experience a remarkable improvement in health. However, Makowe et al (2008), adds that the notion of regarding HIV and AIDS as an ordinary disease has been internalized mainly by people who are on Art for three or more years. Makowe et al (2008), points out that in a study that some respondents spoke of the support they received from their families as having contributed to the peace of mind they were experiencing at the time.

Nachege et al (2004), states that in the face of stigma and discrimination, people living with HIV are compelled to conceal the identity of ARVs by putting them in an unlabeled envelope, or one bearing a drug name that is unfamiliar to most lay people. Nachege et al (2004), adds that this measure was well expressed by one of the respondents that he removed ARVs from their original container and put them in a plain envelope and then takes them even in the presence of other people. According to Fetene et al (2013), sharing experiences about taking ARVs in support

groups play an important role in handling stigma and discrimination. Furthermore, such groups constitute a forum for learning about challenges related to living with HIV and taking ARVs.

Most people infected with HIV struggle with issues of disclosure to others, particularly when first diagnosed. According to Mbonu et al (2009), some people on ART disclose their HIV status to family members, neighbours and/or work colleagues and talk very freely about it and the challenges they face, which in turn helps to preempt gossip. However, Mbonu et al (2009), adds that people of this kind, who disclose and talk freely about their HIV status, can strengthen others living with HIV by helping them overcome internalized stigma, cope with stigma, rebuild their self-esteem and develop skills to take leadership roles in anti-stigma education and action.

Hodgson et al (2012), indicated in the previous studies conducted in South Africa documented that there were low levels of HIV status disclosure among adults living with HIV. Hodgson et al (2012) stated that Over half of the people having never disclosed their HIV status beyond their immediate family due to fear of stigma and discrimination along with the associated problems of rejection, abandonment, abuse and isolation.

2.4 COPING STRATEGIES USED TO MANAGE ADULTS LIVING WITH HIV ON ART

The Ministry of Health (2018) stated that then there is still no cure for HIV, however, with the advances in medical treatment and the availability of ART, HIV was being considered on as a manageable chronic illness. However, developing a healthy, positive lifestyle is a very important part of managing a person with HIV infection. According to Ministry of Health (2018), Zambia has responded positively to the challenge of HIV and AIDS by using strategies ranging from prevention to care continuum in the fight against HIV. In addition, the government recognizes that HIV prevention efforts must be complemented by care and support initiatives, hence, positive steps have been taken to provide antiretroviral therapy to all the people living with HIV in Zambia.

According to the Ministry of Health Guidelines (2018), Zambia implemented the Universal Test and Treatment Strategy in January 2018. It was noted that although all the people living with HIV qualify for antiretroviral therapy regardless of the CD4, not everyone was ready to start straight away then. In addition, it was stated in the Ministry of Health Guidelines (2018), that health care workers offer routine testing which was the practice of systematically approaching

patients with an offer of an HIV test when seeking health care, regardless of known factors or symptoms of HIV infection. The aim of routine HIV testing is to increase the number of people screened for HIV, support the diagnosis of HIV and link people who are diagnosed with HIV to clinical services. Rodriguez et al (2016), adds that HIV diagnosis at the earliest possible opportunity is crucial to maximize the health benefits of HIV care and treatment for people living with HIV. The WHO (2011), recommends HIV self-testing as an additional testing approach that will ensure that as many people as possible are tested for HIV. However, HIV self-testing addresses stigma and confidentiality that may keep at risk individuals from testing through conventional means.

According to The WHO (2016), partner notification or index testing is a voluntary process whereby a trained provider, counselor or health worker asks the index patient about potential exposures, including sexual partners, drug injecting partners, or the patients' children. Partner notification testing services are offered to persons diagnosed with HIV, also known as the index partner. It is a voluntary process and program approach which may support notification with disclosure or without disclosing names, and may involve an offer of services at different points in time, such as time of testing and also at ART enrolment.

According to Cohen et al (2008), antiretroviral drugs have great potential to prevent HIV transmission and acquisition, including through post exposure prophylaxis (PEP) and Pre exposure prep prophylaxis (PREP) and antiretroviral therapy (ART) for treating and preventing HIV infection are provided. According to Hosek (2016), post exposure prophylaxis means taking antiretroviral medicines ART after being potentially exposed to HIV to prevent infection. The WHO (2018), states that pep should be used only in emergency situations and must be started within 72 hours after a recent possible exposure to HIV. The WHO (2018), adds that prep or pre-exposure prophylaxis was an HIV prevention method in which people who do not have HIV take HIV medicine daily to reduce their risk of getting HIV if they are exposed to the virus. Prep can stop HIV from taking hold and spreading throughout the body. The WHO (2018), states further that prep is prescribed to HIV-negative adults and adolescents who are at high risk for getting HIV through sex or injection drug use. Hosek et al (2016), also adds that when taken daily, prep is highly effective for preventing HIV infection and studies have shown that prep reduces the risk of getting IV from sex by 99% when taken daily. In this regard, prep works to keep the virus from establishing a permanent infection.

According to Alubo et al (2002), each person living with HIV needs a wellness programme which is an active programme to encourage HIV infected people to remain physically and emotionally well for as long as possible. A wellness programme promotes healthy lifestyle where both regular follow up by a clinic and a support system from the community are important. However, the media such as radio, television, newspapers, magazines and books also have an important role to play in promoting wellness.

The people living with HIV need to feel that they are still in control of their own lives and can play an active role in managing their illness. However, they must also be empowered to make the best decision for themselves. A good understanding of HIV infection and AIDS helps to reduce their anxiety and develop confidence and hope. According to the Engender Health (2004), it is essential that people living with HIV and AIDS practice safer sex. The Engender Health (2004), adds that the only way of totally preventing the sexual transmission of HIV is to avoid sex. This might be difficult for most people. However, the risk of HIV infection can be greatly reduced by changing to safer sexual practices. Condoms must be used every time the person living with HIV has sex is much safer.

The ABC of safer sex is abstinence that is no sex, be faithful and always sex is abstinence no sex, be faithful and always use a Condom. Worley et al (2009), states that community support is also one of the strategies used to manage people living with HIV. If the HIV epidemic is to be controlled and people living with HIV adequately managed, the community will have to become actively involved in all aspects of prevention, support and care. However, this might be difficult where poverty, gender inequality, stigma and discrimination are common and HIV infected people see themselves as helpless victims. Worley et al (2009), adds that local communities must take ownership of their joint problem and not simply rely on Government to provide the services. Worley (2009), states that fear, denial, stigma and discrimination will have to be overcome before a communal sense of responsibility, can be developed and people believe they can contribute positively to solving the problem and make a difference in their lives and communities. Furthermore, prevention and management of HIV infection must be seen as part parcel of the same integrated community programme; hence, effectiveness of the members depend on the active participation of all members. Everyone in the community partnership and health services becomes important in preventing HIV infection.

According to Nunes et al (1995), the best ways of supporting someone who is HIV positive is to encourage them to join a group of people who are also HIV positive. Hence, when they join such groups, they can share experiences in a safe, non-judgmental environment, group meetings can also be used to provide education, understanding and hope and this can result in an improved quality of life. In addition, many people living with HIV and AIDS may adapt to positively through living their social support networks. Nunes et al (1995), adds that social network, consisting of some individuals who are linked to ego and roles such as emotional support, financial, guidance and advise offered to them in a variety of situations. Nunes et al (1995), adds further, that network studies have shown that family, friends and relatives are important sources of social support that can provide the different types of support systems.

According to The WHO (2008), volunteer health workers are lay members of the community who want to help people who are living with HIV. However, home nursing is the greatest need because people living with HIV who are sick may need to be fed, cleaned, comforted and cared for. Therefore, provision of knowledge, skills and support for volunteer health workers is essential because they play an important role in reducing stigma and discrimination of people living with HIV in the community.

According to Cohen et al (2008), antiretroviral drugs have great potential to prevent HIV transmission and acquisition. Other means include, through pre-exposure prophylaxis and post-exposure prophylaxis, by preventing mother to child transmission and through antiretroviral therapy that achieves viral suppression.

However pre-exposure prophylaxis should be made available for people who have had a significant exposure to HIV. Therefore, guidance on the use of pre-exposure prophylaxis, post-exposure prophylaxis and antiretroviral therapy for treating and preventing HIV infection should be provided. The WHO (2007), states that guidelines on the use of antiretroviral therapy for treating and preventing HIV infection have been provided. In this regard, countries should establish appropriate criteria for risk assessment, develop models of service delivery and decide on the most strategic combination of antiretroviral and other prevention approaches based on their country context. Furthermore, particular attention should be given to testing for HIV before people start pre-exposure prophylaxis in order to minimize the risk of the emergence of HIV

drug resistance. Hence, HIV drug resistance surveillance should be extended to cover pre-exposure prophylaxis services if they are introduced.

According to the Zambia National AIDS Council (2018), a lot of HIV prevention programmes targeted at adolescents and young women exist in Zambia. For example, Zambia is one (1) of ten (10) countries involved in the DREAMS (Determined, Resilient, Empowered, AIDS free, Mentored and Safe) initiative to reduce new infections among adolescent girls and young women. The DREAMS initiative has taken tremendous strides to integrate services and approaches, and to test innovative ways to address the social drivers of HIV, including gender based violence and gender norms. The programme offers a diverse package of interventions, including condom promotion and provision, HIV testing and counseling, educational subsidies, school-based HIV and violence prevention initiatives and parent/care-giver initiatives to change gender norms in the communities.

According to the UNAIDS (2018), voluntary medical male circumcision (VMMC) has been a key pillar of Zambia's HIV prevention strategy since 2007. Zambia's VMMC package also includes HIV testing and counseling, risk reduction, wound care and partner testing. Zambia has adopted 2013 WHO treatment guidelines that recommends anyone who tests positive for HIV should be started on treatment, regardless of their CD4 count. This is particularly important as early treatment can increase the likelihood of someone achieving viral load suppression, when levels of HIV are so low the virus is effectively suppressed and cannot be transmitted considering the huge increase in the number of people eligible for treatment under these new guidelines. The UNAIDS (2018) indicates that Zambia has shown commitment to increasing ART coverage. According to Pakenham et al (1994), indicated that social support from the community groups were correlated with the health status of the individual. Hence, the worse the illness, the more support was needed for the individual.

2.5 GAPS IN THE CURRENT LITERATURE

There has not been sufficient literature on adults living with HIV and AIDS on ART. The research done in this study area is even inadequate in Zambia as well. There are very few in-depth qualitative studies that have been done on the lived experiences of adults living with HIV on ART. However, much of the literature about adults living with HIV is with regard to the physical illness, psychological and social issues, impact of stigma and how they respond to

stigma, and on strategies being used in the management of adults living with HIV on ART. The Zambian case is a very unique one. Although there are non-stigmatization and discrimination laws, the situation on the ground is different as the people living with HIV and AIDS still complain of unfair treatment. Hence, there is need to ascertain this through the study. The focus on adults living with HIV is critical because some of the adults are sexually active. Hence, in considering stigmatization and discrimination, the study focused on them as they lead their lives and how they handle the challenges that come with living with HIV and AIDS.

2.6 CHAPTER SUMMARY

This Chapter provided an overview of the current literature on adults living with HIV on ART with regard to physical illness, psychological, social issues, HIV stigma and how they respond to stigma and strategies used to manage HIV. It has been noted from the literature that adults living with HIV are challenged with many issues related to the complications that arise from the realities of living with HIV and AIDS.

CHAPTER THREE: METHODOLOGY

3.1 OVERVIEW

This chapter discussed the research design, target population, sample size and sampling procedures and research instruments. In addition, the data collection procedure, trustworthiness of data, data analysis, ethical consideration and a summary of the chapter were equally discussed.

3.2 RESEARCH DESIGN

The study employed an interpretive phenomenological approach. This was supported by a qualitative approach to data collection. An interpretive phenomenological approach can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced. It also conjures qualitative aspect in its design (Kombo and Trump, 2006). The interpretative phenomenological approach has the potential of helping to bring out the reality from individual's narratives of their experiences and feelings to produce in-depth descriptions of the phenomenon.

The goal of a phenomenological method is to uncover the meaning of the lived experiences through analysis, intuition and describing a phenomenon from individual's reports in the way they appear and without any preconceived notions (Parse et al, 1985). However, it is qualitative in nature because it focused on the commonality of the lived experience within a particular group. Through this process the researcher constructed the universal meaning of the situation or experience and arrived at a more profound understanding of the phenomenon. Furthermore, a combination of data sources which includes interviews and observations were used as research instruments.

In the gathering of data, interviews and observation were used. These methods are found appropriate because they gather data about people's beliefs, perspectives, feelings, motives, past and present behaviour and events (Botma et al, 2010). The methods also stem from their ability to capture verbal and non-verbal questions. Hence, the researcher was able to pay attention to body language and expressions which may indicate levels of excitement or discomfort brought about by certain questions.

3.3 POPULATION

Bless et al (2006:98), has referred to population as, “the entire set of objects or people which is the focus of the research study, and about which the researcher wants to determine some characteristics.” Therefore, the target population was adults living with HIV and AIDS and on antiretroviral therapy in the selected compound of Lusaka in Zambia.

3.4 SAMPLE SIZE

According to Punch (2005:101), a sample refers to, “the actual group included in the study from which data is collected, while a sample is drawn from the population. The sample is studied, in order to assist in explaining some facts of the population.” A sample of 12 respondents was drawn into this study consisting of 5 male adults and 7 female adults living with HIV and AIDS on antiretroviral therapy. The study employed the principle of data saturation to come up with the sample size. O’Reilly et al (2012), states that data saturation usually means that data should be collected until there are no surprises in the data and no more patterns or themes are emerging from the data. To this effect, a minimum of twelve (12) interviewees were adequate. In relation to this study, the sample size of (5) male adults and (7) female adults living with HIV and AIDS on antiretroviral therapy was adequate since they were above the presented minimum standard of twelve (12).

CHARACTERISTICS OF RESPONDENTS

Participant No.	Age	Appropriate length of time of diagnosis	Marital status	Number of children	Job description	Gender
1	53	4 years	Married	Two	Health worker	F
2	36	4 years	Married	Two	Barber man	M
3	28	3 years	Married	Three	Unemployed	F
4	52	2 years	Married widow	One	Business woman	F
5	26	1 year	Single	Nil	Unemployed	M
6	47	20 years	Married	Four	Bricklayer	M
7	43	8 years	Single	One	Teacher	F
8	27	2 years	Single	Nil	Unemployed	M
9	42	1 year	Married	Three	Business man	M
10	49	10 years	Single	Two	Nurse	F
11	35	3years	Married	One	Unemployed	F
12	30	5 years	Married	Three	Business woman	F

The table above shows the characteristics of the twelve (12) respondents who participated in this study. The table provides data regarding research participants and is necessary for the determination of individuals as they represent the sample of the target population for generalization purposes.

3.5 SAMPLING PROCEDURE

According to kasonde (2013), a sampling procedure is a plan that explains how the respondents for the study are to be selected from the population. A sampling procedure merely helps the researcher in selecting those to participate in the study. This study used critical case sampling. Patton (1990), states that critical case sampling procedure is a type of purposive sampling where the researcher selects a small number of important cases that are most likely to give the important information about the phenomenon he or she is studying.

In this view critical case sampling was chosen for this study because it allowed the researcher to develop logical generalization from the rich produced cases. Possible participants were based on the following criteria; adults who contracted HIV and were receiving HIV treatment, male and female adults. The sample in this study was drawn from twelve (12) adults living with HIV and on Art.

3.6 RESEARCH INSTRUMENTS

The major instruments the researcher used in the study were the interview guide and the observational checklist. According to Seidman (1998), an interview guide is simply a list of questions that you ask your participants during interview, while observation according to Akinde et al (2004), is an instrument that is employed by a researcher in which an individual behavior or situation is observed and recorded.

The interview guide and observational checklist were used mainly to the adults living with HIV and AIDS. The field notes and audio were recorded to support the observation of the participants' behavior and their interactions. Berg (2007), states that semi-structured interview

guide allows for in-depth probing while permitting the interviewer to keep parameters out by the study.

3.7 DATA COLLECTIONS PROCEDURE

Approval was sought from the UNZA-ZOU Ethical Committee. The study site was Phills compound located within Lusaka District of Zambia. The researcher engaged a research assistant who helped to identify adults living with HIV on ART in the compound. The research assistant identified twenty (20) respondents and out of twenty (20) identified, six (6) had commitment outside town, while two (2) were not willing to be part of the study. Hence, the researcher remained with twelve (12) respondents. Hence, after consent was given from the respondents, data collection started immediately. Adults living with HIV and AIDS were interviewed individually in their homes. In this study, the researcher had a list of open-ended questions to be covered and worked through them in a methodical manner. In this regard, similar questions were asked to each participant. The researcher allowed the respondents to choose a convenient time for the interview. The interview lasted for about thirty (30) minutes per participant. The interviews were audio recorded and then transcribed. This technique was chosen, because as Seidman (1998:3), points out that, “at the root of in-depth interviewing is an interest in understanding the experience of other people and the meaning they make of that experience.”

Tutty et al (1996:52), adds that, “interviews provide researchers with an opportunity to learn that which you are able, unable to directly observe in a person’s natural environment, and that is particularly true when you are interested in learning about a person’s experiences, behaviour, thoughts and feelings.” The Semi-structured interview design was appropriate for this study as it permitted a focused exploration of a specific topic. Fossey et al (2002), states that Semi-structured interviews also allow the researcher to be aware of non-verbal cues which are valuable for interpreting the participants’ feelings towards certain questions and around various responses they will give. Sommer et al (1997), adds that the semi-structured interview design does not restrict the interviewer to a prescribed interview schedule, yet it gives the interviewer the opportunity to ask the same questions to all the participants.

As questions were semi-structured, the researcher used an interview guide to help ensure that the same were questions asked to each respondent for data consistency. The researcher also made

sure that the participants were allowed to take the discussions where they wanted to, so that they appreciated and were able to exert control over the nature of their interview experience. The Observation checklist was used to note each participant's behaviour during the visits, because the researcher visited the respondents twice in a week for a month in order to observe their behavior in their natural setting. The field notes were written to support the observation of the participants' behaviours and their interactions. Note taking was helpful where non-verbal communication occurred. Using both techniques served as a way of triangulating the data sources and enhanced claims for validating (Kimchi et al, 1991).

3.8 DATA ANALYSIS AND INTERPRETATION

The analysis that the researcher used for this study was qualitative technique of thematic analysis, which incorporated the inductive approach. According to Boyatzis (1998), thematic analysis is a method to identify, analyze and report themes or patterns within data. Braun et al (2006), states that thematic analysis is a search for themes that emerge as being important to the description of the phenomenon. Additionally, it is a form of pattern recognized within the data, where merging themes become the categories for analysis.

Patton (1990), notes that the analytic process involves moving from description to interpretation, where the significance of the patterns and their meanings will be highlighted. Therefore, in the analysis, the researcher used the six (6) steps of thematic analysis by Braun et al (2006), where she first looked at familiarization with data, generate initial codes, search for themes, review themes, define and name themes and finally produce the report.

Firstly, the researcher familiarized herself with the data by listening to each recorded interview, reading each transcript at least twice and transcribing the entire interview so that she would fully immerse herself in the data and have a better appreciation for the realities of participants' experiences with HIV and AIDS on ART. After familiarizing herself with the data, the researcher then started the process of coding. The researcher went through line by line to generate the initial codes. The researcher generated codes manually by highlighting the different codes with various colours of highlighter and writing notes on the transcript.

After defining the codes, the researcher examined the various codes from all the transcripts and searched for possible themes. She also searched for repeated codes, such as uncertainty, stigma,

guilt, anger, and depression and then she created a table with potential themes from her defined codes. During the stage of defining and reviewing themes, the researcher generated and visualized possible themes from the transcripts. The researcher further embarked on the hard process of defining the themes and including inclusion and exclusion criteria. The researcher defined and named themes according to the essence of what each theme was about and then she finalized them on a table. However, the themes and sub-themes that emerged from data analysis were dealt with in detail in Chapter 4, where findings of the study were discussed. The discussion to conduct data analysis manually was influenced by the number of participants who took part in the study and the researcher's willingness to learn the process of data analysis manually. However, the intimacy with data that was gained by this process which gave valuable insights into the lived experiences of adults living with HIV and AIDS who were on Antiretroviral therapy.

3.9 ETHICAL CONSIDERATION

A consideration of ethical issues is necessary in any research involving human subjects and especially when dealing with sensitive topics like lived experiences of adults with HIV and AIDS on Antiretroviral therapy. Ethical consideration concern principles and guidelines, which researchers must follow in order to ascertain that they do not violate the physical, psychological and emotional state of the participants of the study during the data collection process. For results to be acceptable, the study is obliged to follow certain ethical principles. Devos (2002:63), defines ethics as, "a set of moral principles that are suggested by an individual or group, which are subsequently widely accepted, and offer rules and behavioural expectations about the most correct conduct towards experimental subjects and participants, employers, sponsors, other researchers, assistants and students."

Before each interview, the researcher explained the purpose of the study to each participant. All research participants read and signed a consent form prior to their interview. The research discussions consisted of very sensitive questions and the researcher ensured that each interview was conducted in a safe environment where the participants had access to a professional counsellor if necessary. The signed consent forms, audio-recording transcripts and field notes were kept in a locked file cabinet and on a password protected computer, and each file also had

password protected to maintain confidentiality in order to protect anonymity and help ensure confidentiality. All of the research participants' names were changed to a pseudonym, which was chosen by the research participants if possible or were obtaining a pseudonym was possible. Potential risks of this research included the possibility of some adults living with HIV experiencing an emotional upset as they discussed sensitive sexual health matters or HIV disclosure or other personal issues. However, options to address emotionally upsetting experiences included stopping or postponed the discussion, and talking about possible supports for their distress that were available such as trained counselor, support workers or other clinical care team professionals. However, ethical approval was received from the university of Zambia Ethical Committee.

3.10 CHAPTER SUMMARY

Chapter Three has described the research methods employed in this study, including the qualitative approach, phenomenological approach, population, sampling procedure, data collection procedure, data analysis and interpretation. In addition, ethical considerations and protection of human subjects was discussed. The next chapter deals with the presentation of the findings concerning the lived experiences of the adult with HIV and AIDS on Antiretroviral therapy.

CHAPTER FOUR: PRESENTATION OF FINDINGS

4.1 OVERVIEW

This chapter presents the findings of the study. The findings are based on the set questions. These were as follows:

- i. How are the contextually lived experiences of adults living with HIV and AIDS who are on ARVs therapy in the study site?
- ii. What factors have led to current lived experiences among individuals living with HIV and AIDS and are on ARVs therapy in the study site?
- iii. What are the coping strategies used to manage lived experiences of adults with HIV and AIDS on ARVs in the study?

4.2 WHAT ARE THE CONTEXTUALLY LIVED EXPERIENCES OF ADULTS LIVING WITH HIV AND AIDS WHO ARE ON ART?

Illnesses

Adults living with HIV on ART were asked what kind of physical changes they experienced while living with HIV infection. All the adults living with HIV interviewed indicated that they developed illnesses related to HIV infection and that they also experienced several changes of physical effects or illnesses, such as fungal infections in the mouth, chronic tonsillitis, dizziness, pneumonia, tuberculosis, hepatitis sarcoma, chronic cough, flu, diarrhoea, swollen legs and many others.

Participant number 5 said, *“A lot of little things started to happen, such as a fungal infection in my mouth, chronic tonsillitis and bottom shooting pain. So they were mild stuff but I started to think it is normal since the body is no longer the same anymore.”*

Participant number 6, who was 20 years and a survivor on Art explained his greatest change related to his physical illness said:

“I have just been told I have got tuberculosis, hepatitis sarcoma, diarrhoea and have lost weight.”

Seven women experienced physical changes as a result of the adverse side effects of the medication they were taking. The women experienced hypertension and dizziness. Participant number 10, had three falls and experienced a head injury as a result of hypotension related to the side effects of the medicine she was taking. She said,

“My blood pressure dropped so much that I was not allowed to walk and had to wear special stockings to help me maintain blood supply in the body. Unfortunately, I developed neck problems from the falls.”

Three men explained that they experienced physical illness such as chronic coughs, flu, pneumonia and swollen legs which appeared from time.

Participant number 9 said, *“I normally fall sick from time to time, you will find that I have a dry cough which does not finish, pain in my chest and even my legs get swollen. Maybe it is because of my condition.”*

Sexual behavior changes

Respondents were asked if they ever experienced any changes in their sexual behaviour. Some respondents in the study narrated that sexual thoughts were their worst enemy such that each one of them had to struggle with the thoughts especially with their condition.

Summing up their points, Participant number 5 said,

“I told myself that I will never engage myself in any sexual relationship because I am scared of transmitting the virus to others.”

Participant number 8, said that he has realized how his sexual behavior was a risk as he did not want to infect his wife.

“I was a real man, I could have as many girlfriends/partners as I wanted after all I am handsome and would girls fight over me. Unfortunately, my wife didn't leave me. She really loves me so much that even if she hears stories about me, she stood with me”

4.3 PSYCHOLOGICAL RELATED ISSUES

Adults living with HIV and AIDS were asked how living with HIV and AIDS affected them psychologically including their day to day living. The adults interviewed expressed a variety of

emotional disturbances, which occurred in their day to day living such as anger, guilt, confusion, depression, discrimination, loneliness, stigma and fear of death.

One of the participants stated that people infected with HIV were “in and out” of an “emotional cycle” which was disturbing and continued indefinitely. He added that the cycle started after being diagnosed with HIV infection as follows:

“I have developed an emotional cycle ever since I was diagnosed with HIV, from nowhere when I start to think of my status, I always experience anger, uncertainty, guilt, confusion, depression and fear related to death.”

Anger

Participants experienced feelings of anger related to the HIV infection. In the case of women, they expressed feelings of anger related to the HIV infection resulting to negative social reactions.

Participant number 11 said, *“When I was first told that I am HIV positive, I felt anger towards my husband because I knew that he was the one who had infected me.”*

Participant number 7, felt angry when the results of HIV infection were communicated to her because she had never anticipated ever contracting the virus as she was faithful to her husband. She was in pain and felt hurt. She stated that:

“Being positive makes me angry because when I think of the wasted years of my school and college life, I feel my time has been cut short.”

Uncertainty

Most of the participants were uncertain about their future and some participants such as number 4 asked questions like, *“when will I die?”* or *“how many years am I still remaining with to live?”*

Participant number 12, started that, *“I don’t know what is going to happen in my life later,”* and Participant number 8, added that: *“How can I plan my future since I am HIV positive? I will soon die.”*

Suicidal attempts

Three participants experienced suicidal attempts on two occasions. Their suicidal thoughts and attempts did not develop before being diagnose HIV positive. Participant number 8 attempted suicide when his partner rejected him and broke their relationship after he shared his HIV results with her. It was observed from his contribution when he said that:

“It was so painful to be rejected by the person you love too much especially at a time when you need a shoulder to lean on. I was devastated and I ended up taking doom but fortunately my brother found me and rushed me to the hospital.”

Participant number 6, narrated that he attempted suicide twice because he felt that his long term illness with AIDS was agony and unbearable. He said,

“I am sick and tired of every time going to the hospital. I am tired of taking pills everyday and I am tired of every infection I do get often. I can’t handle it. I took a rope to kill myself but my wife found me in time and rescued me. I also tried to drink doom and lucky enough I was rushed to the hospital and I am still here today.”

Participant number 2 revealed that dying from AIDS was perceived to be great suffering and too painful to bear, she said,

“I didn’t want to die of AIDS, because I heard a lot of stories that in the last stage of AIDS people suffer a lot and die in pain. Therefore, I didn’t want to experience such suffering and my best option was to commit suicide. So when I was about to take doom, my husband rescued me.”

Guilt

Two participants expressed a sense of guiltiness on the issues related to HIV transmission.

Participant number 8 blamed himself for the kind of lifestyle he led before which resulted acquiring HIV and AIDS by not practicing unsafe sex.

Participant number 9 also blamed himself and he said, *“I blame myself because I do not know what came over me to have an extra marital affair outside my marriage, I am now infected with HIV and I have also infected my wife just because of my carelessness.”*

Confusion

Three participants described the experience of confusion in different ways.

“I am confused because I don’t know how I acquired the virus because I have only one girlfriend and I used protection,” said Participant number 5.

Participant number 1 said, *“I am still confused up to now because everything on me is ok because I don’t have any symptoms of HIV.”*

Participant number 11 said, *“I am confused because I don’t know how I should tell my relatives about my HIV status.”*

Depression

Some respondents indicated that they experienced depression in their early diagnosis of living with HIV, resulting into self-stigma. To that effect, Participant number 6 stated,

“I feel sick all the time and I feel all the people I meet know my status so I try by all means to isolate myself from other people.”

Fear related to death

All the participants experienced fear of dying and reported feeling anxious about death most of the time. In most parts of the interviews, they would refer to death.

Participant number 10 said, *“I always think of HIV all the time, more especially if I get sick, and I tell myself that this is the end of me and I will die anytime.”*

Participant number 6 said,

“A year ago I was very sick and I was taken to the hospital where I was diagnosed with T.B. At that time, what was in my mind was that I was dying.”

In summary, adults living with HIV and AIDS in this study passed through many phases in terms of how the HIV infection affected their lives. Each participant experienced psychological effect and sexual behaviour change differently.

4.4 SOCIAL RELATED ISSUES

Respondents were asked to share their social difficulties which they had been experiencing since they were diagnosed with HIV infection and they were also asked to describe any difficulties or traumatic experiences they have had in their lives related to their status. All the respondents viewed AIDS as a “social stigma” and as they frequently experienced rejection, stigma and discrimination.

Rejection

Participant number 3 said,

“The problem is that when you are HIV positive, a lot of people judge and label you as a prostitute.”

Participant number 5 said, *“I was rejected by my husband because I tested positive for HIV AND AIDS.”*

Two people talked about the disruption of their relationships with their partners that happened after their disclosure of the HIV infection.

Participant number 8, experienced rejection from his former partner when he disclosed his HIV status. He said,

“I phoned my girlfriend to meet me at a certain eating place around 18:00hrs. she was very happy and we chatted for about 30minutes before I could tell her. But immediately I mentioned that I was HIV positive, she ran away from me, I couldn't even explain further.”

Discrimination

Participant number 4, felt that everyone knew about her HIV status. She felt that she was discriminated against when she went to a nearby home shop and thought that the shop attendant feared infected by her. She said,

“I went into the shop to buy bread and I felt thirsty, when I saw water in a small container, I asked for a cup of water and she told me she cannot share a cup with me and I felt rejected.”

Avoiding friendship

I observed that some of the respondents in this study seemed to avoid relationships in order to keep their status secret. I observed that three respondents on several occasions were isolating themselves from others. Participant number 7 said,

“I don’t have friends. I talk to my sister. She is like a friend to me when I come back from work. I stay in the house and I don’t go anywhere.”

In summary, adults living with HIV infection in this study experienced social problems such as discrimination, stigma, and rejection. However, each of them experienced it differently and coped differently with the challenges that they faced.

4.5 WHAT FACTORS HAVE LED TO CURRENT LIVED EXPERIENCES AMONG INDIVIDUALS LIVING WITH HIV AND AIDS AND ARE ON ARVS THERAPY?

Participants were asked to state if they disclosed their illness to their families, friends or other persons. The respondents who had disclosed were asked how they choose the people to share their HIV status with. Some participants had stated that they disclosed their HIV status to their close families while others only disclosed to their close friends. Some of the participants said that they only to their counselors because they knew that they disclosed were able to keep secrets.

To sum up their responses, Participant number 3 remarked that,

“I disclosed my HIV status only to my mother and my husband because I trust them and they cannot tell anyone.”

Participant number 2 also stated that, *“People talk a lot, I can never disclose my status to anyone only to my wife and health care providers knows my status because I fear that if the information about status was known by many, news might spread to others.”*

Another participant added that:

“I only disclosed my status to my grandmother and my best friend because trust them and they cannot disappoint me by telling anyone.”

Stigma

When the participants were asked how the other person reacted to the news about their HIV positive status, they responded that their families and friends had accepted them. They added that this had put their minds at rest. The researcher also asked for those who had not disclosed their status, why they have not done so. Some of them said they could not disclose their status to anyone because of fear as they felt that people talked too much, while others because of fear of stigma. Some however, said that they feared to disclose because they did not know how people were going to react towards them. All the respondents who did not disclose their HIV positive status stated that they felt lonely when they talked about their expectations from their social contacts and the realities of being stigmatized by the society.

Participant number 1 experienced some form of stigma from her husband since he was not HIV positive. She noted that:

“I view myself as nothing, because of what my husband says to me. He keeps saying to me that (kaya kanayaka kuti) meaning he doesn’t not know where I got the disease from. I am so angry with myself.”

Participant number 12 also experienced some form of stigma from her family because she is not being invited to most of the functions the family holds. She complained that she would just hear about the functions or gatherings after they had happened. She said,

“I feel the pain of being HIV positive, I am not considered as one of them when there is a kitchen party or wedding in the family. I am always told not to be found in the places where there are a lot of people because of my condition.”

Loneliness

Two participants expressed feelings of loneliness when they talked about their expectation of social contacts and the realities of being stigmatized by the society. Participant number 6, who has been living with HIV for twenty (20) years feels lonely in the way the community treats him. He said,

“I feel very lonely. It is like your whole lifestyle has changed or crumbled. It is like I have been born again because I have lost many of my friends whom we would drink together. My life has

really changed, I can no longer go out with my friends because they are nowhere to be seen or found.”

Participant number 3 felt lonely when her relationships with friends changed because of being positive. She said,

“It hurts and it is so hard to believe because before my HIV status was known, most of my friends would call me and I would do the same. All of a sudden, all of that stopped and I was at home alone all the time. It is not easy I get very lonely.”

Fear of Disclosure

All the 12 respondents expressed great concern about disclosing their positive status to others, the decision to disclose, to whom and when to disclose was a major issue for them.

Participant number 7 narrated that,

“When I was first told I had the HIV infection I just shared it with my wife because I trust her and that she is able to keep it as a secret.”

Participant number 9 also said,

“I have only told my wife and my mother, I could not share the information with any of my other relatives because I fear my HIV status news might spread to others.”

Participant number 1 said,

“I would be judged and blamed by others if I disclose my condition. I did not want any other person to know about my HIV status except my husband.”

Participant number 6 said,

“People will have judged me if they discovered my condition. I did not want to tell my wife at the beginning but I had to disclose to her because she had to take all the necessary precautions to protect herself from getting the virus as well. She is the only person who knows about my status, no one else knows and she promised me she will not tell anyone else.”

Participant number 5 indicated that he was so discrete when it came to the issue of his HIV status and he would not disclose his status even to with his family. He said,

“I have only told my best friend about my status because my relatives talk too much. If I told them, they will take me to be a playful man.”

Community based adherence Support

From the observations during data collection, the researcher visited three respondents twice in a week for two months and during the visits she inquired whether the Community Based Adherence Support had visited. The respondents always stated that they had never been visited. Hence, from this observation, the researcher concluded that adults living with HIV and AIDS lacked community based adherence to medication and emotional support.

However, the researcher was pleased on two occasions to find another adult (friend to one of the participants) living with HIV and AIDS had visited. The researcher was introduced to the visitor who seemed uneasy at the introduction. Nonetheless, he calmed down after further explanation from the host. Hence, they explained to the researcher that, it was the way they supported one another which in turn gave them the ability to cope with HIV and AIDS.

4.6 WHAT ARE THE COPING STRATEGIES BEING USED TO MANAGE LIVED EXPERIENCES OF ADULTS WITH HIV AND AIDS ON ARVS THERAPY?

There were many strategies that the adults living with HIV and AIDS were employing in order to cope with their HIV positive status. All the respondents despite their different circumstances noted that for them to cope with their HIV and AIDS status, they had to adapt to their new ‘normal’ or circumstances of living with HIV for the rest of their lives.

Taking ART Treatment

The participants were asked to state whether they were on Antiretroviral therapy and for those who were, how long have they been on the same. All the respondents stated that they were on ART treatment. They all recommended the commencement of ART treatment once one was diagnosed with HIV. They all said that taking ARVs formed a fundamental part of their everyday life. The participants’ years of taking ART varied from one (1) year to twenty (20) years. They all reported that they did take their ARVs one everyday but their time varied because others take their medicine at 18:00hours every day while others do so between 20:00 to 22:00 hours. Most of the participants identified taking medication everyday as a challenge which reminded them that

they were living with an incurable disease. However, they all knew and appreciated that being healthy required total adherence.

Participant number 2 said,

“I only have a chance to live and as such I have to take my pills everyday and eat healthy.”

Participant number 4 said,

“This is my only life, so I have to take my medication everyday.”

Participant number 5 said,

“If I don’t take my medication I will get more sick and die.”

Another participant said,

“I have no option. I have to take my tablets everyday because this is where my life lies.”

All the participants reported a number of factors that contributed to their negative experiences of taking and adhering to their ARVs and some of these include the following; taking medicine (or ARVs) everyday and at the same time, ARVs regimes being changed to an injection or find a cure for HIV.

Participant number 10 said,

“I have to drink the pills everyday whether am sick or not and they don’t taste nice. How I wish they can change them to an injection once a year or every six months.”

Participant number 6 said,

“I have taken many types of treatments and I feel tired of taking pills for the rest of my life. I wish they can convert the pills to an injection once in a year.”

Another participant said,

“I wake up everyday so that I can eat and take my medicine. How I wish they can find the cure for HIV.”

Family Support

When asked to state if they have any family support or belong to any support group for people living with HIV and if attending any support group makes it easier for them to live a positive life. All the participants reported that they were in the care of family members. Some of them stated that they were experiencing or seeing support from individuals and groups.

Participant number 7 said, *“They give me all the support I need and they care and love me This really makes life a bit easier just knowing that they care.”*

Also Participant number 3 said,

“I cannot complain because all my relatives and my wife give me the necessary support, especially, when I am sick they are always there for me.”

While Participant number 5 said,

“I feel loved by my grandmother because when I am busy and when it’s time to get my medication, she would go and get for me, therefore, I see her as my support.”

Visiting the ART Clinics

All the participants spoke about their long term positive experience of receiving treatment, care and support services at their clinics which they described as a routine. They all visited their clinics every after 3 months and for their scheduled checkup. During the visits, participants reported that they do see their doctor, collect their ART treatment, and attend the support group sessions.

Participant number 6 said that she never misses her appointments because they were part of her life and as such they have become her normal routine.

“I always come to the clinic and I have been coming for twenty (20) years now.”

Participant number 8 also stated, *“the experience is that when I am home, I feel like I am the only one taking ARVs but when I come here and see other adults like me who also take the treatment I do get reassured and encouraged.”*

Participant number 4 said,

“At the clinic, I meet others like me and I don’t have to pretend when I go there.”

Participant number 12 said,

“Every time I come to the clinic for my appointment, I always get more information about HIV and AIDS. They explain everything so that I know exactly what is going on and how to lead my life.”

Seeking out support networks

Most of the participants in the study experienced seeking support from individuals and groups. These supporters include, their husbands or wives, friends, families, volunteers and staff members of AIDS community support groups. Some participants reported that at the beginning, seeking out for support started from people who had closer relationships with them, but then there were a lot of groups like DREAMS and AIDS Health Society which give support to those living with HIV.

Participant number 2 would not manage to take care of his family. He only had support from AIDS Health Foundation (AHF). He said,

“I have a lot of support from the loving and caring people from (AHF) who provide mealie meal and other requisites to my family every month.”

Participant number 3 said, *“I can go to the Determined, Resilient, Empowered, AIDS free, Mentored and Safe (DREAMS) and they will accept me. They will ask me for help which I need. It’s good when somebody comes to ask you, “what can I do for you?” I always say to myself that there are people out there who need me and this makes me feel there is life out there and that I am still wanted, loved and cared for. I have friends and I have life which is worthy holding on to.”*

4.7 Suggestions to improve lived experiences

Participants were asked to suggest how their lived experiences could be improved. All the participants said that the Ministry of Health should revisit the three months’ policy of their receipt of their drugs to six months, while others said the Ministry of Health should introduce a

Smart Care Card which they could use when collecting their ARVs. Some of the respondents said the government should carry out more research so that they can introduce one injection or one single tablet of ARVs for the whole year instead of taking tablets for the rest of their lives because it is so stressing and cumbersome.

To sum up some of their responses, Participant number 5 remarked that,

“I am not employed and sometimes I find it challenging to find transport money to go and collect my drugs. If they can at least be giving me medicine for six months or a year it will be much better.”

Participant number 4 said,

“I have to travel all the way from Kasama where I went to nurse my sister and come back to Lusaka just to come and get my ARVs. If they can introduce Smart Care cards in order for one to get his/her drugs wherever you are it will really help us.”

And Participant number 6 said,

“Let the government find ways to change the ARV pills to an injection which can be given once a year because I am tired of taking these pills.”

4.8 CHAPTER SUMMARY

This chapter presented the findings of the study in line with the study questions. The study found that adults living with HIV experienced physical illnesses such as fungal infections in the mouth, pneumonia, tuberculosis, tonsillitis and chronic cough, but the findings further indicated that they also expressed a variety of emotional disturbances, which occurred in their day to day living such as anger, guilt, confusion, depression, loneliness, stigma, discrimination and fear related to death.

With regard to the coping strategies being used to manage lived experiences of adults with HIV and AIDS, the study found that all participants commended ART treatment after the diagnosis of HIV. Furthermore, they were all in the care of family members and they also experienced receiving support from individuals and groups such as volunteers, staff members of AIDS community support groups and AIDS Health Society.

This chapter endeavoured to present the findings of the study in a coherent manner through qualitative techniques. It can be stated that the study has added new knowledge on lived experiences of adults on ART. It was earlier not known contextually how the lived experiences of adults living with HIV and AIDS who are on therapy were managing their lives but through this study, it is established that in the face of stigmatization and discrimination of adults living with HIV and AIDS. It has also been established that the taking of ART treatment was an indispensable part of their everyday life situation.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 OVERVIEW

This chapter presents the discussion of findings which will be presented according to the themes which were identified during the process of data analysis to answer research objectives 1, 2 and 3. These findings are backed up by quotations from the participants where applicable and they have been subjected to literature control in order to compare and contrast the findings in relation to the existing body of knowledge. The findings are discussed according to set objectives shown below:

- i. To establish the lived experiences of adults with HIV and AIDS on ARVs therapy in the study site.
- ii. To explore factors that might have led to current lived experiences among individuals living with HIV and AIDS on ARV therapy in the study site.
- iii. To ascertain coping strategies adults with HIV and AIDS and ARVs therapy were using to manage their lived experiences study site.

5.2 Lived Experiences of adults with HIV and AIDS on ARVs Therapy

The findings of the study revealed that adults living with HIV experienced recurring or serious illnesses such as tuberculosis, pneumonia, fungal infections in the mouth, chronic tonsillitis, hepatitis, sarcoma cough, flu and many others.

This is in agreement with O'Brien (1993), who reported that participants experienced physical symptoms before diagnosis of HIV infection was made and these symptoms include such conditions as flu like, lymphopathy, upper respiratory tract infection, oral infection and pneumonia. Like in this study, the most frequent diagnosis among respondents was oral infection, pneumonia and tuberculosis.

An analysis of responses of adults living with HIV showed that sexual thoughts were the worst nightmare that each had to struggle with. Some respondents believed that changing sexual behaviour after they tested positive was a way of avoiding transmitting the virus to others while others thought that avoiding engaging themselves in any sexual relationships was helping them

to avoid infecting others. This is in agreement with Parker (2000), who reported that sexual behaviour changes among people with HIV infection is considered an important part of an individual's life. In these studies, like in this study, two respondents indicated that fear of transmitting the HIV to others was a major reason for the study. This was confirmed by their expressions of having mentally active sexual sensation.

5.3 Psychological Related Issues

Some findings revealed that adults living with HIV and AIDS on ART experienced a variety of emotional disturbances, which occurred in their day to day living such as anger, guilt, confusion, loneliness, depression, fear of death and discrimination. The findings indicate that some participants experienced an emotional cycle which was disturbing and continued indefinitely. It was noted that all the participants felt anger when the results of HIV infection were communicated to them. This finding is similar with the study by Bennett et al (1990), who found that feelings of anger experienced by the people with HIV infection were experienced both directly and indirectly. In this study, both types of anger were also found. For example, several respondents felt direct anger towards people who infected them, towards the HIV that affected their life span, and towards people who rejected them.

The findings of the study further established that adults living with HIV expressed a sense of guilty on the issues related to HIV transmission. This finding is congruent with the study by Miller (1988), who found that people with HIV felt guilty following HIV testing, and the guilty feelings were related to self-devaluation with a belief about having engaged in behaviours that resulted in HIV infection and also of spreading the HIV to others. In this study, two respondents expressed the feelings of guilt by having possibly infected others prior to or after testing HIV positive.

In addition, the findings revealed that adults living with HIV were uncertain about their future because they could not tell if they would die soon or how many years were remaining for them to live. These findings support findings from previous study by Maj (1990), who indicated that the feelings of uncertainty by people living with HIV were an actual sense of anxiety, especially at the onset of the early symptoms of HIV related illness. The respondents described the feelings of uncertainty related to the future course of illness, social reactions and their future. However,

these feelings of uncertainty of one's life may not be different from those of other people who may have suffered from other fatal illnesses.

The study also established that some adults living with HIV and AIDS on ART described the experiences of confusion in different ways because they could not understand how they acquired the virus. In addition, one respondent could not believe that he had a virus because he did not have symptoms of HIV. These findings are similar to that of the study by Cohen (1990), who indicated that feelings of confusion by people living with HIV infection may be explained as human response to changes in an individual's physical health when the course of illness is unknown. He also found out in his study that some Australian homosexual people believed that HIV infection would never happen to them because they practiced safe sex.

In this study, some respondents experienced confusion after they were diagnosed with the HIV infection. It was found that the question "Why me?" was often asked by people with potentially fatal diseases. However, the experiences of confusion were related to the diagnosis of HIV infection and physical illnesses related to HIV. They did not know what happened next. Hence, being diagnosed HIV positive as reported resulted in a crisis situation where by support was needed.

The findings revealed further that adults living with HIV and AIDS on ART experienced a feeling of depression in their early diagnosis of living with HIV resulting into self-stigma. These findings are similar to that of the previous study by Deribew et al (2010), who indicated that people living with HIV and AIDS often suffer from depression and anxiety as they adjusted to the diagnosis of being infected and that they would face the difficulties of living with chronic-life threatening illness such as shortened life expectancy, complicated therapeutic regimes, stigmatization and loss of social support, family or friends.

The study established about that the most frequent experienced feeling among the respondents was depression which was as a result of acceptance of living with the HIV infection. The findings of the study further established that adults living with HIV and AIDS on ART experienced fear of dying and reported feeling anxious about death most of the time. These findings are consistent with the study by McClain et al (1992), who indicated that the feelings of fear related to death and dying were perceived as major stressors amongst the people living with

HIV infection. In addition, Holstad et al (2012), points that participants in his study had difficulty in incorporating HIV in their lives.

It was noted, in this study that the fear of dying might be explained as a common human response to terminal illness which was not different from that of other fatal diseases, such as cancer or Corona Virus Disease 19 (COVID 19). In addition, the findings from the study revealed that adults living with HIV experienced attempts to commit suicide on two occasions. And their suicidal thoughts and attempts developed after the diagnosis of HIV infection. These findings support findings from previous studies by Deribew et al (2010), who reported that the risk of committing suicide is significantly high among people living with HIV and AIDS to lessen the shame and grief of loved ones. Mazurk et al (1988), also states that most of the people living with HIV infection talked of killing themselves at some time in the future, but few carried out their threats when time came.

In this study, three participants experienced suicidal thoughts and attempts because of the illness itself which affected the individuals and also the psychological distress related to social rejection resulting from HIV and AIDS.

5.4 Social related Issues

The findings of the study revealed that some of the adults living with HIV viewed HIV and AIDS as a social stigma” and frequently experienced rejection by their own loved ones, families and by the society. These findings support the findings from previous studies by Andrews et al (1993), who indicated that people living with HIV and AIDS experienced negative social reactions after disclosing their HIV status and this caused them to develop a variety of psychological distress which include self-isolation, shame, loneliness, depression and loss of self-respect.

In this study, many respondents experienced social rejection by being categorized as prostitutes particularly those who were single. However, public media related to HIV prevention appeared to have an important role not only in increasing public awareness of HIV, but also influenced positive individual attitudes towards the people with HIV infection.

In addition, adults living with HIV revealed a great deal of discrimination which emerged as the phenomena of being stigmatized and rejected. These findings were similar to the study by

Eliason (1993), who pointed out that there were two powerful social stigma related to the social reactions towards people living with HIV and AIDS. However, these reactions include fear of contracting HIV and homophobia.

In this study, the respondents viewed HIV and AIDS as a “Social stigma and perceived themselves as being discriminated against their HIV status was disclosed.

To sum up the lived experiences of adults with HIV and AIDS, further observation from the study revealed that some of the respondents avoided relationships with other people in order to keep their status secret. This finding is consistent with other research studies in South Africa by Peterson et al (2010), who found that people living with HIV were isolating themselves from others and were more likely to experience problems. It was further observed in this study that some participants avoided relationships and this affected their social interactions whereby they ended up separating themselves from their friends.

5.5 FACTORS LEADING TO LIVED EXPERIENCES

Stigma

The study established that most of the adults living with HIV and AIDS on ART showed that they experienced stigmatization by individuals and by society and this affected their ability to engage themselves in most activities that other people without HIV do. These findings support the findings from previous study by Brown et al (2003), who indicated that people living with HIV and AIDS experience enacted and felt stigma also known as internal stigma or self-stigmatization which refers to shame, blame and the expectation that persons will discriminate against people living with HIV and AIDS infection.

In this study, it was established some respondents also experienced stigma and that they felt that they were being discriminated by individuals, family and the society.

Loneliness

The findings of the study further established that adults living with HIV and AIDS on ART expressed feelings of loneliness when they talked about their expectation of social contacts and the realities of being stigmatized by the society. This finding is similar to the findings of Schultz

(1988), who purported that a deficiency of social interaction or missing something in one's life can cause an individual to feel loneliness. In this study, it was noted that respondents felt lonely when they experienced prejudice and discrimination because they lost friendships as a result of being HIV positive.

Fear of disclosure

The findings of the study revealed that adults living with HIV and AIDS on ART expressed great concerns about disclosing their positive status to others. It was noted that the decision to disclose, to whom and when to disclose was a major issue to them. These findings are similar to the previous studies conducted in South Africa by Hodgson et al (2012), who documented low levels of HIV status disclosure among adults living with HIV. Hodgson et al (2012), adds that over half of the people having never disclosed their HIV status beyond their immediate family due to fear of stigma and discrimination along with the associated problems of rejection, abandonment, abuse and isolation.

In this study, it was established self-disclosure of HIV status by the respondents was related to perceived lack of trust of other family members, friends, or other people to keep the secret and fear of stigma and rejection.

Community based adherence Support

It was established from the observation of the participants in the study that adults living with HIV and AIDS on ART lacked adherence support through home visits by community based health workers or volunteers in order to enhance adherence. This is in agreement with the assertion by Holstad et al (2012), who indicated that in a perspective observational cohort study they compared advocates to patients receiving clinic based care and found that patients receiving home visits were significantly more likely to be retained in care with a suppressed viral load after one year. It was noted, in this study that in order to achieve 100% adherence, there was need for community based health workers to visit the people living with HIV and AIDS in order to help them enhance their adherence to their treatment.

5.6 Coping strategies

Family support

It is interesting to note that adults living with HIV and AIDS on ART reported that they were in the care of family members and recognized the central role that their families were playing in helping them cope with both illness and life in general. These findings are similar to several studies by Hazra et al (2010), who pointed out the importance of a supportive family in enabling adults living with HIV to cope with HIV. It was also noted from the respondents in this study that family meant having people who loved them unconditionally despite their HIV status. Hence such people understood the illnesses of the people living with HIV and AIDS that they would support them even when they fell ill. The study established further that where there was strong family support system, the adults living with HIV and AIDS were able to disclose their status knowing that the family would stand by them and support them.

Taking ART Treatment

It was established that all adults living with HIV and AIDS on ART in the study commended ART treatment after the diagnosis of HIV. They all expressed that taking ARVs formed a part of their everyday lives. They all reported that they took ARVs once every day, although their time of taking medication varied.

This finding is consistent with other studies by Cohen et al (2008), who indicated that antiretroviral drugs have a great potential to prevent HIV transmission and acquisition, including Post-Exposure Prophylaxis (PeP) and Pre-Exposure Prophylaxis (PreP) and antiretroviral therapy for treating and preventing HIV infection. In another study in South Africa, Petersen et al (2010), indicated that adults living with HIV infection identified the importance of the availability of life prolonging medication in assisting them to cope with HIV infection.

In this study, it was noted that all the respondents spoke about their long term positive experience of receiving treatment consistently which was related to their being able to live a longer healthy life.

Visiting ART Clinics

It was established that all the adults living with HIV in the study spoke about their long term experiences of receiving treatment, care and support services at their clinics which they described as routine. The respondents all visited their clinics every after three (3) months and for their scheduled checkups. These findings are similar to previous findings by Midtbo et al (2012), who indicated that people living with HIV infection feel strengthened to engage with others who have a similar illness and life experiences as oneself, which can play an important part in preventing the feeling of depression and loneliness in one's situation and enhance the feeling or sense of belonging. In this study, respondents talked about how the health care providers helps them to understand their illness, specifically matters regarding to HIV and AIDS including issues pertaining on relationships, sex, family planning and pregnancy.

Support Networks

In terms of support networks, some of the coping strategies for adults living with HV and AIDS in the study, it was established that most of the respondents in this study experienced seeking support from individuals and groups such as husbands, wives, families, friends, volunteers, health care providers and AIDS community support groups. These findings are congruent to ones from the study by Pakenham et al (1994), who found that social support correlated with health issues. The worse the illness, the more support needed by the adult living with HIV and AIDS.

In this study, respondents who accessed support from various groups revealed how beneficial the support provided was to them. It was established that the enhancing the quality of their lives. In addition, they also had an opportunity to maintain social activities with people who accepted them.

5.7 Suggestions to improve lived experiences

The study established that adults living with HIV and AIDS recommended that the Ministry of Health should revisit the three months' policy of their collection of their drugs to six months or a year, while other respondents stated that the Ministry of Health should introduce a Smart Care Card for one to access ARVs at any place in Zambia. Some respondents also said that the government should carry out more research on ARV drugs so that it can introduce one injection or one tablet for a year instead of taking tablets everyday which was stressing to them.

This finding is in agreement with McCathy (2017), who indicated that in just eight (8) of Lusaka's fifty-six (56) facilities that were visited, many stable patients were leaving their visits with only one (1) or two (2) months' supply of antiretroviral drugs. He added that only 46% of stable HIV treatment patients received a three (3) months' refill supply of ARVs, despite it being a national policy for stable adult patients.

It was noted that some people living with HIV would arrive early in the morning in order for them to receive their drugs early the crowds but would often be greeted by long queues and this added their stress.

In this study, respondents suggested that the Ministry of Health should revisit the three (3) months' refill on ARVs to six (6) months in order to cut down on the cost of the transport and stress of queuing up whenever they have to collect their medicines.

5.8 CHAPTER SUMMARY

The findings from the study on lived experiences of adults with HIV and AIDS on ARVs therapy revealed that adults experienced recurring illness, sexual behavioural changes, emotional disturbance, anger, guilt, uncertainty, confusion, depression, fear related to death and suicidal attempt.

In addition, the findings also revealed that adults living with HIV and AIDS also experience social related challenges such as frequent rejection, discrimination and avoidance of friendship.

The findings also revealed that there were a number of factors that led to lived experiences such as stigma, loneliness, fear of disclosure and people's attitudes towards them. With regards to coping strategies, the study found that participants were in the care of family members and they recognized the cardinal role their families played in helping them cope with both illness and their lives in general. Furthermore, the participants expressed that taking ARVs formed an indispensable part of their everyday lives. The respondents also shared, both the positive and negative experiences of visiting their clinics every after 3 months and for their scheduled checkups and seeking support from individuals and groups.

This chapter endeavoured to discuss the findings of the study in a more coherent manner through qualitative techniques. The next chapter gives the conclusion and further recommendations based on the study's findings.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Overview

While the previous chapter discussed the findings, this chapter summarizes the entire study, and the chapter ends by suggesting areas of further research.

6.2 Summary

The purpose of this phenomenological study was to explore the lived experiences of adults living with HIV and AIDS on ART. The findings indicated that living with HIV affected all aspects of an individual's life. The meaning of living with HIV and AIDS for the respondents in this study was captured into five major themes, which included physical changes, social issues, stigma and coping strategies. The respondents in the study experienced multiple changes. They endured tremendous hardship of their physical illnesses and sexual behavior changes. They also experienced loss of relationships with their significant others because of the fear of contracting the virus. Some respondents in the study experienced a lack of friendship as most of their former friends shunned them. This resulted in most of them being lonely.

Some respondents living with HIV infection in this study experienced suicide attempts. The factors precipitating suicide attempts were related to the fear of suffering death from AIDS psychological distress developed in relation to long term illness and disruption of relationships with a lover and subsequently influenced suicide attempts. A great amount of psychological problem was reported in relation to the HIV illness itself and its impact on the participants which included social rejection and disruption of relationships with others. The respondents experienced feelings of fear related to death and dying, confusion, guilt and loneliness. The respondents also experienced social rejection, social discrimination and stigmatization from various sources such as their loved ones, friends and society in general. The study respondents had tried to deal with the difficulties by utilizing various strategies such as concealing their HIV status and isolating themselves from others which were used in order to avoid facing social rejection. The participants disclosed their HIV status to those they trusted, they were able to obtain emotional support.

The emotional distress related to the fear of dying was released by maintaining optimum health. Medical monitoring was regularly practiced. The experiences of living with HIV and AIDS on

ART captured in this study led to the conclusion that HIV infection had a significant effect on an individual's day to day living. However, the dimensions underlying this phenomenon, the experiences of living with HIV and AIDS were identified and presented as chronic illnesses with a significant impact on social stigmatization on human beings. This study showed that adults living with HIV and AIDS on ART need sufficient support from the family, friends, healthcare workers and society in general.

6.3 CONCLUSION

The main objective of the study was to explore the lived experiences of adults with HIV and AIDS on ARVs therapy. Based on the findings, the study concludes that adults living with HIV and AIDS experienced frequent illness, sexual behaviour changes, emotional disturbance, anger, guilt, uncertainty, confusion, depression, fear related to death and suicidal attempt.

Although the study showed that adults living with HIV and AIDS on ART needed a lot of support from the family, friends, health care providers and society. It was noted from the study that all adults interviewed suggested that there was need for the Ministry of Health to revisit the three (3) months' policy of refilling ART to six (6) months or one year in order to reduce on the stress of looking for transport money and long queues that they had to endure at the health facilities.

6.4 RECOMMENDATIONS

Based on the findings above, the following recommendations are hereby made:

- i. The Ministry of Health should revisit the three (3) months' policy on refill of ARVs to six (6) months or a year in order to reduce on the burden of transport on adults living with HIV.
- ii. The Ministry of Health should introduce a Smart Care Card for any person living with HIV to access ARVs in any other town or district where he or she is found during the time of collection of drugs in order to minimize movement from one place to another.
- iii. The Ministry of Health should employ community based health workers in order to support adherence to adults living with HIV and AIDS.

6.5 FUTURE RESEARCH

Arising from the research findings of this study, some other aspects of this study area may need to be studied further. The areas of the study which may be studied include:

- i. Social support and coping strategies that came to light during the analysis. Further research will require other researchers to make a more concerted effort to include participants who are less connected with the community support groups. It is also necessary to explore how people with HIV receive support from their families and how the support affects the value and meanings of their lives.

Research in relation to the use of religious beliefs to enhance an individual's inner strength is also essential in order to appreciate well the lived experiences of adults living with HIV and AIDS and ART.

- ii. It is also recommended that a larger randomly selected sample, covering a larger geographical area be drawn in future research studies in order to improve the generalizability of the findings. In addition, the inclusion of health care providers and caregivers in a follow up study would provide a valuable holistic view on the lived experiences of adults living with HIV and AIDS and are on ART.

REFERENCES

- Aggleton, P., and Parker, R., (1989), *AIDS: Scientific and social issues. A resource for Health Educators*, New York: Churchill Livingstone.
- Aggarwal (2008), *Psychosocial of patients living with HIV AND AIDS*, Delhi Psychiatry Journal, Vol. 11. No. 2.
- Akinde, E.A., and Owolabi, T., (2009), *Research Methods: A pragmatic Approach for Social Science Behavioural Sciences and Education*.
- Alubo, O.A., Zwander, T.J, and Omudu, E., (2002), *Acceptance and Stigmatization of people living with HIV in Nigeria*, *AIDS Care*, 14:117-120.
- Ana, L.O., (2004), *Library and Information Science Text for Africa*, Ibadon: Third World Services Limited.
- Andrews, S., Williams, A.B., and Neli, K., (1993), *The Mother-Child relationship in the HIV-1 positive family*, *Journal of Nursing Scholarship*, 25(3), 193-198.
- Ankrah, M., (1993), *The impact of HIV AND AIDS on the family and other significant relationships: The African Clan revisited*, *AIDS Care*, 5.5-22.
- Babbie, E., (2007), *The practice of social research 11th Edition*, Belmont: Thomson Wadsworth.
- Badahdah, A., and Foote, C., (2010), *Role of shame in the stigmatization of people with Human Immunodeficiency Virus: A survey of female college students in 3 Arab countries*, *Eastern Mediterranean Health Journal*, 16:982-7.
- Belkin, G.S., Fleishman, J.A., Stein, M.A., Piette, J., and Mor, V., (1992), *Physical symptoms and depressive symptoms among individuals with HIV infection*, *Physical symptoms and depressive symptoms among individuals with HIV infection*, *Psychosomatics*, 33, 416-427.
- Bennett, M.J., (1990), *Stigmatization: Experiences of persons with acquired immune deficiency syndrome*, *Issues in Mental Health Nursing*, 11, 141-154.
- Bless, C., and Higson-Smith, C., (2006), *Fundamental Social Science Research Methods: An African Perspective 4th edition*, Cape Town: Juta.

- Bond, V., Levy, C., Suc, D., Titus, K., and Laura, N., (2003), *Kanayaka "The light is on": Understanding HIV and AIDS related stigma in Urban and Rural Zambia*, USAID, Glaxosmith Kline SIDA.
- Bogart, L.M., etal (2000), *Psychological issues in the era of New AIDS Treatments from the perspective of persons living with HIV*, *Journal of Health Psychology*, 5:500-516.
- Bonuck, K.A., (1993), *AIDS and families: Cultural, Psycho-Social and functional impacts*, *Social Work in Health Care*, 18:75-89.
- Botma, Y., Great, M., Mulaudzi, M., and Wright, S., (2010), *Research in Health Sciences*, Cape Town: Heinemann.
- Boyatzis, R.E., (1998), *Transforming qualitative information: Thematic analysis and code development*, California: Sage Publications.
- Braun, V., Clarke, V., (2006), *Using thematic and analysis in Psychology*, *Qualitative research in Psychology*, 3(2), 77-101.
- Bravo, P., Edwards, A., Rollnicks, S., and Elwyn, G., (2010), *Tough decision faced by people living with HIV: A literature review of Psychosocial problems*, *AIDS Rev*, 12(2): 76-88.
- Bronfenbrenner, U., and Morris, P., (1998), The ecology of developmental processes. In Learner, R. M., (Ed.), *Theoretical Models of human development*, Vol. 1, 5th ed, pp. 993-1028, New York: Wiley.
- Bronfenbrenner, U., (1999), Environments in developmental perspective: Theoretical operational Models, in Friedman, S.L., and Wach, T.D., (Eds.), *Measuring environment across the life span: Emerging Methods and concepts*, Washington, DC: American Psychological Association.
- Brown, L.K., Lourie, K.J., and Pao, M.J., (2000), *Children and adolescents living with HIV AND AIDS: A review* *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 41(1):196.
- Bucker, A., (2008), *Before your very eyes, illness agency and the management of Tourette Syndrome*, *Medical Anthropology Quarterly* 22(2):167-192.
- Bush Parker, T., (2000), *Perinatal HIV: Children with HIV grow up*, Focus, San Francisco, Calif, 15(2), 1.

Central Statistical Office (2015), *Analyzing and presenting statistics with Gender lens: Women and men in Zambia*.

Chuang, H.T., Devins, G., Hunsley, J., and Gill, J., (1989), *Psychosocial distress and wellbeing among gay and bisexual men with Human Immunodeficiency Virus infection*, American Journal of Psychiatry, 146, 875-880.

Cluver, L., Gardner, F., and Operaro, D., (2007), *Psychological distress amongst AIDS orphaned Children in Urban South Africa*, Journal of Child Psychology and Psychiatry 48:755-63.

Cohen, M.S., Chen, Y., McCauley, M., Gambe, T., Hosseinipour, M.C., and Kumarasamy, M, N., (2016), *Antiretro-Viral therapy for the prevention of HIV-1 transmission*, N Engl J Med 375:830-839.

Coward, D.D., (1994), *Meaning and purpose in the lived experiences of persons with AIDS*, Public Health Nursing, 11(5), 331-336.

Croft, N., (1992), Patterns of infection, in Timewell, E., Minichiello, V., and Plummer, D., (Eds.), *AIDS in Australia*, pp. 24-54, Sydney: Prentice Hall.

Deacon, H., (2005), *Understanding HIV AND AIDS stigma: A Theoretical and Methodological Analysis*, Cape Town: HSRC Press.

Deribew, A., Tesfaye, M., and Had-Michael, Y., (2010), “*Common mental disorders in TB/HIV co-infected patients in Ethiopia*,” *BMC infectious Diseases*, Vol. 10. No 1-article no. 201.

Devos, A.S., (2002), *Research at Grassroots: A primer for the caring professions*, Pretoria: Van Schalk.

Dugue, M., etal (2011), *Stigma and discrimination experiences of people living with HIV and AIDS in the Philippines*, Philippines: Positive Action Foundation.

Eliason, M.J., (1993), *AIDS-related stigma and home-phobia implications for nursing education*, Nurse Educator, 18 (6), 27-30.

Engender Health (2004), *Preventing HIV AND AIDS through family planning*, New York, NY.

Erickson, E.H., (1968), *Identity: Youth Crisis*, No. 7, WW Norton and Company.

- Fetene, G.T., and Mesfin, R., (2013), *Antiretroviral treatment in Sub-Saharan Africa: Challenges and prospects*, Addis Ababa: OSSREA.
- Fernet, M., Boucher, K., Richard, M., Levy, J.J., Utis, J., Samson, J., and Trottier, G., (2007), *Issues of sexuality and Prevention among adolescents living with HIV AND AIDS since birth*, Canadian Journal of human Sexuality, 16 (3/7), 101.
- Fielden, S.J., Sheckter, L., Chapman, G.E., Alimenti, A., Forbes, J.C., Sheps, S., and Frankish, J.C., (2006), *Growing up perspectives of children, families and service providers regarding the needs of older children with perinatally acquired HIV AND AIDS care*, 18 (8) 1050-1-53.
- Fife, B., (2005), *The Role of constructed Meaning adaptation to the onset of life threatening illness*, Social Science and Medicine 38 (4):309-316.
- Firn, S., (1995), *Psychological and emotional impact of an HIV diagnosis*, Nursing Times, 91 (18), 37-39.
- Flicker, S., Skinner, H., Read, S., Veinot, T., McClelland, A., Saulier, P., and Goldberg, E., (2005), *Falling through the cracks of big cities: Who is meeting the needs of HIV-positive youth?* Canadian Journal of Public Health, 96 (4), 308-312.
- Fox, J., and Fidler, S., (2010), *Sexual transmission of HIV-1*, Antiviral Research Jan, 85 (1) 27-39.
- Fossey, E., Harvey, C., McDermott, F., and Davidson, C., (2002), *Understanding and Evaluating Qualitative Research*, Australian and New Zealand Journal of Psychiatry, 36:717-732.
- Grossman, C.I., and Sting, A.L., (2013), *Global Action to reduce HIV Stigma and Discrimination*, Journal of the International AIDS Society, Vol. 16, Supplement 2, Article 1D 18881.
- Hatcher, A., Tsai, A., and Kumbakumba, E., (2012), *Sexual relationship, power and depression among HIV-infected women in rural Uganda*, Plos One, 7(12) e4982.
- Hazra, R., Siberry, G.K., and Motenson, L.M., (2010), *Growing up with HIV: Children, adolescents and young adults with perinatally acquired HIV infection*, Annual Review of Medicine, 61:69-185.

- Herek, G.M., (1990), *Illness, Stigma and AIDS, Psychological aspects of serious Illness: Chronic conditions, fatal diseases, and Clinical care*, 107-150.
- Herman, C., and Leah, T., (2005), *Baseline Survey of Stigma and Discrimination in the greater Mekong region: Report of qualitative surveys in Lao PDR, Thailand Vientenan and Guangxi and Yuman provinces*, China Bangkok Asia Pacific Network of people living with HIV AND AIDS and the Policy Project.
- Hodgson, I., Ross, J., Haamujoma, C., nd Gitau-Mburu, G., (2012), *Living as an adolescent with HIV in Zambia-lived experiences, sexual health and reproductive needs*, AIDS are, 24(10): 1204-1210.
- Hosek, S.G., Harper, G.W., and Robinson, W.L., (2002), *Identity development in adolescents living with HIV*, Journal of Adolescents, 25 (4), 355-364.
- Hosek, S.G., and Harper, G.W., (2005), *Psychological predictors of Medication Adherence among HIV-infected youth*, Psychology Health and Medicine 10 (2):166-179.
- Hosek, S.G., Harper, G.W., Lemos, D., and Martinez, J., (2008), *An ecological Model of stressors experienced by youth newly diagnosed with HIV*, Journal of HIV AND AIDS prevention in children and youth 9(2), 192-218.
- Holstad, M.M., Essien, E.V., Ekong, E., Higgins, M., Teplinsky, I., (2012), *Motivational groups support adherence to antiretroviral therapy and use of risk reduction behaviours in HIV positive Nigerian women: A pilot study*, African Journal of reproductive health 6(3): 14-20 PMID: 23437496.
- Holzemer, W., Human, S., and Arudo, J., (2009), *Exploring HIV stigma and quality for persons living with HIV infection*, Journal of the Association of Nurses in AIDS Care 20:161 ACA A8.
- Kasonde-ng'andu , S, Ndhlovu, D, and Phiri , J,T (2009); *Impact of guidance in counselling services on high school pupils in Zambia*. Lusaka: unza press
- Katz, I.T., etal (2013), *Impact of HIV related stigma on treatment adherence: Systematic review and meta-synthesis*.

- Kazak, A., Segal-Andrew, A.M., and Johnson, K., (1995), Pediatric Psychology Research and Practice: A family systems approach, in Roberts, M.C., (ed.), *Handbook for Pediatric Psychology*, New York: Guilford Press.
- Kermode, M., (1995), *Patients' experiences of nursing interventions during hospitalization with an AIDS-defining illness*, *Australian Journal of Advanced Nursing*, 12(3), 20-30.
- Kimchi, J., Polivka, B., and Stevenson, J., (1991), *Triangulation: Operational definitions*, *Nursing Research*, 40(6), 364-366.
- Koenig, L.J., Pals, S.L., Chandwani, S., Hodge, K., Abramowitz, S., Barnes, W., and D'Angelo, L., (2010), *Sexual transmission risk behaviour of adolescents with HIV acquired perinatally or through risk behaviour*, *AIDS Journal of Acquired Immune Deficiency Syndromes*, 55 (3) 380-390.
- Lang, N.G., (1991), *Stigma, self-esteem and depression: Psycho-social responses to risk of AIDS*, *Human Organization*, 59 (1), 66-72.
- Macks, J., (1988), *Women and AIDS: Countertransference issues*, Research Article, <http://doi.org/10.1177/104438948806900603>
- Maj, M., (1990), *Psychiatric aspects of HIV-1 infection and AIDS* *Psychological Medicine*, 20, 547-563.
- Makowe, L.N., Greeff, M., and Phetihu, R.D., (2008), *Coping with HIV related stigma in five African Countries*, *Journal of the Association of Nurses in AIDS Care*, Vol. 19. No. 2, pp. 137-146.
- Marcia, J.E., (1968), Identity in adolescence Chapters, in *Handbook of adolescence Psychology*, New York: Wiley and Sons.
- Martin, J.L., and Dean, L., (1993), *Effects of AIDS-related bereavement and HIV-related illness on psychological distress among gay men: A 7 year longitudinal study, 1985-1991*, *Journal of consulting and Clinic Psychology*, 61, 94-103.

Marhefka, S.L., Valentin, C.R., Pinto, R.M., Demetrious, N., Wiznia, A., and Mellins, C.A., (2011), *“I feel like I’m carrying a weapon.”* Information and Motivations related to sexual risk among girls with prenatally acquired HIV AND AIDS care, 23 (10)1321-1328.

Mavhu, W., Beriwick, J., Chirawa, P., Makamba, M., Copas, A., Dirawa, J., Willis, N., Araya, R., and Abas, M.A., (2010), *Enhancing psychosocial support for HIV positive Adolescents in Harare Zimbabwe*, Plos One 8(7) e70 254.

Mazurk, P.M., Tierney, H., Tariff, K., Gross, E.M., Morgan, B.E., Hsu, M., and Mann, J., (1988), *Increased risk of suicide in persons with AIDS*, Journal of the American Medical Association, 259, 1332-1333.

Mbonu, C.N., Van Denburne, B., and De Vrces, N.K., (2009), *Stigma of people with HIV AND AIDS in Sub-Saharan Africa: A literature review*, Journal of Tropical Medicine, Vol. Article 1D 145891, 14.

McCathy, E., (2017), *Clinton health access initiatives*, Scientific director, Applied Analytical team.

McClain, N.L., Schenker, M.B., and Samuels, S., (1991), *Report of occupational injury and illness in the semiconductor manufacturing industry*, Am I Public Health? 81 (1), 85-89.

McQuarrie, K., etal (2009), *HIV-related stigma and discrimination: A summary of recent literature*, Geneva: Joint United Nations Programme on HIV AND AIDS.

Midtbo, V., Shirima, V., Skovadal, M., and Daniel, N., (2012), *How disclosure and antiretroviral therapy help HIV-infected adolescents in Sub-Saharan Africa cope with Stigma*, African Journal of AIDS Research, 11(3): 261-271.

Miller, D., and Brown, B., (1988), *Developing the role of clinical psychology in the context of AIDS*, The Psychologist, 2, 63-69.

Ministry of Health (2011), *Zambia National Guidelines for HIV Counseling and Testing*, National HIV AND AIDS Council, Lusaka: Government Printers.

Ministry of Health (2015), *Zambia Country Report for Monitoring and Declaration of Commitment on HIV AND AIDS and the Universal Access*, Lusaka: Government Printers.

Ministry of Health (2018), *Zambia consolidated Guidelines for Prevention and Treatment of HIV Infection*, Lusaka: Government Printers.

Murnan, H, and Prince, J (2004), “*Research limitations and the necessity of reporting them*” American Journal of Health Education 35:66-67

Moon, B., (2008), *The stigma factor*, Washington Times.

Nachega, J.B., Stein, D.M., and Lehman, D.A., (2004), *Adherence to Antiretroviral therapy in HIV infected adults*, AIDS Research and Human Retroviruses, Vol. 10, no. 10, pp. 1053-1056.

Nicholas, S.E., (1985), “*Psychosocial reactions of persons with the acquired immunodeficiency syndrome.*” Annals of Internal Medicine, 103, 765-767.

Northcott, H.C., and Reutter, L., (1991), *Public opinion regarding AIDS policy: Fear of contagion and attitude toward homosexual relationship*, Canadian Journal of Public Health, 82, 87-91.

Nunes, J.A., Raymond, S.J., Nicholas, P.K., Leuner, J.D., and Webster, A., (1995), *Social support quality of life, immune function and Health in persons living with HIV*, Journal of Holistic Nursing, Vol. 13, no. 2, pp. 41-98.

O’Brien, M.E., Alston, G., Ayoub, M., Magnus, M., Peterman, T.A., and Kissinger, P., (1993), *Physical and psychosocial nursing care for patients with HIV infection*, Nursing Clinics of North America, 2(28), 303-317.

O’Reilly, M., and Parker, N., (2012), *Unsatisfactory saturation: A critical exploration of the notion of saturated sample sizes in qualitative research article*, Sage Journal, <https://doi.org/10.1177/1468794112446106>

Patton, M.Q., (1990), *Qualitative Evaluation and Research Methods (2nd ed.)*, Newbury Park, CA: Sage Publications.

Pada, S., Chatterjee, A., Quaser-Abdul, S.A., (2002), *Living with the AIDS Virus: The epidemic response in India*, New Delhi: Sage Publications, pp.29-30.

Pakenham, K.I., Dadds, M.R., and Terry, D.J., (1994), *Relationships between adjustment to HIV and both social support and coping*, Journal of Consulting and Clinical Psychology, 62(6), 1194-1203.

Parse, R.R., Coyne, A.B., and Smith, M.J., (1985), *Nursing Research: Qualitative Methods*, Bowle: Brady Communication Company.

Pilcher, C.D., Tren, H.L., and Eron, J.J., (2004), *Brief but efficient: Acute HIV infection and the sexual transmission of HIV infect*, DIS, 189, 1785-1792.

Rabkin, J.G., Remein, R., Katoff, L., and Williams, J.W., (1993), *Suicidality in AIDS long-term survivors: What is the evidence?* AIDS care, 5(4), 401-411.

Rao, N., Kekwaletswe, T.C., Hosek, S., Martinez, J., and Rodriguez, F., (2007), *Stigma and Social barriers to Medicine adherence with urban youth living with HIV AND AIDS Care*, 19 (1), 28-33.

Rice, E., Batterham, P., and Rotheram-Borus, M.J., (2006), *Unprotected sex among youth living with HIV before and after the advent of highly active antiretroviral therapy*, Perspectives on Sexual and Reproductive Health, 38 (3), 162-167.

Rodriguez, V., Lester, D., and Connelly-flores, A., (2016), *Integrating Routine, HIV Screening in the New York city*, Community Health Center Collaborative Public Health Reports, 131 (Suppl 1) 11-20.

Schrimshaw, E.W., and Siege, K., (2003), *Perceived barriers to social support from family and friends among older adults with HIV AND AIDS*, Journal of Health Psychology, 8:738-752.

Seidman, I., (1998), *Interviewing as qualitative research: A guide for researchers in Education and the Social Science*, 2nd edition, New York: Teachers College Press.

Selnes, I., Adrina, S.A., and Henraya, F., etal (2005), *Clinical infectious diseases*, Vol. 41. No. 6, Sep 15, pp. 875-882, published by Oxford University Press.

Shultz, C., (1988), Loneliness in Beck, C.K., Rawlins, R.P., Willims, S.R., (Eds.), *Mental Health Psychiatric Nursing: A holistic life-cycle Approach* (2nd Ed., pp. 382-399, Philadelphia: JB Lippicott Company.

Simbayi, L., Kalichman, S., and Strebel, A., (2007), *Internalized stigma, discrimination and depression among men and women living with HIV AND AIDS in Cape Town, South Africa*, Soc-Scl Med 64 (91).

Sommer, B., and Sommer, R., (1997), *A practical guide to behavioural research: Tools and techniques*, New York: Oxford University Press.

Tarimo, E.A.M., and George, J., (2004), *Providing anti-retroviral therapy in the context of self-perceived stigma: A mixed methods study from Tanzania*, Tanzania Journal of Health Research Vol. 16, no.2.

Tesch, R., (1990), *Qualitative Research*, New York: Farmer Press.

Thiangthan, W., and Bennett, T., (2009), *HIV positive pregnant women: A case study of lived experiences of people living with HIV AND AIDS*.

Turner, H.A., Hays, R.B., and Coates, T.J., (1993), *Determinants of social support among gay men: The context of AIDS*, Journal of Health and Social Behaviour, 34(March), 37-53.

UNAIDS (2004), *Report on the global HIV AND AIDS epidemic, 4th Global Report*, Geneva: Joint United Nations Programme on HIV AND AIDS.

UNAIDS (2006), *Report on the Global AIDS epidemic, policy document*, Geneva: UNAIDS.

UNAIDS (2012), *Joint United Nations Programme on HIV and AIDS, Global Facts Sheet*.

UNAIDS (2017), *Agenda for Zero discrimination in Health Care Settings*.

UNAIDS (2018), *AIDS-free: Strengthening high impact interventions for an AIDS-free generation*, AIDS-free Project.

UNAIDS (2020), *Global AIDS update: Seizing the amount*, July, UNAIDS Info.

Van-Breda, A., (2012), *A stigma as 'othering' among Christian theology students in South Africa*, Sahara- J.J Soc Aspects, HIV AND AIDS, 9 (4): 181-91.

WHO (2007), *Guidance on Global Scale up of the prevention of Mother to Child Transmission of HIV*.

WHO (2008), *Essential prevention and care intervention for Adults and Adolescents living with HIV in Resource-Limited settings*.

WHO (2010), *Towards universal access: Scaling up priority HIV AND AIDS interventions in the health sector*, 20 Avenue Appia CH-1211, Geneva: Switzerland.

WHO (2014), *HIV AND AIDS JUNPO: A short tech update on self-testing for HIV*.

WHO (2016), *Global Health sector strategy on HIV: Towards Ending AIDS*, Geneva: WHO Document Production Services.

Worley, S., Didiza, Z., Nomatshila, S., Porter, S., Makwedini, N., Machara, D., and Hoos, D., (2009), *Wellness programme for persons living with HIV AND AIDS. Experiences from Cape Province, South Africa*, Columbia University International Centre for AIDS care and treatment.

Zambia National AIDS Council (2018), *National HIV AND AIDS Strategic Frame Work 2017-2021*, Lusaka: Government Printers.

Appendix i: Information form

Dear Sir/Madam,

I wish to kindly introduce myself and the purpose behind this interview guide. Am currently conducting a study as a final part of a Master Degree in Master of Science in Counselling at the University of Zambia. The purpose of this study is to explore your experience of living with HIV and AIDS and on ART. I am hoping that the results of this study will assist in understanding persons having HIV infection. Not only do I hope for a change in social attitude, but the results may contribute to our knowledge in caring for persons with HIV and AIDS.

I would like your permission to include you in this study. Your information will be very valuable and important to help people uncover and understand the real experience of HIV infected persons. The study will take approximately an hour of your time for the interview. This will involve asking you to describe your experience after having HIV infection.

Your participation is purely voluntary, and you may withdraw at any time. Whether you agree to participate or refuse to do so, your treatment will not be affected in any way. You will remain anonymous in the study.

If you agree to participate, please sign the initial of your first name on the consent form at the bottom part of this letter.

Thank you for your time.

Phyllis Nyirenda.

Appendix ii: Consent Form for adults living with HIV and AIDS

I _____
Initial Name

Have read and understood the information and agree to participate in this study. I have had the method of maintaining my anonymity explained to me. I am assured that my identity will not be disclosed during the study or when the study is completed. All my questions have been answered to my satisfaction.

Signed informant _____ Date _____

Signed Researcher _____ Date _____

Appendix iii: Interview Guide for Individuals Living with HIV and AIDS and on ART

1. Personal Information

Gender: Male: Female:

Marital status: Married..... Single.....Widow.... Widower..... Divorced.....

Age: Job description:

Number of children:

2. (a) Can you share with me how you first became aware of your HIV AND AIDS status?
(b) Who told you, when, where, what were the circumstances?
(c) How did you feel when you learned about your diagnosis results?
(d) What did you do to come to a level of acceptance of your current condition?
3. What physical change have you experienced while living with HIV infection in terms of.....
 - (a) Illness
 - (b) Sexual behaviour change
4. (a) How has your life been since you found out you were HIV positive?
(b) How does living with HIV affect your day to day living?
5. (a) Have you disclosed your illness to your family, friends or other persons?
(b) For those to whom you have disclosed, how did you choose these people to share your HIV status?
(c) What were the circumstances?
(d) How did the person (s) react to this news?
(e) How did you feel yourself after disclosing to him or her or them?
(f) For those you have not disclosed to, why have you not disclosed to these people?
6. Are you on Anti-retroviral therapy and for how long have you been on ART?
7. (a) Do you attend any support group for the people living with HIV? Why?
(b) Does attending any support group make it easier for you to live a positive life?
8. Any suggestions on how your lived experiences could be improved?

