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ABBREVIATIONS

ABC   Abstain, be faithful, condomise

ADHD   Attention deficit disorder

AIDS   Acquired Immune Deficiency Syndrome

ART   Anti-Retroviral Therapy

CNS   Central nervous system

EPR   Empirical psychological reflection

FAO   Food and Agriculture Organization

GPS   General Psychological structure

HIV   Human Immunodeficiency Virus

IPD   Individual phenomenal description

IPS   Individual psychological structure

NAC   National AIDS Council

MPEG   Moving pictures expects group

NNRTI   Non-nucleoside reverse transcriptase inhibitors

NRTI   Nucleoside reverse transcriptase inhibitors

NSM   Neuman Systems Model

SDT   Social identity theory

SSA   sub-Saharan Africa

TOVA   Test variables of attention

UNAIDS

VCT   Voluntary counselling and testing

WHO   World Health Organization

CHAPTER ONE

BACKGROUND AND ORIENTATION OF THE STUDY

1. INTRODUCTION

Paediatric and adolescent HIV infections are one of the many public health challenges facing resource constrained countries and communities. In 2014, more than two million adolescents between the ages of 10 to 19 years were living with Human Immunodeficiency Virus (HIV) worldwide (Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath and Ferrand 2014: 1). United Nations Children's Educational Fund (UNICEF) corroborate this by indicating that adolescents account for about five percent of all people living with HIV and about 12 percent of new adult infections. Of the two million adolescents living with HIV infection, about 1.6 million (12%) live in sub-Saharan Africa (SSA) (UNICEF 2014:1). With the maturing of the HIV epidemic and scaling up of antiretroviral therapy (ART), children born with HIV are reaching adolescence in great numbers (Lowenthal *et al 2014*:2). Beyond the perinatal period, young people still remain vulnerable to HIV due to a host of social, economic and biological factors (Hazra 2010:1). These vulnerabilities and the successes of the ART programmes have brought in a lot of challenging experiences for the adolescents (Hazra2010: 2). The needs of adolescents living with HIV are more sensitive and varied than those of adults as they must concurrently deal with adult issues such as stigma disclosure while also addressing issues traditionally associated with adolescents such as body image, peer pressure and forming personal identity (Madiba 2012:2; Lowenthal *et al 2014*:1 and Gross, Bandason, Langhaug, Mujuru, Lowenthal and Ferrad 2014:3). In addition, adolescents face particular challenges to adhere to HIV treatment and according to UNICEF (2016:4) it is mainly caused by lack of support from the significant others to disclose their status and lack of information regarding their sexual and reproductive health rights and self-stigma.

1.2 BACKGROUND TO THE RESEARCH QUESTION

1.2.1 Geography and economy

Zimbabwe lies just north of the Tropic of Capricorn between the Limpopo and Zambezi rivers. The country is landlocked, bordered by Mozambique to the east, South Africa on the south, Botswana on the west and Zambia on the north and northwest. It is part of a great plateau which constitutes the major feature of geology of Southern Africa. About 70% of the surface rock in Zimbabwe is granite, schist or igneous and it is rich in mineral wealth. The climate in Zimbabwe is a blend of cool, dry, sunny winters and warm wet summers. Mining and agriculture are the backbone of the country's economy, even though the country is endowed with some of the world's most impressive natural tourist attractions such as the Great Zimbabwe Ruins and the Victoria falls. The economy is diversified but biased towards agriculture and mining.

Zimbabwe is divided into ten provinces and according to the National AIDS Council (2013), Bulawayo, the province where this study was carried out has the highest prevalence rate of HIV (21%) and it is even higher than the national prevalence (14.7%). Bulawayo is the second largest city in Zimbabwe after the capital Harare, with any estimated metropolitan population of 655575 (Census 2012). Bulawayo has two central(tertiary) hospitals both of which are used as university teaching hospitals, one national mental health referral institute, twenty primary care clinics and one private hospital.

Figure1.1: Map of Zimbabwe

Source: www. nationsonline. org/oneworld/map/zimbabwe_map. htm

1.2.1.1Demographic and health profile of Zimbabwe

Zimbabwe has a young population with 39.4% under the age of 15 years and 22.5% of the population between the ages of 15 to 25 years (the group in which the study population falls). Life expectancy in Zimbabwe is 53.4 and 55.2 years for males and females respectively. The main cause of death in Zimbabwe is HIV and AIDS related causes (54.4%) and was the highest in the world (WHO 2011). Zimbabwe's HIV prevalence rate currently stands at 14.7%, which is the fifth highest in the world.

Male | Zimbabwe - 2016 | Female

| Age Group |
| 100+ |
| 95 - 99 |
| 90 - 94 |
| 85 - 89 |
| 80 - 84 |
| 75 - 79 |
| 70 - 74 |
| 65 - 69 |
| 60 - 64 |
| 55 - 59 |
| 50 - 54 |
| 45 - 49 |
| 40 - 44 |
| 35 - 39 |
| 30 - 34 |
| 25 - 29 |
| 20 - 24 |
| 15 - 19 |
| 10 - 14 |
| 5 - 9 |
| 0 - 4 |

Population (in millions)   Age Group   Population (in millions)
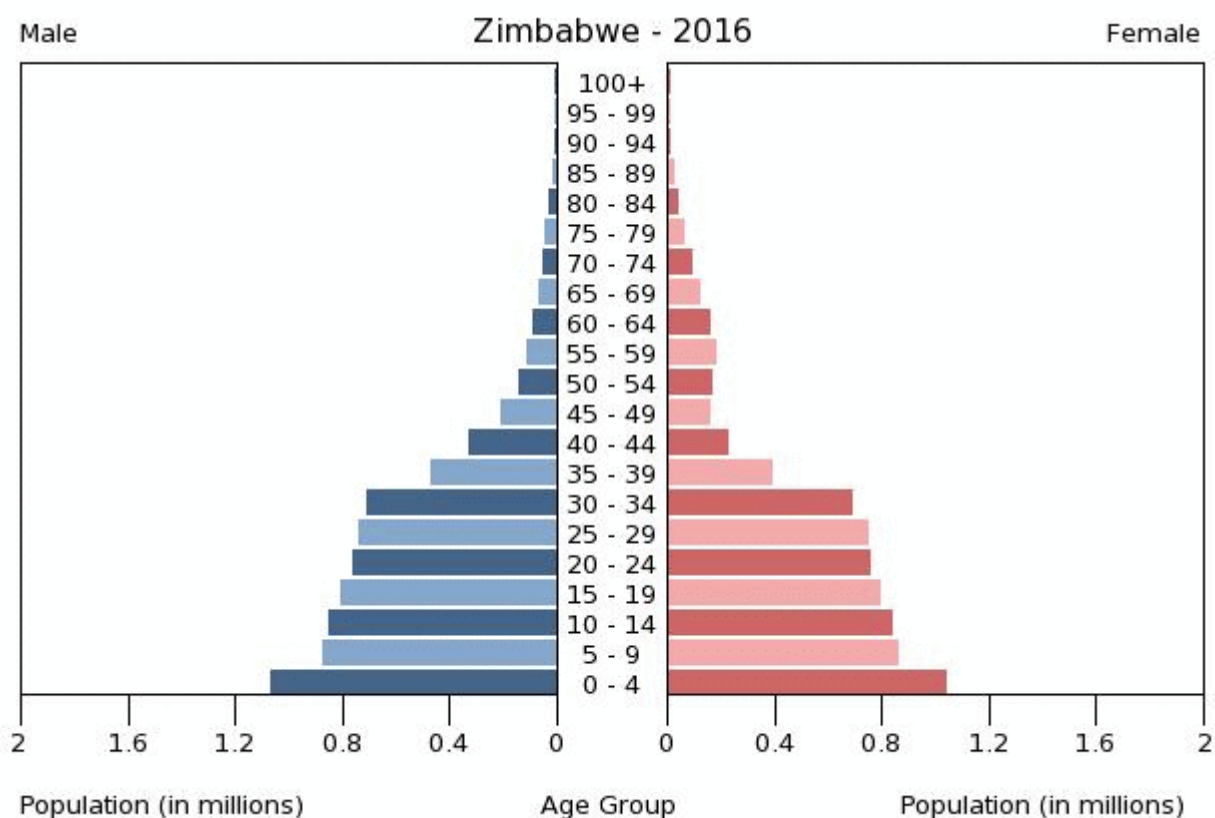
Source: CIA World Fact book (November, 6, 2016)

Figure 1.2: Population Pyramid of Zimbabwe

1.2.2 Background to the research question

HIV infection has been around for more than 30 years, with SSA continuing to have the highest incidence of HIV than any other region in the world (Lowenthal *et al 2014*:2).Close to 90% of adolescents living with HIV, in SSA have been infected through mother to child transmission of HIV (MTCT) either in utero or through breast feeding (Agwu & Fairlie 2013:3). Before the introduction of Antiretroviral Therapy (ART), children perinatally infected with HIV were not expected to survive through their first decade of life but the expanding coverage of ART has promoted survival of these children. The growing number of perinatally infected children maturing into adolescents and adulthood coupled with the increasing numbers of adolescents behaviourally infected with HIV presents great challenges across SSA (Madiba 2012:3). The results from a Zimbabwean study Gross *et al (*2014:3) indicated that HIV positive adolescents felt that they needed more support in order to adhere to their treatment regime of drugs. Moreover, the studies on drug

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adherence done in Zimbabwe and other SSA countries have focused mainly on the determinants and levels of adherence (Lowenthal *et al 2013*:3; Gross *et al 2014*:1 and Nyogea, Mtenga, Henning, Franzeck, Gloss, Letang, Tanner and Geubbels 2015:4). None so far has focused on the lived experiences of this particular target group. However, fulfilling the needs of these adolescents requires an in-depth understanding of the determinants and their barriers to well-being and lived experiences specifically focusing on drug adherence, hence this study.

1.2.2 .1 HIV and AIDS in Zimbabwe

The first reported case of AIDS in Zimbabwe occurred in 1985. By the end of the1980s, around 10% of the adult population was thought to be infected with the HIV (UNAIDS 2010:5). This figure rose dramatically in the first half of the 1990s, peakingat more than 36% between 1995 and 1997 (USAID2010:5). Since the late 1990s, the HIV prevalence has been consistently declining. With a national adult prevalence of 14.3% at the end of 2013, Zimbabwe was one of the 10 highest-prevalence countries globally and in sub-Saharan Africa (UNAIDS 2013:3). According to national estimates, prevalencedecreased to 13.6% in 2010. However, the prevalence rate has once again gone up to 14.7% as of December 2016 (National AIDS Council (NAC) 2017:1). The epidemic has reduced lifeexpectancy, deepened pervasive poverty among vulnerable households andcommunities, skewed the size of populations, undermined national systems andweakened institutional structures (UNAIDS 2013:1). Surveillance data from severalstudies suggest a trend of declining prevalence that has been observed among menand women in rural and urban areas and in pregnant women (UNAIDS 2013:2).Among the latter, HIV prevalence declined from 17.7% in 2006 to 16.1% in 2009. Asimilar decline occurred in the 15 to 24-year age where the prevalence dropped from12.5% in 2006 to 11.6% in 2009 (UNAIDS 2016:7). According to UNICEF (2015: 3), they are currently about 110 000 adolescents aged between 15 to 19 years living with HIV and are on treatment in Zimbabwe. Willis, Frewin, Miller, Dziwa, Mavhu and Cowan (2014:3) corroborate this statement and further add that they were about 7 801new paediatric and adolescent infections in 2013. Though the epidemic is believed to be declining and a substantial number of adolescents are on ART, the actual figure of HIV positive adolescents in the country is not known (NAC 2015:5).

1.2.3 Adolescents and HIV

Adolescents are developmentally at a difficult crossroad (World Health Organization (WHO) 2013:18). The adolescents' needs for autonomy and independence and their evolving decisional capacity intersect and compete with their concrete thinking processes, risk-taking behaviours, preoccupation with self-image, and need to fit in with their peers (UNICEF 2015:3; WHO 2013:17). This makes it challenging to attract and sustain adolescents' focus on maintaining their health, particularly for those with chronic illnesses (Madiba 2012:3; Gross *et al 2014*:3). These challenges are not specific to HIV infected or non- infected adolescents, they embrace all. Of note as well is that these challenges are the same to those perinatally or behaviourally HIV infected or the stage of the disease (Madiba 2013:3). Thus, irrespective of disease duration or mode of HIV transmission, every effort must be made to engage and retain adolescents in care so they can improve and maintain their health for the long term (WHO 2013:18).

Individuals living with HIV and AIDS have been the subject of stigmatizing attitudes and differential treatment in nearly every part of the world, including the sub-Saharan African region (WHO 2013:8). For several years, widespread misconceptions about the disease contributed to its portrayal as a result of divine punishment, witchcraft, or an invariable outcome of promiscuous sexual behaviour, which always resulted in death (UNICEF & UNESCO 2015:22). These perceptions are believed to have contributed to the persistently high rates of spread in the sub-Saharan African region compared to other regions of the world, primarily through individuals' and families' efforts to avoid being identified with HIV (UNAIDS 2014:6). As such, individuals with HIV avoid voluntary testing, and women insist on breastfeeding their babies to avoid suspicion in several African societies (Willis *et al 2014*:2).

Recent studies among adolescent populations have revealed that there is a persistent high stigma among the adolescent with regards to one's HIV positivity (Madiba 2012:3). A study conducted in Kenya identified discriminating attitudes against the youths who were HIV positive from their peers and school teachers (Adejumo, Malee, Ryscavage, Hunter and Taiwo 2015: 1). Such stigmatizing behaviours included name calling and avoidance. These stigmatizing behaviours

are associated with a myriad of problems bedevilling HIV positive adolescents such as poor adherence, loss to follow up, and failure of disclosing status, decision to drop out of school, suicidal tendencies and refusal of HIV testing to pregnant adolescents (Adejumo *et al 2015*:2). In another study carried out in Zimbabwe, HIV positivity was regarded by the adolescents as their "secret" (Willis *et al 2014*:3). This taken into context would mean that they did not want to be known that they were on ART and this impacts on adherence because the adolescence would not want to be seen taking their drugs as long as they were among people. They would rather preserve their secret than their health. In another study focusing on comprehensive health services for adolescence especially for those with HIV in Nigeria and South Africa, Adejumo *et al (*2015:3) noted that there was a "death" in care especially regarding drug adherence for adolescents and yet it was much better for other age groups. They noted that most adherence interventions were targeted at adults with HIV. Therefore, rigorous evaluations of more innovative adherence interventions for adolescents are currently lacking for adolescents (Mavhu, Berwick, Chirawu, Makamba, Copas, Dirawo, Willis, Araya, Abas, Cabett, Mungofa, Lawer and Cowan 2013:3).

1.2.3.1 Impact of HIV on adolescents

About 90% of adolescence living with HIV in SSA have been infected through mother to child transmission (MTCT) (Mavhu *et al 2013:1*).The growing number of perinatally-infected children maturing into adolescence and young adulthood coupled with the increasing numbers of adolescents behaviourally-infected with HIV presents unprecedented challenges across sub-Saharan Africa and beyond (Mavhu *et al 2013:1*). The needs of adolescents living with HIV are more sensitive than those of adults as they must simultaneously deal with adult issues such as disclosure, practicing safe sex and stigma while addressing issues traditionally associated with adolescence such as body image, peer pressure and forming personal identity (Mavhu *et al 2013*: 2).

Fulfilling the needs of these adolescents requires an in-depth understanding of the determinants and barriers to wellbeing within this population. HIV and AIDS affect every dimension of an adolescent's health; physical, social, emotional, and spiritual

wellbeing. As Mavhu *et al (*2013:2) noted, one of the challenges of understanding HIV in children and adolescents is determining which of the biological, psychological, neuropsychiatric and social factors is most relevant for wellbeing at any given moment (Mavhu *et al 2013*:2).

1.2.4 Antiretroviral therapy

The advent of antiretroviral therapy (ART) has been very instrumental in reducing HIV and AIDS morbidity and mortality rates worldwide (Baker, Peng, Rapkin, Abrams, Silverberg, MacArthur, and Neaton 2008:3; UNAIDS 2013b:4) and transforming HIV and AIDS from a death sentence to a chronic illness. Since 1996, ART has prevented about 6.6 million deaths worldwide including 5.5 million deaths in middle- and low-income countries (UNAIDS 2013b:4). ART has also contributed to the reduction in HIV transmission at both individual and population levels (Mavhu *et al 2013:5*). At individual level, ART has reduced the transmission of HIV from mother to child, while at population level ART mediated virologic suppression and reduced infectiousness (Reynolds *et al 2011*:5). By reducing morbidity and mortality rates, ART has played a critical role in reversing the economic impact of HIV and AIDS by restoring productivity (Baker *et al 2008*:3). ART has also reduced strain of over-burdened health care systems in SSA and continues to play a major role in preventing the increasing number of AIDS-orphaned children (Anema, Au-Yeung, Joffres, Kaida, Vasarhelyi, Kanters and Hogg, 2011:2).

1.2.5 Drug adherence

Antiretroviral therapy is a lifelong treatment and to get the total benefits requires strict adherence to the treatment regimen (WHO 2010:10; Giil, Hammer, Simon, Thea and Sabin 2005:2). According to WHO (2003:1), adherence is broadly defined as the extent to which a patient's health behaviours correspond with the medical advice or recommendations. However, there are no standard criteria for adherence to ART as each ART drug regimen has a specific adherence-resistance relationship (Bangsberg, Moss and Deeks 2004:4). Earlier drug regimens required levels of adherence greater than 95% but classes including the protease inhibitor (PI) boosted regimens and non-nucleoside reverse transcriptase inhibitors (NNRTI) may achieve full virologic suppression at adherence levels lower than 70% (Bangsberg

2006:3; King, Brun and Kempf 2005:2). In Zimbabwe, drug adherence among the adolescents varies from between 55% to about 95% while for the adult population is around 80% to 90% and the adherence levels for adolescents are dependent on the support systems available to the individual (Mavhu *et al 2013*:3; Gross *et al 2014*:4). They further go on to state that young people on ART need support to maximize the benefits of therapy.

1.2.6 Adolescents and drug adherence

HIV-infected adolescents are especially vulnerable to specific adherence problems because of their psychosocial and cognitive developmental trajectory (UNAIDS 2016:5). Comprehensive systems of care are required to serve both the medical and psychosocial needs of HIV-infected adolescents, who frequently lack both health insurance and experience with health care systems (UNAIDS 2016:5). Studies in adolescents infected in their teen years and in adolescents infected through perinatal transmission demonstrate that many adolescents in both groups face numerous barriers to adherence (Rudy, Murphy, Harris, Muenz and Ellen 2009:6). Compared with adults, these youth have lower rates of viral suppression and higher rates of virologic rebound and loss to follow up (MacDonnell, Naar-King, Huszti, and Belzer 2013:3).Reasons that HIV-infected adolescents often have difficulty adhering to medical regimens include the following:

- Denial and fear of their HIV status.
- Distrust of medical establishment.
- Lack of support.
- Fear of disclosure of status.
- Low self-esteem.

In a study assessing the levels of drug adherence on adolescence living with HIV carried out in Zimbabwe (Gross *et al 2014:4*) one respondent said "*I do not see myself swallowing these tablets the rest of my life, it is not easy. I will try but already, I have not taken my drugs for a week*".

This current study focused on adolescents who are HIV infected (regardless of how they got infected) and aware of their HIV status and were currently receiving some

HIV related management and only on adolescents aged 18 to 21 years. The study hopes to bring out the adolescents' lived experienceswith regards to drug adherence and also propose guidelines to manage drug adherence in this population.

1.3 DESCRIPTION OF THE STUDY SITE

The study was carried out at Mpilo Central Hospital in Bulawayo, Zimbabwe. The Hospital is the third largest tertiary hospital in Zimbabwe and was established in 1956.The opportunistic infection and antiretroviral therapy (OI & ART) clinic was establishedat this hospital in 2006. Since then, the hospital has been offering ART services to adults including adolescents. Separate clinics for children, adolescents and adults were established after a realisation that the unique needs of these different age groups (Gamanya, Mujaji and Nzou 2012:2). Opening of a separate clinic for adolescents allowed them to share their experiences and air theirconcerns in a free environment without adults. Paediatric ART services were also introduced in 2009. Mpilo Central Hospital is a regional hospital and is a referral centre of four of the ten provinces in the country and serves a population of more than three million people. It has an annual registration of close to 2000 adolescents and 11 106 adults for HIV care.

 Mpilo Hospital was the first hospital to open a separate adolescent HIV unit in the country. This was necessitated by the fact that they were more HIV positive adolescents in its catchment areas because of the proximity of the region to South Africa and Botswana were adolescents would flock for search of employment and come back home HIV infected. The hospital is an initiating centre where patients are commenced on ART, thenreferred to peripheral clinics for monthly review and refills. However, those who defaulttreatment are referred back to this hospital for re-assessment by a medical practitioner.Also, those who are commenced on second line therapy due to treatment failurecontinue to get their medication at the hospital. All the patients receive ARVs freeof charge from the hospital pharmacy which is funded by The Global Fund and some ofit from National Aids Council (NAC).

Furthermore, the ART clinic is attached to a non-governmental organisation (food programme) that supports the patients on ART withfood hampers and cash.

However, the food ration is given to only those who meet theeligibility criteria which are based on nutritional screening and only underweight clients onART are eligible to food handouts. Periodic nutritional assessments are done, and if thepatient's nutritional status improves the food ration is terminated.Besides the food programme, the hospital also works with another non- governmental organisation (Million Memory Project Zimbabwe) whose mission is to contribute to the development of adolescents living with HIV through advocating for the developing of appropriate policies and practices. Because of the various activities aimed at attaining the 90 90 90 goal by 2020 being done at the hospital, the researcher found it to be the most appropriate place to conduct the research.

1.4 STATEMENT OF THE RESEARCH PROBLEM

Data descriptive and epidemiological are necessary to inform local policies and support decision making on issues affecting the general health and wellbeing of HIV infected adolescents in Zimbabwe and some SSA countries. Studies on ART adherence which have been done in Zimbabwe and some SSA countries have primarily focused on adults and no information is available on adolescents. Though these studies focused on adherence, no study in Zimbabwe has explored the lived experiences of adolescents regarding drug adherence. Almost all the studies have focused primarily on the levels of adherence and psychosocial issues. Adolescents face difficult and often confusing emotional pressures as they grow from being children to adults. HIV infection brings an extra burden to the already burdened adolescent. According to WHO (2013:1), adolescents are falling through gaps in HIV services, they need services and support tailored to their needs. They need to be equipped to manage their HIV infection and take ownership of their health care. In-depth understanding of the lived experiences of adolescents living with HIV is critical to determining the development of appropriate services aimed at improving the adolescents' psychosocial wellbeing, continued health and overall quality of life hence this study. This problem leads to the following research question:

1.5 RESEARCH QUESTION

What are the lived experiences regarding drug adherence of adolescents on ART?

1.6 RESEARCH AIM AND OBJECTIVES

16.1 Research aim

The main aim of this study was to explore and describe the drug adherence lived experiences of HIV infected adolescents in Bulawayo, Zimbabwe in order to improve their therapeutic outcomes.

1.6.2 Research objectives

The following objectives guided this study:

- To explore and describe the drug adherence lived experiences of HIV infected adolescents on ART.

- To make informed recommendations to policy with regard to improving the adherence experiences of adolescents on ART.

1.7 PARADIGMATIC PERSPECTIVE OF THE RESEARCH

1.7.1 Meta-theoretical (ontological) assumptions

According to humanistic theory, as proposed by George (2011:265), human beings areviewed as an existential framework of becoming through choices. Human beings arecharacterised as being capable, open to options, have values and unique manifestations related to their past, present and future. It is through these relationships
that the human being becomes, which, in turn, allows for each person's individuality to become actualised. The implication is that people act on choices, which are determined by what they value from what they have learned from the constellation of their culturalbeliefs. George (2011:265), suggest that health is more than the absence of disease, and that we become healthier by being in relationships with others. According to George (2011:265), health can be found in the person's willingness to be open to the experiences of life, regardless of a person's physical, social, spiritual, cognitive or emotional status. In the context of the phenomenon to be   investigated,   the

lived experiences of adolescents may affect their decision making. Consequently, adolescents' drug adherence will be directly affected by their lived experiences (Bowling 2000:35). To appreciate the domain of care implies meeting people's needs, with the goal of nurturing well-being. According to George (2011:267), this can

be realised through dialogue, meeting, relating, and the presence of caregivers through openness to a range of ideas.

1.7.2 Theoretical (epistemological) assumptions

Theoretical (epistemological) assumptions are the researcher's reflections of what is regarded to be true as the theoretical framework to address the questions raised in the study indicates the relationship between the inquirer and what is being studied Polit and Beck (2014:13). In this study the lived experiences of adolescents were examined within the parameters of Neumann's Systems Model which is discussed below.

1.7.2.1Theoretical grounding of the study

This study is grounded in Neuman's Systems Model (NSM). The Neuman Systems Model views the client as an open system that responds to stressors in the environment (George 2014: 359). The client variables are physiological, psychological, socio-cultural, developmental, and spiritual. The client system consists of a basic or core structure that is protected by lines of resistance (Stanhope and Lancaster 2014:659). The usual level of health is identified as the normal line of defence that is protected by a flexible line of defence. Stressors are intra-, inter-, and extra-personal in nature and arise from the internal, external, and created environments (George 2014:359; Stanhope and Lancaster 2014: 660). When stressors break through the flexible line of defence, the system is invaded and the lines of resistance are activated and the system is described as moving into illness on a wellness-illness continuum. If adequate energy is available, the system will be reconstituted with the normal line of defence restored at, below, or primary prevention occurs before the stressor invades the system; secondary prevention occurs after the system has reacted to an invading stressor; and tertiary prevention occurs after secondary prevention as reconstitution is being established.

1.7.2.2 Definition of key concepts

In this study the following key concept or terms will be used to mean the following unless indicated otherwise in the text:

Adolescence

adolescence is a stage of life which individuals have unique psychological, social and health needs (WHO 2003: 9). The defined age range of adolescence varies but is generally accepted to begin with puberty and end in the transition to adulthood: may be roughly divided into three stages: *early* adolescence, generally ages eleven to fourteen; *middle* adolescence, ages fifteen to seventeen; and *late* adolescence, ages eighteen to twenty-one ibid (9). Rapid physical and hormonal development during adolescence is sometimes accompanied by a desire for self-discovery, an emerging sense of autonomy, separation from caregivers and the assertion of independence as well as a quest for recognition and acceptance which could lead to risk taking behaviour (Lowenthal *et al 2014*: 2). In this study adolescence will refer to late adolescence which is ages between 18 to 21 years and these are the ages which will be included in the study.

Adherence

WHO (2003:10) broadly defines adherence as the extent to which a patient's health behaviours correspond with the medical advice or recommendations. In this study, adherence will be defined as taking the ART drugs, right dose at the prescribed right time every day for life. This is the definition which will be used in this study.

1.7.3 Methodological assumptions

Methodological assumptions relate to the way the researcher obtains knowledge (Polite and Beck 2014:142). The methodological assumptions which were applied in this study were based on the understanding that knowledge is maximized when the distance between the inquirer and the participants is minimised (Polit and Beck 2014:35). The researcher considered the importance of the adolescents' lived experiences regarding ART adherence. To achieve this, the researcher subjectively interacted with the participants in their natural settings in order to gather contextual

data. These assumptions were applied to the study using the research design described below.

1.8 RESEARCH DESIGN

A research design is the blue print or overall plan of fulfilling the objectives which will be encountered during the research process (Burns and Grove 2011: 253). It guides the researcher in planning and implementing the study in a way that is likely to achieve the intended goal ibid (253). LoBiondo-Wood and Haber (2014:56) explain the research design as an organisation of elements in a masterful work of art which incorporates the processes and techniques used. In this study a phenomenological research design which is qualitative, exploratory, descriptive and contextual will be used.

In line phenomenological design, the study was qualitative, exploratory, descriptive and contextual in nature. This entailed that the researcher entered the real world, the natural setting of the participants where the phenomenon of interest was occurring to conduct observations with the aim of creating a conceptual meaning. The focus in this preliminary stage was to increase understating of the phenomenon (the drug adherence lived experiences of adolescents) and not necessarily make predictions. This interface helped the researcher to conduct in-depth exploration of those aspects of the phenomenon that are judged to be salient (Polit and Beck 2014:320). With this design the interest was to learn more about the phenomenon within the context of the participants' own world. To understand the lived experiences of adherence among adolescents on ART (18-21 years), the researcher spent time with adolescent informants at Mpilo Central Hospital Opportunistic infection clinic conducting in-depth interviews in order to gather data. Phenomenological research aims at describing the 'lived' experience in relation to what is being studied (Balls 2009:1).

1.8.1 The qualitative aspect of the design

Qualitative research is defined as a systematic subjective approach used to describe life experiences and give them significance to gain insights through discovering meanings through a comprehension of the whole (Burns and Grove 2011:250). Golafshani (2003:600) defines qualitative as that which uses a

naturalistic approach that seeks to understand the phenomenon of interest in a context specific setting as a real world were the researcher does not attempt to manipulate the phenomenon. According to Polit and Beck (2012:48), the qualitative aspect of the design often involves merging together various data-collection strategies, and it is flexible, capable ofadapting to new information. These authors assert that qualitative research requires thatthe researcher become intimately involved in the research, so as to understand thephenomenon, and that the researcher applies ongoing data analysis, so as to determinesubsequent strategies for gathering data and whether data saturation has been reached.Regarding data collection during the study, the researcher becomes the research instrument. This aspect of the design will enable the researcher to understand the "emic" perspective or views of insiders regarding the drug (ART) adherence lived experiences of adolescents.

1.8.2 The exploratory aspect of the design

The exploratory aspect of the study aims at investigating the full nature of the phenomenon, the manner in which it manifested and other factors with which it is related (Polit and Beck 2008:20). The need for such approach arises from there being a lack of basic information about a new area of interest (De Vos *et al 2011:95*). The aspect of the design was used to explore the lived experiences of the adolescents regarding drug adherence.

1.8.3 The descriptive aspect of the design

According to Burns and Grove (2001:248), descriptive research designs are usually used in conjunction with exploratory approaches to explain and describe explored aspects within the current practice. The authors further state that the description is presented in an audit trail and the success of a descriptive approach is based on how

well phenomena are presented. The objective of a descriptive research study is to accurately portray the characteristics of persons, situations, or groups, and/or the frequency with which certain phenomena occurs (Polit and Beck2008:752). This is done to generate more understanding about the characteristics of entities within a particular field of study by providing a clear picture of the situation as it occurs naturally (Burns and Grove 2001:247). This aspect of the design enabled the

researcher to describe the lived experiences of adolescents regarding ART adherence.

1.8.4 The contextual aspect of the design

The greatest interest with this approach is to learn about participants within the contextof their own world (De Vos *et al 2011:335*). Thus the aim of a contextual aspect of thedesign is to describe and understand events within concrete, natural contexts in whichthey occur, in order to understand the dynamics of human meanings as fully as possible. Since exploring the lived experiences of adolescents regarding ART adherence is the primary interest, the participants were observed and spoken to in theirnatural setting. Building on the premise of the above design the researcher had structured steps, procedures and strategies, determined by the lens of this design, to select anappropriate sample, gather data, and analyse information systematically. A fulldescription of the processes to be undertaken is given in the study methodology, in the following section.

1.9 RESEARCH METHODS

Research population

A population is the entire aggregation of cases that meet the designated set of criteria (Polit and Beck 2012:278) while Strydom, Fouche, Poggenpoel and Schurink (2001:190) define population as a universe, as all the potential subjects that possess the attributes in whichtheresearcher is interested, while the term "population" sets boundaries to the studyunits,and refers to individuals in the universe who possess specific characteristics.Accordingto Bailey (1997:45), a population is the entire group of people or items that meet the criteria set by the researcher.

In Zimbabwe, adolescents who are currently on ART are from 13 to 19 years. In this study however, the researcher excluded all adolescents aged of 13 to17 years, owingtothefact that participation in research studies for subjects below the age of 18 yearsisdependent on the receipt of parental consent. The involvement of parents or guardiansinthe studymight have inhibited thefree expression of views by this age group, and the likelihood for bias might have been high, hence the inclusion criterion for this study was as follows:

- Informants were all adolescents aged between 18 to 21 years who collect their supply of ART from Mpilo Central Hospital Opportunistic Infection Clinic. Informants for the in-depth interviews had been on ART for at least 6 months and are aged 18 to 21 years.

Sample and sampling techniques

A sample according to Polit and Beck (2012: 279) is the smallest subset of the population that has been selected to participate in the study. In this study, the following techniques were used:

Data gathering technique

Data collection was conducted at the hospital and every effort was made to ensure that respondents felt comfortable. Research participants were recruited when they came to the clinic forreviews. Polit and Beck (2012:533) posed the need for qualitative researchers to gainand maintain a high level of trust with the participants and "be like them" as this willallow them to get rich data. During the data collection period the researcher on a daily basis joined the patients as they all first assembled in a hall awaiting reviews and hold devotional prayers which were usually followed by health education sessions from the health care providers. Face to face in-depth interviews were conducted with those participants who volunteered to participate. The researcher ensured that the interview process was done according to the research protocol. Data was collected until saturation occurred. Data saturation occurs when sampling isdone up to a point at which no information is obtained and redundancy achieved (Creswell 2007:64; Polit & Beck2012:521).

Data analysis technique

The data that was gathered from the field in form of notes and tape recordings was analysed using Giorgi's (1985) method for data analysis as cited by Mavundla (2000:1572). The following steps were applied to this process;

- Data from the tape recorder and field notes were transcribed and coded.
- Major categories represented in the universum were identified.
- Units of meaning related to the identified categories were identified.
- Units of meaning were placed in these major categories.

- Sub-categories within the major categories were identified.

- Relationships among major categories and sub-categories were identified and reflected as themes.

- Consensus between the researcher and an independent coder were conducted.

- The results were then reflected within the universal categories of the Neuman's Systems Model.

1.10 DESIGN TRUSTWORTHINESS

Establishing the trustworthiness of a research study lies in the heart of issues conventionally discussed as reliability and validity also being central to any conception of the quality of qualitative research. Establishing trustworthiness gives assurance that the research instruments were capable of providing accurate and meaningful answers to the research questions and when qualitative research accurately represents the experiences of the participants (Curtin and Fossey 2007:56). Trustworthiness of this study were enhanced by employing the four criteria of trustworthiness namely credibility, dependability, conformability and transferability proposed by (Lincoln and Guba 1985: 300).

1.10.1 Credibility

Credibility is involved in establishing that the results of the research are believable. This is based on 'quality not quantity'. It depends more on the richness of the information gathered, rather than the amount of data gathered. A pilot was conducted to test the grand question for the study and other strategies such as data triangulation, triangulation through multiple analysts, member check, and attention to negative cases, bracketing and providing verbatim quotes to gauge the accuracy of the findings.

1.10.2 Dependability

Having dependable findings is paramount to any research study. The researcher's concern is whether the research process is logical, well documented and auditable (De Vos, Strydom, Fouche and Deport 2011:420). Polit and Beck (2012:567) posits that dependability of a study refers to the stability of data over time and over
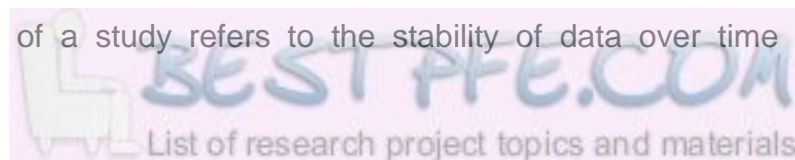
conditions. The dependability of this study was achieved by making sure that the sample was appropriate for the current study.

1.10.3 Conformability

Conformability evaluates the extent to which findings are qualitatively confirmable. The researcher used the following techniques to ensure the conformability of the findings: debriefing, examination of the audit trail and also researcher reflexivity.

1.10.4 Transferability

To ensure transferability, examination of the processes to be applied in a study is essential. Transferability is the extent to which findings from the data can be transferred to other settings or groups, and is more a consideration of the research design and sampling technique used than of the soundness of the data gathered (Polit & Beck 2008:539).

Due to the fact that the researcher's concern was to investigate natural behaviour occurring in a natural and unique setting, which usually is never repeated, because it isunique, generalization to other settings may be problematic (Bailey 1997:148). To counter this challenge, the researcher enhanced transferability by employing severalstrategies. Description of how the researcher collected and analysed the data within thetheoretical parameters used to determine whether the cases are transferable is vital (DeVos *et al 2011:420*). In this study a full description of the data-collection process and analysis was given, and the researcher's position in terms of the role that sheplayed was described in field notes. Based on the attempts by the researcher to establish the trustworthiness of the findings, it can be said that an in-depth understanding of the lived experiences of adolescents with regard to ART adherence will apply only to the context of Mpilo Hospital. However, in the case of similar settings with the same attributes as defined in the study, application of the study findings will be appropriate.While undertaking these activities, the researcher took cognizance of the ethical obligations required during the entire process.

1.11 ETHICAL CONSIDERATIONS

Conducting research requires not only expertise and diligence, but also honesty and integrity (Burns and Grove 2011:107).When human subjects are used in

research study, they have to know the activities they will be involved in, that their rights need to be protected and their person should be safeguarded: hence, the researcher needs to ensure adequate protection of the respondents. Working with human subjects emphasizes informed consent, avoidance of harm, non-violation of privacy, anonymity and confidentiality, not deceiving human dignity and objective presentation and interpretation of data (Polit and Beck 2012:144; Burns and Grove 2011:252). According to Polit and Beck (2012:753), ethics refers to a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the study participants. De Vos *et al (*2005:57) in their exploration of terminology state that ethics refer to a set of moral principles which is suggested by an individual or a group, is subsequently widely accepted and which offers rules and behavioural expectations about the most correct conduct towards people and institutions involved in the research process. The following ethical principles were followed by the researcher:

Beneficence

According to Burns and Grove (2011:107), the principle of beneficence encourages researchers to do good and "above all, do no harm". The dimensions of this principle include:

- *Right to freedom from harm and discomfort*

Freedom from harm and discomfort means that it is the researcher's obligation to avoid, prevent or minimise harm (non-maleficence). The discomfort and harm could be physical, emotional, spiritual, economic, social or legal (Burns and Grove 2011:108). In this study, no invasive methods were used to collect data nor were coercion employed. Since most of the review and drug collection is done in the mornings, data collection was restricted tomid-afternoons only to allow participants to travel back home before dark. This helped in minimising the disruption in the participants' lives.

- *Right to protection from exploitation.*

According to Polit and Beck (2012:171), the principle of right to protection from exploitation ensures that participants are assured that their participation or the information they provide will not be used against them in any way or expose

them to situations for which they will not have been prepared. The fact that respondents were not compensated for their participation in the study and yet this researcher is aiming at attaining a doctoral degree based on the information provided could be seen as a form of exploitation. To maintain this ethical principle the researcher assuredrespondents that the findings of the study will only be shared with the concerned Ministry Health and Child Care to whom such study findings may be helpful in developing strategies to help the participants in the areas of drug adherence especially regarding antiretroviral drugs.

- *Right to self-determination*

Self-determination means that the prospective participants have the right to decide voluntarily whether to participate in the study without fear or risk of prejudicial treatment. This also includes the right to ask questions, to refuse to give information or to withdraw from the study. In this study, the respondents had a right to independent decision without any form of coercion whether or not to participate. The participants were assured that none of them would be victimised or disadvantaged from any services provided by the hospital. They were informed that they had a right to withdraw from the study at any time and have a right to ask any questions if they so wished.

- **Right to full disclosure**

Right to disclosure means that the researcher has fully explained the nature of the study, the person's rights to refuse participation, the researcher's responsibilities and likely risks and benefits. Every participant in this study was given a summary of thepotential benefits and risks; these were printed on each consent form.

- **Informed consent**

Informed consent implies that the participants are given adequate information on the goal of the investigation, the procedures to be followed in the study, possible advantages, disadvantages and dangers to which they may be exposed as well as the credibility of the researcher (De Vos *et al 2005*:59). A signed informed consent was obtained from the participants before the data collection as proof of

their willingness to participate in the study. Information regarding the respondents' right of refusal to participate or to participate in the study was given to them before they signed the consent form.

Justice

The Penguin Reference Dictionary (2004:760) defines justice as the quality or principle of being impartial or fair. Justice connotes fairness and equity (Burns and Grove 2011:107; Polit and Beck 2012:173).

- ***Right to fair treatment***

Fair treatment means that the researcher must treat people who decline to participate in the study or withdraw from the study after agreeing to participate in a non-prejudicial manner. This involves honouring all the agreements with participants say to make payments as promised. In this study, no participant was given preferential treatment or was prejudiced based on their age, gender, cultural beliefs, social background or other characteristics. Participants were informed that no monetary benefits will be given for participating in the study.

- ***Right to privacy***

Privacy is defined as freedom from undesirable intrusion (Penguin Reference Dictionary 2002:1108). This basically means that the respondent has the right to determine the extent to which, and the general circumstance under which, their private information might be shared with or withheld from others. In this study the participants will not be identified using the information theyprovided.

- ***Confidentiality***

Confidentiality refers to the management of data in research in such a way that it will not be divulged or made available to any person not entitled thereto (Burns and Grove 2011:535).In this study, confidentiality was ensured by keeping all information collected at the researcher's office in a lockable cabinet and the electronic data was secured by the use of a password that is only known by the researcher.

- *Anonymity*

Anonymity refers to having no outstanding or distinguishing feature (Penguin Reference Dictionary 2004:52). This refers to the researcher's act of keeping the respondent's identities not known with regard to their participation in the research study and the researcher cannot also link the respondents to their data. In this study, anonymity was be ensured by using pseudo-names nameson the transcription documents.

Permission to conduct the study

Permission was granted by the ethics review board of Mpilo Central Hospital and also from the Higher Degrees Committee (Ethics Committee) of the Department of Health Studies at UNISA.

Avoidance of disruption or interference

To avoid interference with the daily clinic review activities or programmes, the researcher collected data after the participants had collected their medications.

Besides protecting the rights of the participants, the researcher will demonstrate respect for the scientific community by protecting the integrity of the scientific knowledge. With regard to the scientific integrity of the researcher, Van der Wal (2005:157) states, "the scientific integrity of a researcher must be indisputable and incontrovertible". This involves ethical responsibilities of the researcher with regard to competence, conduct and communication of the research findings.

Competence of the researcher

Competence and scientific integrity of the researcher are relevant to the entire research process. For academic purposes, the research should be assessed in the same way as other academic projects and the researcher competence in academic research is often supplemented by the input of the research supervisors and promoters. For academic research a formal contract a formal contract between student researcher and supervisor of promoter is very important (Van der Wal 2005:158).

Conduct and reporting of research findings

- ***Veracity***

Veracity concerns telling the truth and incorporates the concept that individuals should always tell the truth and this principle compels that the whole truth be told. In the current study, all procedures and data collected will be made available and open for scrutiny to all the appropriate persons and institutions involved in the study. No data will be fabricated by the researcher or anyone else.

- ***Fidelity***

Fidelity means that one has to keep their promises or commitments. In this study, all agreements made with the respondents and institutions will beupheld. For instance, should any need for modification of the approved research proposal been encountered during the research, a refined or adapted research proposal will be submitted to all authoritative bodies for re-approval.

- ***Avoidance of plagiarism***

Burns and Grove (2011:137) define plagiarism as the appropriation ("stealing") of another person's ideas, processes results or words without giving appropriate credit including information obtained through the confidential review of research reports.To ensure scientific honesty in this study, all sources of information used were duly referenced.

- ***Avoidance of fabrication/falsification***

According to Burns and Grove 2011:137) fabrication is the making up of results and recording or reporting them. Falsification is manipulation of research materials, equipment or processes or changing or omitting data or results such that the research is not accurately represented in the research record (Burns and Grove 2011:137).All data and findings, which were generated in this study, will be reported as is without any intentional misinterpretation. The data will also be availed to the authorities should they want to verify the findings.

- *Maintaining attribution and citation*

Attribution refers to crediting an author, artist or scientist with a particular work or idea while citation is the precise rewriting or quoting or acknowledgement of "intellectual credit" to a person's scholarly or artistic creations (Van der Wall cites University of Alberta; Ashcroft, 2011:3).To ensure scientific integrity with regard to attribution and citation, all sources of information, authors and content were duly acknowledged within the text and in the list of references.

- *Maintaining copyright and intellectual property*

Copyright refers to the legal entitlement an author, artists or scientist and publisher or distributer has to exclusive financial benefits from a work (Van der Wal 2005:160). Intellectual property refers to the original creative outcome of the artistic and scientific ventures of individuals that can be protected through copyright, trademark, patent, industrial design or integrated circuit topography (Van der Wal cites University of Alberta; MRC par 10.4.1). All copyright, intellectual property, authors and publishers will be acknowledged in the list of references so that scientific integrity is maintained.

- *Ensuring equality*

Equality refers to equal opportunity and equal treatment for the participants to be included in the study: this ethical principle is crucial during the participant sampling and recruitment stage especially when the respondents know the researcher. . Since this study employed the qualitative research approaches, the principle of equality was ensured by performing purposive sampling during participant recruitment. All participants were treated equally regardless of age, gender or other characteristics.

- *Cooperation with contributors*

Research projects are often so expensive and comprehensive that researchers may not be able to handle it on their own terms of finances and time De Vos *et al (*2005:64-65). Because of this, the researcher involves colleagues in the research project either formally and informally to assist with different aspects in

the course of study. It is therefore of paramount importance that the extent to which acknowledgement is given to each participant is given careful consideration. All contributors to this study were acknowledged.

- *Debriefing and referrals*

The Penguin Reference Dictionary (2004: 354) defines "debriefing" as interrogating a person about a mission or task after its completion. According to Polit and Beck (2008:182) debriefing sessions after data collection is completed, gives an opportunity to the participant to ask questions or air out complaints regarding the data collection processes or the research. Debriefing also permits the researcher to rectify any misconceptions that may arise in the minds of the participants (De Vos *et al 2005:66*). Every participant was given any opportunity to ask questions regarding the research or data collection process or express any complains they might have. Clarifications were made.

- *Dissemination or publication of findings*

Dissemination and publication of research findings entail the publication aspect of research. All information about the research, including the research findings,must be formulated and conveyed clearly and unambiguously to avoid misinterpretation and misappropriation of the information. Well-defined and scientific approved terminology is essential to ensure uniform interpretation of study findings by readers. The findings of this study will be represented as accurately and objectively as possible in a clear written form. The research findings will be summarised and a copy of the research report willbe handed over to the clinical director of Mpilo Central Hospital, in Bulawayo and the University of South Africa in Pretoria where the report might be published in the University's website or repository. An article of the report findings will be published in a renowned journal as part of the researcher's ethical obligation to the scientific community.

1.12 LIMITATIONS OF THE STUDY

The study was conducted at a tertiary hospital in Bulawayo the second largest city in Zimbabwe. The results that emerged from the study may not be representative of

all the cities in the country. Purposive sampling was used in the study and therefore, the possibility of leaving out eligible participants in the selection process cannot be guaranteed. Furthermore, the views of the participants may not completely represent the targeted adolescents age 13-21 years due to the exclusion of ages 13 to 17 that require parental consent to participate in the study. The nature of data gathering method may make openness with some participants difficult since recording of voices was done. Others may feel uncomfortable talking about HIV cultural/religious background and ability to express self during in-depth interviews.

1.13 STRUCTURE OF THE THESIS

The report will be presented in form of chapters and the content of each chapter is indicated below:

Chapter 1: Introduction and orientation of the study

The study is introduced and contextualized by providing the background information about the study as well as the design chosen for the study.

Chapter 2: Phenomenology; methodological foundations of the study

An account of the origins and essence of phenomenology as a philosophy and research approach that will inform the conduct of this study.

Chapter 3: Preliminary literature review

HIV, drug adherence and its implications to quality of life

Chapter 4: Research design and methods

Research design, methods and techniques employed in generating the data, data analysis as well as data presentation including ethical considerations will be discussed.

Chapter 5: Data analysis

The plan which will be used to analyse adolescence's lived experiences regarding drug adherence will be discussed.

Chapter 6: Presentation of data with literature support

The synthesized data will be presented in form of themes, categories supported with post hoc literature to enhance the audit trail and credibility of the findings.

Chapter 7: Relating the emerging construct to existing theories

Chapter 8: Summary, conclusions, recommendations and limitations

1.14 CONCLUSION

An outline of some of the experiences faced by HIV infected adolescents was done in this chapter. The background to the research problem focused on studies conducted elsewhere on HIV infected adolescents. The researcher further went on to outline the research methodology, the conceptual framework and the ethical principles which were followed during the execution of the study.

CHAPTER TWO

PHENOMENOLOGY: METHODOLOGICAL FOUNDATIONS OF THE STUDY

2.1 INTRODUCTION

In the previous chapter, chapter one, the researcher presented the summary of the research project. This chapter presents the methodological inferences of phenomenology as a research method and philosophy. Phenomenology was chosen based on Creswell (2014:252) and Finlay's (2009:6) assertion that it is well suited to explore human phenomena that require understanding from thefirst-hand perspective of those who have experienced it by returning fresh and rich description of the of the experience. The word phenomena originated from the Greek word '*phaenesthai*' which means to flare up or show itself. Therefore, a phenomenon is anything that presents itself to human consciousness (Moustakas 1984 in Dowling 2007:132). The term "phenomenology" was introduced by philosophers Kant, Hegel and later Brentano who intellectually motivated Husserl to developphenomenology (Dowling 2007:132). The main aim of this current research was to explore and describe the drug adherence lived experiences of HIV infected adolescents in Bulawayo, Zimbabwe in order to improve their therapeutic outcomes.

2.2 ORIGINS AND ESSENCE OF PHENOMENOLOGY

Phenomenology originated from the disciplines of philosophy and psychology in the 20th century against the reductionist approach in the natural sciences, which tended to explore human phenomena independent of the person experiencing the phenomenon (Patton 2002: 252; Lin 2013:2). Husserl sought to create a rigorous and unbiased approach to study things as they appear in human consciousness to enable the inquirer come face to face with the ultimate structures of consciousness or essence of the experience (Koch 1995:827). Husserl was interested in essences because he wished to turn philosophy into a process which could find logic, laws and absolute facts grounded in a perfect method (Owen 1994:3; Smith 2011:2). Husserl wished that this method of inquiry would have no crises of its foundations with no paradoxes arising along the way. He also desired that this method would be internally coherent and based on unquestionable self-evident truths (Husserl 1981;

Owen1994:3). Phenomenology differs from other human science approaches like ethnography, grounded theory and ethno-methodology because phenomenology makes a distinction between the appearance and essence of things with emphasis on the first-personexperience (Wertz 2011:52) to be achieved by aiming for truth, logic and rigorous self-critical thought (Owen 1994:18).

Phenomenological inquiry starts with what appears primarily in the first person's consciousness (non-verbal awareness) and studies the overall relations of meaning that appears through sensation to verbalised thought, in definitive experiences, turning abstract philosophical ideas and imperatives into "**tangible**" object-directed (intentional) awareness and deriving specific meanings from these experiences (Owen 1994:20; Wertz2011:52). Phenomenology concentrates on asking; **"what the nature or meaning of something is"** and demands the inquirer to look at the world **"as we meet it in the immediate experience"**. Unique to phenomenology is that it does notproduce empirical or theoretical observations; rather it offers an explanation of experienced time, body, space and human relations as we live them, altered by unique lived experiences (Van Manen 1990:184), which is the researcher's key focus. Stewart and Mickunas (1990) as explained in Creswell (2014:58) declare that the "phenomenological method" is grounded in the following presuppositions:

- A return to traditional tasks of philosophy which according to Owen (1994: 18) and Creswell (2014:58) is a return to search of wisdom. This reorientation arose as a result of philosophy becoming limited only to exploring human phenomena called "*scientism*" Wertz (2011:52) explains that Husserl developed phenomenological method on the premise that because human beings have the capacity for consciousness, human beings are fundamentally different from the material nature of the objects of science, thus requiring investigative approaches that are different from those existing within the physical sciences (Flood 2010:8).

- A philosophy without presuppositions meaning phenomenology is founded on the assumption that investigating human phenomena requires suspension of all judgments but what is considered real (Creswell 2014:58). The suspension of pre-understanding is what Husserl calls "epoche" of natural

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attitude (Wertz 2011:124). According to Flood (2010:9), Husserl believed that in order to bring out the essential components of a particular lived experience, the inquirer needed to shed all their prior knowledge about the subject to prevent their personal biases and preconceptions from unduly influencing the findings of the inquiry (La-Vasseur 2003:409; Finlay 2009:6-7 and Groenwald 2004:6).

- *The intentionality of consciousness*; which means that phenomenology is grounded on the assumption that consciousness is always directed "outwards" towards an object, implying that human reality is inextricably related to one's consciousness of it (Creswell 2014:59; Wertz 2011:52) This suggests that consciousness is always "*intentional*" and indivisible from its object and not self-subsisting Husserl (1929/1973) as explained in Le-Vasseur (2003:411).

- *The refusal of the subject-object dichotomy*, which means that the reality of an object is only perceived within the "meaning of the experience" from an individual's perspective. Creswell (2014:59) explains that informed by the presupposition of intentionality, Husserl rejected the notion of Cartesian dualism of subject-object differentiation. This gave rise to the notion of reality as perceived by one being constructed in and out of the interaction between oneself and the social as well as the cultural context of the world in which one exists (Crotty 1998 in Flood 2010:8; Van der Zalm and Bergum 2000: 212-214).

2.2.1 Definitions of phenomenology

Various scholars have defined the term phenomenology slightly differently and is not always used in reference to the tradition begun by Husserl in European philosophy during the 20th century (Wertz 2011:52). In psychology, the word phenomenology has been generally used to characterise any work in research, theory or practice that emphasises a first-person experience while in psychiatry its use denotes descriptive knowledge of symptoms of mental disorders (Wertz 2011:52). Despite the variant ways in which phenomenology is understood, it has become a credible approach for studying human consciousness and for clarifying

the foundations of philosophy and science. This method has continued to influence scholars in various disciplines such as humanities and arts just to name a few (Wertz 2011:52). In this current study, phenomenology is used to refer to the approach to knowledge originated and strongly influenced by Husserl and other proponents who subscribe to his epistemological perspectives. In this regard, Wertz (2005:175) describes phenomenology as a low hovering, in- dwelling, meditative philosophy that glories in the concreteness of person-world relations and accords lived experiences with all its intimacy and ambiguity, primacy over the known. This view is further expanded by Wertz (2011:52) were phenomenology is explained as a knowledge discipline that investigates consciousness in both ordinary day life and in science, while emphasising the intentionality of consciousness, the self-transcending way that relates to other objects. In the context of this research, the focal object is articulating the phenomenon of having to adhere to ART regimen both as a client and adolescent.

According to Patton (2002:104) "*phenomenology asks for the very nature of a phenomenon, for that which makes a "some-thing what it is andwithout which itcould not be what it is".* While Dowling (2007:132) describes phenomenology as a rigorous and unbiased study of things as they appear in consciousness in order to arrive at their "essence". In a like manner, phenomenology to Finlay (2006:6) is a "*return to embodied, experiential meanings, through methods that are responsive to both the phenomenon and the subjective interconnection between the researcher and the researched; aiming for fresh, complex, rich descriptions of experiences as concretely lived".* While Polit and Beck (2014:267) see phenomenology as a method whose principal aim is to explore and understand people's everyday life experiences, Streubert and Carpenter (2011:73) consider phenomenology as a science that explores and describes the appearance of things or phenomena. Therefore, in this regard, phenomenology refers to a descriptive human science methodology which seeks to pertinently explore and describe human phenomena in order to find hidden meanings and requires the researcher to assume an attitude of openness to let the unexpected meanings emerge (Mostert 2002:3-4).

2.2.2 Evolution of phenomenology

Phenomenology has its origins in psychology and philosophy. This evolution according to Streubert and Carpenter (2011:75) progressed through three main developmental phases namely the (1) preparatory phase, (2) German phase and the (3) French phase.

2.2.2.1 Preparatory Phase

The preparatory phase of phenomenology according to Streubert and Carpenter (2011:75) was given prominence by the works of philosopher and psychologist Franz Brentano (1838-1917) and his student Carl Stump (1848-1936). At this stage according to Cohen, Kahn and Steeves, (2006: 6-8) explain, Brentano wanted to make psychology the precursor to phenomenology, a scientific discipline, whilst Stump used experimentation to discover the connection between elements of human perception and thus founded experimental phenomenology. The primary focus at this point was mainly *clarification* of the concept of *intentionality*(see section 2.3.4).

2.2.2.2 German Phase

The two prominent leaders in this phase are Edmund Husserl (1857-1938) and Martin Heidegger (1889-1976) (Pringle, Hendry and McLafferty 2011:7). Husserl advocated for philosophy to become a pure science that would restore deeper contact with human concerns and thus fronted the idea that phenomenology should become the ideal foundation for all philosophy and science (Dowling 20017:131-132). The focus of the Husserlian phenomenology is epistemological, emphasising knowledge generation from lived experiences (Racher and Robinson 2003; 465). Husserl believed that everyday lived experience as perceived by consciousness was valuable and that consciousness should be the primary object of scientific inquiry and human knowledge development (Lopez and Willis 2004:727-728). Husserl's student Martin Heidegger moved his idea that human consciousness equated to knowledge at a higher level Racher (2003) as explained in Dowling (2007:133). Dowling further went on to say that though Heidegger agreed with Husserl that phenomenology should focus on lived experiences, he did differ from Husserl on the latter's insistence on describing rather than understanding lived

experience. Heidegger thus promoted the idea that the focus of phenomenology should move from knowledge generation (epistemology) to interpretation and meaning (ontology) of lived experience. As explained by Koch (1996:827, McConnell-Henry, Chapman and Francis (2009:8) that the focus of phenomenology should be deriving meaning and understanding from those who have had a particular lived experience first- hand. The concepts that emerged during this developmental phase are *essences, intuition* as well as *reduction* or *bracketing.*

2.2.2.3 French Phase

The predominant leaders of the French phase of the phenomenological movement are philosophers Gabriel Marcel 1889-1973; Jean-Paul Sartre 1905-1980 and Maurice Merleau-Ponty 1908-1961. According to Treanor (2010:1-2), Marcel emphasised that philosophy should begin with concrete experiences rather than abstractions, while Sartre pursued philosophical reflection and literary creativity Flynn (2012:2-3) and Merleau-Ponty concentrated on analysing concrete human experiences, perceptions, as well as difficulties of human existence (Flynn2011:1-3). Furthermore, Merleau-Ponty is also acclaimed for championing the idea that human beings are their bodies and that because of lived experience, one cannot separate the mind from the body; and the object of a thought from the subject. The concept that emerged at this phase is *embodiment* or *being-in-the-world.*The phenomenological view of human nature evolved as the philosophical movement progressed and have come to influence the process of phenomenological research. The concepts that emerged are *lifeworld, lived experience, consciousness, intentionality, essence, reduction, bracketing, embodiment, being in the world, intersubjectivity, being in the world with others and hermeneutic cycle.*

2.3.1 Life world

The concept *life world* is defined as the everyday world we live in with all it taken for granted attitude, the world of lived experience (Mostert 2011:2). Husserl described *life world* as the world of immediate experience, the world as we already live there. Life world should thus be understood as the world as lived by a person, complete with worldviews, relations and experiences within which one has lived experience and dwells (Mostert 2011:3).

2.3.2 Lived experience

Mostert (2011:2) describes lived experience as *that which is lived by a person at a given time, in a given place, in their world. It is pragmatic and implicates the totality of life. It is already there and is part of our awareness.* Lived experience is central to phenomenology and without it there would be no phenomena to investigate (Mostert 2011:3). In support, Van Manen (1997) cited in Mostert (2002:3) affirms that lived experience is very central and may be considered the starting point and the end point of phenomenological research.

2.3.3 Consciousness

The online dictionary defines consciousness as a state of being aware of one's surroundings while Mostert (2011:4) defines it as those things that present themselves in the world. Without being conscious of the presence of a thing- it cannot be part of the lifeworld of a person, and cannot be investigated. To explore a phenomenon in the lifeworld is to explore it first as it presents itself to consciousness within the context of the lifeworld (Mostert 2002:3-4).

2.3.4 Intentionality

Intentionality is the inseparable connectedness of the human being in the world (Prim and Cunha 2006: 2-5). It is the phenomenological concept that structures the relation between the person and the world Van der Wal (2005) as cited in Mongwe (2007:37) further explains that the term intentionality is not to be understood to mean the intention or having good intentions, but rather it is the driving force that helps humans to know what they intend to know. Intentionality means that if a person is angry (object) then they are angry about something (subject) and this is because conscious is always conscious of and directed at something concrete implying that to be in a state of desire implies something is being desired (Mostert 2011:4). In view of this affirmation, it therefore suffices to note that the orientation to intentionality (object directedness) is not always conscious but rather only available to human consciousness upon careful retrospective reflection (Mostert 2002: 5-6).

2.3.5 Essence

Essence refers to the essential or core meaning of a thing before social and cultural meanings are attached to it (Mostert 2002:3). Essence is that which makes a thing

what it is without which it could not be perceived as is (Van Manen1997). In order to discover the essence of an occurrence, the inquirer should begin exploring the 'whatness' of the phenomenon by asking *what it is like to experience the phenomenon* and then proceed to the question *what it is like for me in my circumstances (*Mostert 2002:3).

2.3.6 Reduction

The term "*reduction*" or "*bracketing*" is defined as a return to the original awareness of the phenomenon under investigation (Streubert and Carpenter2011:76). Husserl believed that bracketing would help researchers to achieve a state of '*transcendental subjectivity'* which Wojnar and Swanson (2007:173) consider as the state of consciousness where the researcher successfully abandons their lived reality and describes the phenomenon being investigated in pure form.   This original awareness, Wertz (2005:168) maintains arises when the researcher adopts a "*phenomenological attitude*" characterised by two methodological procedures, referred to as 'epoches'. According to Giorgi (2008:41), 'epoches are cautions or abstentions which help to shield researchers from undue influences that may short-circuit or bias their description of the experience in the purest possible form.   The first   is   the   *'epoché   of the natural sciences'* (Husserl 1939/1954, as cited in Wertz 2005:168) which requires the researcher to set aside all knowledge that is not part of the phenomenon, including scientific theories, explanations, hypotheses and conceptualisations and past knowledge, especially beliefs emanating from the researcher's   past   experiences..
This "*epoche*" facilitates researcher's access, *"to the things themselves* , and requires one to identify prior knowledge and to put it out of play, making no use of it while listening to, interacting with and analysing the entire research data.

This first epoche delivers the researcher to the *pre-reflective* world, the "natural attitude", the pre-scientific life-world where there is unreflective (takenfor-granted) apprehension of the world, exactly as it is experienced in everyday life by participants (Wertz 2005:168). It is at this point that the second procedure, the *"epoche of natural attitude"* comes to play. As Wertz (2005:168) explains, it requires a transformation of the researcher's attitude from the *"natural (uncritical) attitude",*

assuming every existence and taking "things" (situations) for granted, to one where, the researcher questions reflectively what different aspects of a lived experience mean for those who experience them. This second "*epoche*" allows the researcher to empathically enter and reflect upon the lived world of the other and apprehend the various meanings of lived experience as "*given*" to the participant (Wertz2005:168).

2.3.7 Being in the world (embodiment)

The concepts "being in the world" and "embodiment" refer to the belief that all human acts are constructed on the foundation of perception or original awareness of   some phenomena Merleau-Ponty (1956), as cited in Streubert and Carpenter (2011:77). Munhall (1989), points out that "being-in-the-world" refers to the way human beings exist, act or are involved in the world; as a nurse or as a parent, while "embodiment" relates to the reality that "one is aware of being-in-the world only through the body; that is , one gains access to the world only through their body; one feels, thinks tastes, touches, hears and is conscious through the opportunities the body offers" Munhall(1989), as cited in Streubert and Carpenter (2011:77). Hence, embodiment and being-in-the-world imply that individuals cannot be defined as a separate entity, awayfrom the way they relate to their world and with others (Todres and Wheeler 2001:3-4).

2.3.8 Being in the world (intersubjectivity)

Anderson (1991:29) says that the notion of „*being-in-the-world-with-others*, means that humans make sense of the world and create meanings out of them through socially constructed approaches through on-going relations between people. Becker (1992:14) asserts that according to Heidegger, human beings should best be understood as "*being-in-the-world-with-others*" because any experience of oneself and another always occurs within an interpersonal framework. Cohen, Manion and Morrison (2000:84-90) agree that meanings of situations are constructed through a *dialectical* process that arises out of the interaction between people.

Husserl expanded the notion of *being-in-the-world-with-others* to the concept of *transcendence*, which implies that humans have a capacity for *self-awareness*. This means that *self-awareness* leads to *intersubjectivity*, the awareness that others have the same self-reflective ability. The awareness of the self, promotes awareness of others which makes intersubjectivity basic to human understating. In fact, Husserl (1989) in Duranti (2010:7) noted that self-consciousness and consciousness of the other is inseparable meaning one's perception of a situation may be used to derive perceptions of others about the subject since meanings are derived intersubjectivity.

2.3.9 Hermeneutic circle of understanding

Hermeneutic circle of understanding is described as *"a process that moves forward and backward, never closing and final, uncovering the phenomenon through a rigorous interaction with the parts and the whole" (*Allen and Jensen 1990:245; Annells 2006:707). It refers to processes from which meanings are derived out of interactions between researcher and participants, working outward and backward from self to the event and from the event to the self (Allen and Jensen 1990:245 and Dowling 2007:134).

In the thinking of Fry (2009:2-4), hermeneutic circle is the relationship of understanding between the reader and the text, manifested by the reader moving between parts and whole text, beginning with preconception about the whole experience from studying a part of the text, and then clarifying it by moving back to the whole experience again, and then back to the "*part*" already "*understood*" and further returning to the whole text again, until a deeper understanding of the whole and the parts of the experience are achieved. This circular process involves the researcher constantly clarifying their understanding of the part and whole of the text as the reading and reflection continues. As the interpretative reading continues, the researcher's understanding of the whole and parts of the phenomenon is continuously challenged and clarified by the insights that continue to emerge as the researcher penetrates deeper into the lived experience accounts, revealing what lies hidden in the texts (Allen and Jensen 1990: 245; Dowling 2007:134-135 and Fry 2009:4-5).

The processes resulting in *"hermeneutic circle of understanding"* have been referred to as the *"scientific phenomenological reduction"* Giorgi (1997), Giorgi and Giorgi (2003) in Finlay (2008:11) and "reflexivity" Finlay (2008:11) and Van Manen (2011:1-2). To gain access to the essence of a phenomenon, the process of understanding requires the researcher to *"become fully and thoughtfully involved as if engaging in a dance of moving forward and moving back"* (Halling and Goldfarb 1991:328; Finlay 2008:11-12).

2.3.10 Reflexivity

The term **reflexivity** can be understood as thoughtful evaluation of the intersubjective dynamics between the researcher and researched (Finlay 2008:3). It involves critical self-reflection of how the researcher's background, assumptions, position and behaviour impacts on the research process. A closely related concept of reflection involves thinking about something after the event. Therefore, through reflection or reflexivity an immediate, dynamic self-awareness about an occurrence can be captured (Finlay 2008:3; Finlay 2009:12).

2.4 TRANSITIONS OF THE PHENOMENOLOGICAL MOVEMENT

The phenomenological movement has transitioned over the centuries from emphasizing only pure description of Husserlian years focusing on interpretation and later embodiment in the later years characterised by interpretation of people's experiences (Lopez and Willis 2004:727; McConnell-Henry *et al 2009:8*). Gorgi (2008:34) also supports, and maintains that Husserl's ideas about pure psychologism gave rise to descriptive phenomenology the fundamental premises from which the transition to interpretive phenomenology would later take place. This transition from pure description to interpretation was led by (Heidegger McConnel-Henry *et al 2009:8*). This change to interpretation emphasised the bodylines of human beings and led to emergence of the concepts of embodiment and being-in-the-world through the works of Marcel and Sartre (Streubert and Carpenter 2011:76).

2.4.1 Descriptive phenomenology

In descriptive phenomenology, the researcher explores, analyses and describes a phenomenon as free as possible while maintaining its richness, breadth and depth so as to gain a near real picture (Matua and Van der Wal 2015;23). Husserl was convinced that the subjective experience is central to scientific investigation because human actions are influenced by what they perceive as being real to them and what is real is what is in consciousness (Lopez and Willis 2004:727; Giorgi 2008:33). In order to grasp this reality, the researcher should seek to obtain the content of human consciousness in a pure form devoid of any preconceptions. This is what led to the notion phenomenological *epoche* which is the Greek word for bracketing. This requires that the researcher during the inquiry process sheds out all their prior knowledge to grasp essential elements of an experience they are studying (Streubert and Carpenter 2011:76-78; Giorgi 2008:38). Another assumption is Husserl's belief in *"universal essences"* or *"eidetic structures"* which are claims of features of lived experience that are common to all human beings who have experienced a particular phenomenon (Lopez and Willis2004:728). Husserl maintained that there is only one correct interpretation ("universal essence") of lived experience regardless of the person's history and context (Wojnar and Swanson 2007:173). This belief that '*essence'* of lived experience could be abstracted without consideration of the context reflects the value of traditional science and was Husserl's attempt to make phenomenology a rigorous science, consistent with prevailing tenets of the scientific paradigm to promote approval of these views (LeVasseur 2003:413).

2.4.2 Interpretive phenomenology

Interpretive phenomenology arose when Heidegger steered away from some of the views of Husserl and began to search answers to the *meaning of being* and to focus pertinently on gaining a deeper understanding of lived experience (Van der Zalm and Bergum 2000:212; Van Manen 2011:3-4). Although related to Husserlian descriptive phenomenology, interpretive phenomenology has distinct features that define how it guides inquiry. In support, Dowling (2005:133) and Van Manen (2011:3) concur that phenomenology becomes hermeneutical when its method and

focus is *interpretive*; to attain deeper understanding rather than simply *describing* people's lived experiences.

This shift of focus to *interpretation* and *understanding* is evident in the work of Heidegger who argues that all description is always already an interpretation Finlay (2008:8) saw understanding as an inevitable basic structure of our being-in-the-world (Heidegger 1929/1962 in Finlay 2008:8). Heidegger championed the belief that human beings are *interpretive* by nature and are always trying to find significance and meanings in their lives influenced by the *context* in which they find themselves (Wojnar and Swanson 2007:174). Buttressed by this belief, Heidegger held the conviction that, understanding human beings should not occur in isolation of their culture, social context or the historic period in which they live. This belief implied that for the current study, the lived experiences of adolescents should be understood from within the *local context* of each of the study participants. However, descriptive phenomenology will be used in this current study. Interpretive phenomenology was developed further by Heidegger's followers Gadamer, Ricoeur, Marcel, Sartre and Merleau-Ponty. Gadamer explored the role of language, nature of questioning, phenomenology of human conversation, significance of prejudice, historicity and tradition in human understanding (Van Manen 2011:4). Gadamer held the view that hermeneutic experience is made possible through language and therefore developed a distinctive and dialogical approach to phenomenology emphasizing understanding from within the linguistically expressed perspective of tradition (Malpas2009:2). Ricoeur's contribution to the hermeneutic discourse regards how meanings are deposited and mediated through myth, religion, art and language (Van Manen2011:4). Key to Ricoeur, according to Dauenhauer and Pellauer (2011:2) was the affirmation that human understanding comes through our relation to the world and our life with and among others in the world in which we live.

Marcel is credited for insisting that philosophy "*speaks*" in ordinary language with a focus on concrete human experience. *"We should employ current forms of ordinary language which distort our experiences far less than the elaborate expressions in which philosophical language is crystallized",* Marcel emphasized Marcel (1965) in Treanor (2010:2). Sartre explicated the notion of intentionality by insisting that

human reality, which Heidegger called; *"being-in-the-world"* is primarily posited through its *ontological* concerns rather than its *epistemic* relationships (Flynn 2011:2). This means that for human beings what matters is what has "*meaning*" to them and not necessarily what may be considered as important aspect of *knowledge*. This assertion implies people live their lives concentrating on *meaningful* aspects of life.

Merleau-Ponty (1945/1962) emphasized that phenomenology seeks to understand the relationship of human consciousness and the nature of being: whether biological, psychological or social (Flynn 2011:3). He held the view that consciousness meant existence in and toward the world through the body, experiencing the world through the possibility of our bodies (Van Manen2011:1-2). He further clarified that phenomenological inquiry does not yield unquestionable or 'absolute' knowledge as earlier affirmed by Husserl.

Instead, Merleau-Ponty declares that the "most important lesson which the (phenomenological) reduction, [methodological process of researcher suspending prior knowledge], teaches us, is the impossibility of a complete reduction" (Merleau-Ponty 1945/1962, in Finlay 2008:10; Van Manen 2011:2) because humans are incapable of transcending pre-understandings which is key in knowledge generation.

2.4.3 Influence of descriptive phenomenology on research

Whilst both approaches to phenomenology depend on lived experience and have a shared history, differences exist between the research methodologies in relation to:

- Focus of the research study.

- Role of prior knowledge in the research process

- Outcome and goal of the research process.

- Value of context in the research process.

- Application of knowledge generated within professional processes.

According to Lopez and Willis (2004:727), these differences influence knowledge generation, including how findings are used to augment disciplinary understanding. In the following subsections, descriptive phenomenology which is the chosen methodology of this study will be discussed.

2.4.3.1 Focus of the research study

Descriptive phenomenology focuses mainly on knowledge generation that emphasises direct exploration, analysis and description of a particular human phenomenon as free as possible from unexamined presuppositions aiming at maximum intuitive presentation of the experience Matua and Van Der Wal (2015:24). In other words, descriptive phenomenology seeks to answer the question, "what is it like to undergo a particular experience?" In order to get a clear picture of what the experience is like, the researcher focuses on describing the experience in question as faithfully as possible so that others are able to "*see*" and "*feel*", the first-hand experience, without the researcher articulating any information related to the social or cultural or political context of the person whose lived experience is being articulated (Van Manen 1990:184; Dowling 2007:132-133).

2.4.3.2 Role of prior knowledge in the research process

In descriptive phenomenological research, the researcher is expected to shed and keep in abeyance all their personal knowledge related to the subject of inquiry (Lopez and Willis 2004:727) through bracketing. Bracketing according to Husserl helps in achieving a state of transcendental subjectivity which Wertz (2005:172) say helps researchers to abandon their lived reality and glean the lived experience in question in its pure form. Wojnar and Swanson (2007:173) contend that it is this desire for reduction that has led some descriptive phenomenologist albeit with opposition to propose that researchers should withhold and in-depth literature review prior to investigation to prevent getting contaminated with prior knowledge. Descriptive phenomenology attempts to ensure that the researcher's pre-understandings do not creep inadvertently into research findings (Dahlberg 2006:16; Finlay 2008:11). In the current study a preliminary literature review was done but the main review was done with data analysis.

2.4.3.3 Outcome of the research process

In descriptive phenomenology, the outcome of research is arriving at what Husserl called *"universal essences"* or *"eidetic structures"* which are "pure" description of what an experience is without being unduly tainted by the researcher Husserl (1936/1970:152) in Finlay (2008:8). Descriptive phenomenology Wertz (2011:124) clarifies, aims to "unveil" how a particular lived experience presents itself, with "nothing added and nothing subtracted", ensuring that the knowledge generated reflects the *"situation-as-experienced-by-participants-first-hand"*. This is why Newstrom and Davies (2002:77) portray descriptive phenomenology as a form of inquiry that aims to accurately describe an experience and not generate theories or explanations about it, resulting in the description of *"what an experience is like"* (Giorgi 2008:34; Wertz 2011:125). The process of generating *"pure description"* and the *"universal essences"* is facilitated by reduction and supported by the belief that there are features to any lived experience that are common or "given" to all persons who have had the experience (Lopez and Willis 2004:728; Giorgi2008:38). Descriptive phenomenological inquiry, considers the researcher as an *"alien"* whose role is to grasp *"what something is",* from the first-hand ("I") perspective of those who experience it (Wertz 2011:52) and then meticulously describe critical elements with emphasis on its *"individual"* or *"universal"* features as desired (Giorgi2008:39; Streubert and Carpenter 2011:82).

2.4.3.4 Value of context in the research process

Plotka (2011:423) explains that for Husserl, human beings are free agents uninfluenced by the environment and culture in which they live, implying that, for him and his followers the impact of culture, society, and politics on the individual to choose and act does not matter (Lopez and Willis 2004:728). Accordingly, the environment in which a person lives is believed not to influence their lived experiences (Wojnar and Swanson 2007:174) and so researchers operating within this realm of phenomenology simply concentrate on describing the essential features of the phenomenon without paying attention to socio-cultural contexts of the people experiencing the phenomenon (Mackey 2005:183 Dowling 2007:132). Husserl also fronted the idea that this approach results in a *single* correct interpretation of lived experience because reality is understood as being objective

and independent of history and context (Allen 1995 in Lopez and Willis 2004:728). Hence knowledge obtained within this philosophical framework extracts the essence of lived experience in a context free manner, consistent with the views of traditional positivist science.

2.4.3.5 Application of the knowledge generated within the professional disciplines

According to Lopez and Willis (2004:729) because descriptive phenomenology results are knowledge that is context free and universal in nature, research efforts within this framework are largely geared towards understanding what it is like for a person or a group of people to experience a phenomenon. Hence professional knowledge is built by generating new knowledge about a poorly understood phenomenon so that others can know its "distinct" or "essential" elements to allow for a "generalised description" of the said phenomenon (Lopez and Willis 2004:728; Streubert and Carpenter 2011:82). Since HIV drug management is a lifelong and the experience of individuals starting ART from infancy is a new phenomenon, this current study sought to generate new information.

2.5 FOCUS OF PHENOMENOLOGICAL INVESTIGATIONS

In literature, there are largely two broad areas of phenomenological inquiry: first, description of unique individual (*idiographic*) essences of lived experience and second; description of the universal (*general*) aspects of lived experience. These considerations that underlie both descriptive and interpretive approaches have formed the basis for the contest between phenomenological investigators.

2.5.1 Focusing on the essential and universal essences of lived experiences

This approach to phenomenology is championed by descriptive phenomenologists such as Giorgi (2008:36) and Wertz (2011:50-52) whose work is strongly influenced by the transcendental tradition of Husserl, where the focus is to throw light on both essential and general structures of phenomenon (Finlay 2009:9). These scholars concentrate on elucidating the "general structures" of lived experience; that is, aspects of the lived experience shared by many, by clarifying the nature of the phenomenon in a more traditional, normative and scientific sense. To do this, the

phenomenologist starts by distinguishing single individual's particular way of experiencing the phenomenon being investigated from a more general way that belongs to all people experiencing the same experience through the process of *"free imaginative and empirical variation"*. Then to arrive at the "general" aspects of the lived experience in question, the researcher obtains several *"individual"* descriptions in order to come up with a *"typical essence"* of the phenomenon (Giorgi2008:37). Typically, this approach begins with constructs of several accounts of individual experiences and comparing them to one another for individual uniqueness as well as universal similarities (Van der Wal2013:1). Then to arrive at general aspects of the experience, the researcher projects the idiographic analysis (individual) findings through imaginative and empirical variation processes to explicate the general sense of the phenomenon. This means that after identifying each participant's *"individual psychological structure"* of the experience, the researcher then moves beyond these particular individual instances of the phenomenon to *"general aspects"* of the phenomenon. In the context of this study, the experience may vary from experiencing the effects of ART adherence /non-adherence as unique personal experiences to general aspects of surviving effects of non-drug adherence and related life-threatening conditions. Explicating "*individual*" experiences of the phenomenon is consistent with the first-hand, *"I"* perspectives which grounds phenomenology (Wertz 2011:52). The *"general"* aspect of the experience agrees with Husserl's belief that such research should emphasise *"universal aspects"* of people's lived experiences. This is relevant because this study is informed by Husserlian perspectives (Finlay 2009:9-10).

By focusing on both individual and universal essences of lived experience, scholars such as Wertz (1985/2011) and Halling (2008) in Finlay(2009:10) have adopted a middle position by towing the line that phenomenology should emphasise both the particular (idiographic) and general (universal) aspects of lived experience, focusing more or less on individual or general aspects of the experience; depending on the level of generality or individuality the researcher would like to achieve as dictated by the research objectives. The scholars who espouse both aspects of lived experience argue that idiographic aspects of lived experience can also be considered general, because it is through these idiographic perspectives that general structures emerge.

Certainly, Wertz (2005) lays credence to this view by asserting that it is possible to move beyond particular *individual* instances to the *general* because *"what is generally qualitatively true is also necessarily evident in each individual instance encountered"* as long as the researcher goes through a series of procedures to establish general qualitative knowledge from individual psychological structures (Wertz 2005:172-3). It is for this reason that Wertz's (1983, 2005 and 2011) method was chosen so as to tease both idiographic and general aspects of the ART adherence experience.

2.6 PHENOMENOLOGY AS A RESEARCH METHOD

As a research method, phenomenology is principally concerned with elucidating first-person experience of a phenomenon (Wertz 2011:52). This focus on the "I" aspect of lived experience is underpinned on the notion that reality is best understood when "seen through the eyes" of those who experience a phenomenon first-hand. In explicating, first-person experience, the inquirer needs to focus on understanding what these lived experiences are like and what they mean to those who go through them (Vivilaki and Johnson 2008:86; Giorgi 2008:380 and Streubertand Carpenter 2011:78).

In order to ensure accurate conceptualisation of a first-person perspective of an experience, the researcher during the phenomenological investigation is expected to:

- Conform to the tenets of phenomenology as a philosophy and research method throughout the process of data generation, analysis and reporting ensuring that the study is appropriately descriptive, employs reduction, explores intentional relationships between persons and situations and discloses the essences of meanings engrained in the live experiences using techniques such as imaginative variation and adopts phenomenological attitude and reflexivity (Giorgi 1989 in Wertz 2005:75).

- Generate data that is narrative, rich and concrete Wertz (2005:171), clearly reflecting accounts of lived situations rather than researcher's hypotheses, opinions and explanations of the phenomenon. The narrative data should reflect participants' firsthand accounts of what happened and what the

occurrence means to them in their contexts as parents' teachers. This means that the phenomenological researcher seeks, explicates and derives meaning from the first-person accounts of a live experience, starting off with descriptions in everyday language (Wertz 2005:171; Wertz 2011:52).

2.6.1 Conducting phenomenological study

In this current study, the researcher chose Wertz's (1983, 1985, 2005, 2011) Empirical Psychological Reflection (EPR) research approach. This analytical approach is linked to the Duquesne tradition and inspired by Husserl's descriptive phenomenology, the methodology chosen for the current study.It has evolved over the years to include features that are consistent with general hermeneutic phenomenological research principles such as those advanced within Ricoeur's (1976) hermeneutic-phenomenological philosophy.

Wertz's (1983/2011) research framework was chosen because its detailed approach to inquiry allows the researcher to capture both *"unique individual"* experiences(drug adherence) as well as *"general aspects"* of lived experience (Wojnar and Swanson2007:177) at the same time, allowing for examination of *contextual features* of these experiences in embodied, relational and temporal ways, in this case as lived by adolescents to promote deeper understanding (Koch 1999:21-22; Benner 2001:40).

2.6.1.1 Wertz's (1983/2011) empirical psychological reflection approach

Wertz's (1983/2011) analytical framework consists of three specific phases of reflection. The researcher is required to adopt a specific attitude or stance while performing the methodological procedures or research activities in each phase. These three phases of reflection are followed by the fourth phase, phenomenological describing or writing (Giorgi 2009, as cited in Wertz 2011:132; Wertz 2011:131).

2.6.1.1.1 Phases of empirical psychological reflection

The empirical psychological reflection proceeds through the following four phases:

- Constitution of revelatory descriptions (open reading).
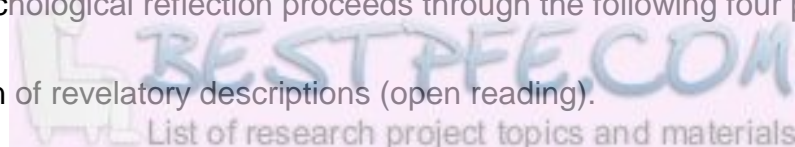
- Psychological analyses of the individual (idiographic analysis)

- Psychological analysis of the general (nomothetic analysis)

- Structural understanding and description (comprehensive understanding).

Constitution of revelatory Descriptions

This first phase of data analysis according to Wertz (1985:164) aims at generating well-organised description of the lived experience, expressed in everyday language of each participant. Also referred to as *"data cleaning"* or *"open reading"* phase, it consists of several steps, where the researcher reads entire transcripts to get sense of the whole Wertz (2011:131) and culminates in exclusion from each transcript all irrelevant data from the interview, leaving only those statements that reveal the experience *precisely* as it occurs.

This first step is consistent with principles of general hermeneutic research enterprise, which begins with the researcher reading the text as whole to gain an impression of the whole text, followed by formulation of thoughts about its meaning (Streubert and Carpenter 2011:85). This phase culminates in the documentation of the researcher's general *"impression of the text"* is what scholars of the general hermeneutic phenomenological movement Lindholm, Uden and Rastam (1999:103), Lindseth and Norberg (2004:149) and Bäckström and Sundin (2007:246) term *"writing the descriptive summaries" of individual interviews and coding for emerging themes"*.

In this phase of data analysis, all interview data will be individually reviewed to gain a "better sense" of the phenomenon of the lived experiences of drug adherence. This initial reading, termed *"open reading"* (Wertz 2011:131) or *"naïve reading"* (Bäckström and Sundin 2007:246), focused on how adolescents perceive drug adherence including what they thought people's reaction towards them symbolised, including how it affected their everyday lives. These "*initial impressions"* of the lived experience were documented and discussed with the thesis promoter (supervisor) who served as an external expert and qualitychecker.

Psychological analyses of the individual (idiographic analysis)

This second phase of analysis, refers to as the procedure of *"intentional analysis",* in Wertz (2005:172; and 2011:126) is a reflective process which involves the researcher carefully reading each revelatory description (clean description), in order to arrive at what Wertz (2011:142) terms *"Individual Psychological Structure" (IPS)* of the phenomenon. This step involves the researcher empathetically immersing in and reflecting deeply upon each participant's revelatory description Wertz (2005:172), (2010:272) and (2011:126), the specific details of which is presented in a later chapter. This second step is consistent with general hermeneutics' *structural analysis* or *thematic analysis* step Lindseth and Norberg (2004:150) and involves identifying patterns of meaningful connections through *"interpretive reading" (*Streubert and Carpenter2011:85). This is what Wertz (2011:131) describes as discriminating "*meaning units"*, that is, segments of the description that are relevant to the research interests and whose size and content leads to fruitful analytic reflection to answer the research question, which upon further reflection, results in themes (Lindseth and Norberg 2004:150; Wertz 2011:132).

Psychological analysis of the general (Nomothetic analysis)

The third phase of data analysis as Wertz (1983:227) and(2011:132) explains, involves further psychological reflection to learn and portray the lived experience in "*general*" terms. This requires that the researcher move from the "*psychology of individual experience*" to the "*psychology of the experience in general terms*", that is, across individuals and circumstances with similar attributes. This phase culminated into "*General Psychological Structure*" of the experience (Wertz 1985:188; 2011:150). In the context of this study, the unique individual aspects of the phenomenon which each meaning unit revealed was explicated through the reflective processes of "free imaginative variation" Wertz (2011:132) and "empirical variation or reflection" (Van der Wal 2013:1). This will entail keeping in mind the various contexts of adolescents and reflecting upon them deeply until *"general knowledge"* about the phenomenon emerges.

Structural understanding and description (comprehensive understanding)

The fourth step, which Wertz (2011:132) refers to as *structural understanding and description* phase, involves integration and description of insights that where be gained during reflections on the meaning units. This final step entails meaningful organisation of the investigated psychological phenomena as a "*structural whole*". This concept is referred to as *"comprehensive understanding"* in general hermeneutic research tradition (Lindseth and Norberg2004:150 and; Bäckström and Sundin 2007:244). Here the researcher reflected on the themes in relation to the research questions and the study context, to generate comprehensive understanding of the experience. The phase culminates in presentation of a holistic and comprehensive view of the experience, gleaned from reflections during open reading and in-depth reflection of the themes. The details of this phase will be articulated in later chapters.

2.6.1.1.2 Basic stances or attitudes during empirical psychological reflection

To facilitate meaning making and theme identification process, Wertz (1983:204; 2011:132) advocates that the researcher should adopt five (5) basic stances or attitudes throughout the idiographic and nomothetic levels of data analyses, through:

- Empathetic immersement in the situations described.

- Slowing down and dwelling in each moment of data.

- Magnification and amplification of the situation as experienced.

- Suspension of belief and employment of intense interest in experiential detail.

- Turning from objects to personal and relational meanings and significance

The details how each of the five stances will be observed will be discussed in a later chapter.

2.6.1.1.3 Specialised procedures of empirical psychological reflection

To arrive at unique individual or general essence of lived experience, Wertz (1983:206; 2011:132) clarifies that the researcher needs to engage in several active operative procedures throughout idiographic and general levels of data analyses. The entire analysis phase consists of 15 procedures, 11 of which are utilised during the individual level of analysis phase to obtain unique individual aspects of the experience; then, more 4 steps are engaged during general level of analysis, where general elements of the phenomenon are identified, as will be highlighted in subsequent chapters.

2.7 MOTIVATION FOR SELECTING PHENOMENOLOGY

The following factors explicated by scholars Koch (1999:22), Finlay (2009:6), Polit and Beck (2010:267) and Wertz (2011:124), as well as Streubert and Carpenter (2011:72), motivated the researcher to employ a phenomenological method to illuminate the phenomenon of lived experiences of HIV infected adolescents regarding drug adherence:

- Phenomenology is a descriptive, qualitative study of human experience that attempts to faithfully conceptualise the processes and structures of mental life including meaningful ways the world is given through experience. The aim is to provide descriptive and meaning-oriented knowledge that reflects *situations-as-experienced* (Wertz 2011:124). This method allowed the clarification of adolescents' lived experiences regarding drug adherence in their daily lives.

- Phenomenology, a rigorous, critical, systematic method of investigation is a recognised qualitative research approach applicable to the study of phenomena important to nursing Streubert and Carpenter (2011:72). The phenomenological method brings to language perceptions of various human experiences, especially poorly understood phenomena, like lived experiences regarding drug adherence. This research approach was chosen to study the lived experiences of adolescence as a strategy to understand salient issues related to the human side of such devastating situations so

that these perspectives may inform, enrich patient care and serve to improve treatment outcomes.

- Phenomenology investigates subjective phenomena in the belief that critical truths about reality are grounded in people's lived experiences (Polit and Beck 2010:267). This study that is geared towards a clearer and a broader understanding of human experience of suffering in this case lived experiences of drug adherence of adolescence falls within the "*realm*" of human knowledge inquiry scrutinisable using a phenomenological approach. Phenomenology provides researchers opportunity to "return to embodied, experiential meanings aiming for a fresh, complex, rich description of a phenomenon as it is concretely lived" (Finlay 2009:6). The rich descriptions of lived experience accounts evoke in the reader "*impressions*" of the phenomenon and through the shared meanings we have as humans, different people may come to understand what it means to experience a particular phenomenon. The method is thus believed that it will provide the rich descriptions that will help to broaden people's current understanding of the human side of drug adherence. Phenomenology provides nursing (healthcare) the possibility for improving care or understanding issues critical to nurses themselves and the nursing clientele as individuals, families and the larger community. Koch (1999:22-24) maintains that phenomenological inquiry augments nurses' understanding of patients' life experiences and their interpretation of such experiences. Therefore, a clear understanding of the meaning and the relevance of lived experience consolidates nursing's position to foster the well-being of clients who often require health care in unfamiliar and complex situations. This reality makes phenomenological research approach attractive for nurse researchers.

- Streubert and Carpenter (2011:94) add that phenomenology offers the opportunity to describe and clarify phenomena that better inform nursing education, research and practice. These perspectives have continued to provide impetus for evidence-based practices within nursing, thereby promoting advancement of nursing education, management and practice. (Jasper 1994:313 as cited in Streubert and Carpenter 2011:94) explains that the relevance of phenomenological method for nursing is that it

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supports new initiatives for nursing care especially where the subject matter is not amenable to other investigative and experimental methods as in the natural sciences. The phenomenological method provides a credible approach through which phenomena pertinent to nursing can be explored, analysed and documented.

2.8 CONCLUSION

Phenomenology is a fundamental field of inquiry in nursing. As a research method, phenomenology aims at elucidating human experience by bringing to language human experience. Phenomenology has developed from the works of philosophers Brentano, Stumpf, Husserl, Heidegger, Merleau-Ponty, Gadamer and Ricoeur among others. Central to the phenomenological movement are concepts such as intersubjectivity, embodiment, being-in-the-world, intentionality, essence, lived experience, reduction, bracketing and fusion of horizons, fore structures, hermeneutic circle and interpretation. As the philosophical movement transformed over the years, and across continents, two forms of phenomenology have come to dominate the research platform: descriptive phenomenology and interpretive phenomenology, both of which have as their central goal description of lived experiences Streubert and Carpenter (2011:94). Descriptive phenomenology is thus the most suited method for this study.

CHAPTER THREE

PRELIMINARY LITERATURE REVIEW

3.1 INTRODUCTION

Literature review refers to a systematic search of information about a phenomenon being studied and it entails reviewing and summarizing existing evidence (Polit and Beck 2014:558). Some authors such as Streubert and Carpenter (2011:25), suggest that in qualitative research, literature review should be done only after data analysis claiming that it contributes to bias and it interferes with the description of the phenomenon. However, some authors such as Creswell (2014: 85) indicate that preliminary literature review is essential because it helps to focus and give direction to the study. Also, related literature according to Streubert and Carpenter (2011:26) post hoc review of literature helps the qualitative researcher to place the findings of the study within the context of the already known. While Creswell (2014:27) considers review of literature before, during and after data collection vital to ensure that the research reflects current knowledge in the area and incorporates what others have done to enrich the process and outcome of the study.

The researcher did a preliminary literature review prior to data collection to give direction for the study followed by thorough review of literature following data analysis as advocated for by (Streubert and Carpenter 2011:27). Van der Wal (1999) as cited in Mongwe (2007:51) indicates that reviewing literature early in the study facilitates the researcher's entry into the first moment of the research process; that is identification of the phenomenon and its articulation. Investigator bias which is believed to arise by engaging in preliminary literature review will be countered through reflexivity. This was achieved by remaining aware of these *pre-understandings and open to participants' ideas.* The post hoc literature review will help in placing the findings in context of what is known.

3.2 Impact of HIV and AIDS on adolescents

Close to 90% of adolescents living with HIV in sub Saharan Africa have been infected through mother to child UNAIDS (2015;3). Prior to the advent of ART perinatally infected children were not expected to survive through their first decade of life. The growing numbers of these children are now maturing into adolescence

and adulthood. Adolescence itself is one of life's critical transitions. The biological and psychosocial changes that take place during this period affect every aspect of adolescents' lives. This coupled with HIV infection brings a plethora of problems to the adolescent. HIV affects the physical, social, emotional and spiritual wellbeing of an adolescent.

3.2.1 Developmental challenges

Adolescents are developmentally at a difficult time. Their needs, desires of independence and their evolving capacity traverse and compete with their concrete thinking processes; risk-taking behaviours, pre-occupation with self-image and need to fit in with their peers (AIDS info 2016: 3). This transition from childhood to adulthood involves changes in the physical, cognitive; biological, social and emotional domains in an adolescent's life. The adolescent experiences rapid physical growth, develops secondary sexual characteristics, cultivates a personal and sexual identity as well as intimate relationships and begins to transition towards autonomy and independence from parents (Paul and White 1990:1).

HIV infected adolescents need to negotiate the complexities of normal adolescent development such as identity development, romantic relationships and sexual activity in the context of a chronic and highly stigmatized disease and in due consideration of issues such as disclosure, HIV transmission and adherence to medication Sherr *et al (*2014:2) all of which could impair their social and psychological wellbeing.

In developing countries, HIV infection has been associated with impairment of linear growth and causing delayed sexual maturation among perinatally-infected adolescents and this further exacerbates the adolescent's feeling of being different and unwell leading to psychological distress (Isanaka, Duggan and Fawzi 2009:3). Also, because of the adolescents' premature cognitive decision-making skills impacts negatively on strategies to cope with HIV infection and its association with self-management demands. Preventive action requires an appreciation of future consequences, but adolescent's poor estimation (or lack of it altogether) of their own risks and the apparent need for immediate pleasure or gratification limits their ability to make rational assessments on the consequences of their behaviours (Diamond and Savin-Williams 2011: 3).

Peer groups are central to identity development process of an adolescent. Peers provide the adolescent with social support in form of role models, very personal social feedback, advice, comfort and companionship(Albeit, Chein and Steinberg 2014: 1). However, peer relations could either promote or hinder adolescent' wellbeing including their adherence to ART. Perceived differences between the peers and the adolescent may lead to feelings of isolation resulting in psychological distress. Fear of rejection by the peers may lead the HIV infected adolescent to abandon their medication in order to fit in with the peers and this occurs if the HIV self-care interferes with group activities. Peer beliefs and attitudes regarding HIV and its management create additional sources of stress for the HIV infected adolescent. For example stigma against HIV infected persons remains rife in Zimbabwe (www.msf.org/en/articles/stigma); perceived stigma from friends creates barriers to adherence especially if the HIV infected adolescent has not disclosed their status to peers as taking ART in the presence of peers could lead to unintentional disclosure of their HIV status(Albeit, Chein and Steinberg 2014:2). This peer to peer relation makes it very challenging to attract and sustain adolescents' focus on maintaining their health particularly for those with chronic conditions such as HIV infection.

3.2.2 Neuro-cognitive disorders

Globally, an estimated 3.4 million children are living with HIV and yet little is known about the effects of HIV and antiretroviral treatment on the developing brain and the neuro-developmental and behavioural outcomes of perinatally HIV infected adolescents (Laughton, Cornell, Bovin and Rie 2013:1). The key developmental tasks during adolescents are to develop identity, to become more independent and to consider the future in terms of career, relationships, families and housing. Traditionally adolescents are viewed as the age when abstract thoughts develop, together with improvement in memory, language, processing speed, attention and concentration (Keil and Ferrer 2007:2). While the adolescent's brain does not increase substantially in volume, changes in maturation reflect reorganization of regulatory systems and correlate with neuro-cognitive and behavioural outcomes (Keil and Ferrer 2016:3). Neuro-cognitive disorders which have been observed among HIV infected adolescents include subtle neuro-behavioural abnormalities such as impaired language and motor skills, cognitive deficits, impaired executive

functions to frank encephalopathy (Smith *et al 2012*:2). In a retrospective study done in the United states, Papola, Alvarez and Cohen (1994:1) found that 44% of the adolescents were functioning in the below average to average rage of intelligence and 56% demonstrated significant language impairments. In a study of 93 HIV infected children in Uganda Ruel *et al (*2012:3), found that HIV infected adolescents had worse neurological outcomes on the Test of Variables of Attention (TOVA) visual reaction times, sequential processing, simultaneous processing, planning or reasoning and global performance. These neuro-cognitive disorders have been attributed to ART, sexually transmitted infections, teratogens such as alcohol and illicit drugs and some neurotoxicity associated with HIV infections and abnormal immune activation

3.2.3 Psychiatric disorders/ mental health

HIV infected adolescents are at an increased risk for psychological disorders due to the direct effects of the HIV virus on the central nervous system (CNS) structures responsible for emotional, behavioural and cognitive functions and due to accumulation of stressors related to coping with medical, social and psychological demands of a life-threatening chronic illness (Wolters and Schmitt 1994: 1). One study on mental health outcomes among HIV infected adolescents found that 61% of HIV infected youths met the diagnostic criteria for a non-substance use psychiatric disorder compared to 49% of uninfected youths (Mellins, Leu, Elkington, Dolezal *et al 2009*:4). The most common diagnoses in this study among HIV infected adolescents included anxiety (49%), behavioural disorders (25.7%), and attention deficit hyperactivity disorder (ADHD) (18%), mood disorders and substance abuse (1.9%). In another systematic review study on psychiatric disorders among HIV infected children and adolescents (Scharko 2006:3) found that in a pool of 328 children aged between 4-21 years, 25% had ADHD, 24% had depression, and 24.3% had anxiety disorders. Psychiatric disorders among infected and uninfected adolescents have been associated with increased alcohol and substance abuse, poor health care seeking behaviours, poor adherence to ART and HIV care (Brown, Danovsyky, Lourie, DiClemente and Paton 1997:4).

3.2.4 What is adherence?

Antiretroviral therapy is a lifelong treatment and to get the total benefits requires strict adherence to the treatment regimen World Health (Organization (WHO) 2010:10); Giil, Hammer, Simon, Thea and Sabin 2005:2). According to WHO (2003:1), adherence is broadly defined as the extent to which a patient's health behaviours correspond with the medical advice or recommendations. However, there are no standard criteria for adherence to ART as each ART drug regimen has a specific adherence-resistance relationship (Bangsberg, Moss and Deeks 2004:4). Earlier drug regimens required levels of adherence greater than 95% but classes including the protease inhibitor (PI) boosted regimens and non-nucleoside reverse transcriptase inhibitors (NNRTI) may achieve full virologic suppression at adherence levels lower than 70% (Bangsberg 2006:3; King, Brun and Kempf 2005:2). In Zimbabwe, drug adherence among the adolescents varies from between 55% to about 95% while for the adult population is around 80% to 90% and the adherence levels for adolescents are dependent on the support systems available to the individual (Mavhu *et al 2013*:3) and Gross *et al 2014*:4). They further go on to say that young people on ART need support to maximize the benefits of therapy.

3.2.5 Measuring adherence

Several measures have been developed to monitor adherence to ART across different populations including self-reports of adherence, electronic monitors, unannounced pill counts, provider assessments, pharmacy refills and biological indicators such as CD4 cell count and virologic loads (Vreeman, Nyandiko and Liu *et al 2014*:3). However, there is no perfect measure as each measure has its own limitations such as cost and accuracy. Self-reported adherence is the most frequently measure in clinical practice and research especially in resource- limited settings such as Zimbabwe. Additionally, there is no standard cut-off for adherence on measures such as pill counts, in a recent review on gender effects in treatment adherence found that adherence cut- offs vary widely across studies ranging from 80%-100% (Vreeman*et al 2015*:2). This lack of a standard criterion for defining adherence prompted Holzemer *et al (*2009:1) to conclude that adherence is defined as measured. However, majority of the ART regimens in Zimbabwe and most of the

sub-Saharan Africa are largely based on nucleoside reverse transcriptase inhibitors (NRTI) (Ministry of Health Zimbabwe) which are susceptible to resistance at levels of adherence less than 95% (Vreeman*et al 2014:2*).

3.2.6 Adherence to antiretroviral therapy among HIV infected adolescents

Adherence to ART is a principal determinant of virologic suppression (Vreeman, Nyandiko and Liu 2014:3). HIV-infected adolescents are especially vulnerable to specific adherence problems because of their psychosocial and cognitive developmental trajectory (UNAIDS 2016:5). Comprehensive systems of care are required to serve both the medical and psychosocial needs of HIV-infected adolescents, who frequently lack both health insurance and experience with health care systems (UNAIDS 2016:5). Studies in adolescents infected in their teen years and in adolescents infected through perinatal transmission demonstrate that many adolescents in both groups face numerous barriers to adherence (Rudy, Murphy, Harris, Muenz and Ellen 2009:6). Compared with adults, these youth have lower rates of viral suppression and higher rates of virologic rebound and loss to follow up (MacDonnell, Naar-King, Huszti, and Belzer 2013:3).Reasons that HIV-infected adolescents often have difficulty adhering to medical regimens include the following:

- Denial and fear of their HIV status.
- Distrust of medical establishment.
- Lack of support.
- Fear of disclosure of status.
- Low self-esteem.

In a study assessing the levels of drug adherence on adolescence living with HIV carried out in Zimbabwe (Gross *et al 2014:4*) one respondent said "*I do not see myself swallowing these tablets the rest of my life, it is not easy. I will try but already, I have not taken my drugs for a week*".

3.2.7 Barriers to non-adherence

Barriers to adherence among HIV infected adolescents have been extensively explored in various studies conducted in low, middle- and high-income countries. The global barriers to adherence include; side effects, pill burden, appointment schedules that interfere with daily schedules, disorganized natural families, parent – child conflict, having too many people involved in pill supervision, residential instability, incomplete disclosure of the adolescent's HIV status, household poverty, lack of comprehension of HIV and its management (Arrive *et al* 2012:2, Vreeman *et al* 2012:3, Haberer *et al* 2011:3, Vreeman, Wiehe, Pearce and Nyandiko 2008:1).

In resource constrained settings such as SSA, household poverty and orphan-hood have also emerged as some of the most important predictors of adherence of ART among HIV infected adolescents. Lack of food and transport money to a clinic or hospital to refill their prescriptions has been associated to ART (Haberer*et al* *2011:3*). In a study of 96 HIV infected children done in Zambia (Haberer *et al* *2011:3*), the results were that the number of missed ART days increased by 8% per 100,000 ($20) income. Negative life events such as bereavement and orphan-hood have been identified as antecedents to psychological distress and non-adherence to ART among HIV infected adolescents (Kikuchi *et al 2012:5*). In a retrospective study of adherence on ART outcomes among HIV infected adolescents in Kenya, Vreeman *et al (*2011:3) found that the non-adherence to ART was higher among orphaned children particularly those who lost both parents.

3.2.8 Adherence facilitators

A few studies have sought to identify the psychosocial resources that facilitate adherence among HIV-infected children and adolescents. A majority of these studies have focused on elaborating on the role of coping and social support in dealing with adversity among HIV-infected adolescents, and these are described below.

Coping

Lazarus and Folkman (1991:141) define coping as a dynamic process that entails deployment of cognitive and behavioural efforts to manage specific external and or internal demands that have been appraised as stressful. Adolescents living with chronic illnesses are likely to use a variety of coping strategies in dealing with different aspects of stressful situations. The type and complexity of copying strategies utilised varies with the adolescent's age and gender (Keller and Nicolls 1990:2, Warady 2004:1 and Snethern, Broom and Warady 2004:2). Older adolescents are more likely to use emotion management and cognitive strategies such as cognitive restructuring, while younger adolescent's incapable of abstract thinking is more likely to use emotion focused strategies such as venting or avoidance and problem-solving coping strategies (Bull and Drotar 2004:2). Females are more likely to use emotion management coping strategies while males are more likely to use problem solving strategies.

Among HIV-infected adolescents, active coping styles such as confrontation or seeking social support have been associated with positive psychologicaladjustment, while passive coping styles such as withdrawal or depressive reactions are related to poor psychological adjustment.

Social support

Social support refers to the flow of emotional concern, instrumental aid, informational and appraisal resources between people (House, 1981:1). It is the functionalcharacteristic of social networks (Israel and Rounds, 1987:2). The association betweensocial support and health is well documented (DiMatteo, 2004; Krause, 1987; Lee,Detels, Rotheram-Borus, and Duan, 2007; Sopeña, Evangeli, Dodge, and Melvin, 2010).Social support mitigates the potentially deleterious effects of stress (physical orpsychological) on health across all levels of the life course (Krause, 1987; Murphy et al.,2000b; Sopeña et al., 2010:4). House (1981:1) hypothesizes that social support may enhancehealth and wellbeing either, directly by meeting basic human needs for security,socialcontact, approval, belonging and affection or reducing levels of perceived stress, orindirectly enhance health and wellbeing by moderating the relationship between stressandhealth (stress-buffering hypothesis) (House, 1981).

Improved social support among HIV-infected adultshas been associated with reduced psychological distress and increased adherence to ART (Chesney, Chambers, Taylor, and Johnson, 2003; Kalichman, DiMarco, Austin, Luke, and DiFonzo, 2003:5). Among HIV infected youth, social support has been associated with reduced distress Battles and Wiener (2002:7) but its relationship with adherence in this population has been less consistent.The lack of association between social support and adherence among adolescentshas been attributed to differences in the measurement of social support, especially thetype of social support assessed. For example, in a meta-analysis on the role of socialsupport in predicting patient adherence to medical treatment, DiMatteo (2004) foundthat practical social support had the highest correlation to adherence to medications.

Emotional social support was not associated with adherence (DiMatteo, 2004). Additionally, the lack of association between social support and adherence among HIV-infected adolescents could also been attributed to conflicts between the functions of social support and adolescents' desire for autonomy. Instrumental supportsuch as provision of foods and transport to the clinic (practical support) could beperceived as helpful but accompanying the adolescent to the clinic or reminding theadolescent about medication could be perceived as annoying or crippling the adolescent's desire for autonomy, thereby affecting their adherence to ART. However, formal support systems are largely non-existent in Uganda, where survival largely depends on family and kinship networks (Mills et al., 2006: 4). For these reasons, thesignificance of social support may supersede adolescents' desire for autonomy.

Spirituality and religiosity

Religiosity and spirituality have been identified as important psychosocial resources for coping with illness, as religious persons are less likely to experience negative psychological states such as depression and anxiety (Schapman and Inderbitzen-Nolan,2012:3). Religiosity and/or spirituality have been identified as coping strategy among HIV infected adults (Coleman and Holzemer, 1999;

Cotton, Zebracki, Rosenthal, Tsevat, and Drotar, 2006:4; Ironson *etal.,* 2002; Makoae *et al 2008*:6, Nooney and Woodrum, 2002:8 Prado et al, 2004:2 Tuck, McCain, and Elswick Jr 2001:7). Religious institutions also play a major role in providing health care and support to people living with HIV/AIDS (Kaldjian, Jekel, and Friedland, 1998:3). However, the role of spirituality and religiosity among HIV-infectedadolescents has not been fully explored. However, the role of spirituality and religiosity among HIV infected adolescents has not been fully explored. Emerging data in sub-Saharan Africa indicates that religiosity may have detrimental effects on the wellbeing of HIV infected persons as religious beliefs have also been associated with HIV related stigma. Additionally, religious beliefs and/or religious leaders may interfere with patient's adherence to ART (Kagee and Delport (2010:3).

3.2.9 Public health implications of non-adherence

Taking HIV medicines every day prevents HIV from multiplying, which reduces the risk that HIV will mutate and produce drug-resistant HIV. Skipping HIV medicines allows HIV to multiply, which increases the risk of drug-resistant HIV developing. Research shows that a person's first HIV regimen offers the best chance for long-term treatment success. So, adherence is important from the start—when a person first begins taking HIV medicines.

Drug resistance can develop as HIV multiplies in the body. When HIV multiplies, the virus sometimes mutates (changes form) and makes variations of itself. Variations of HIV that develop while a person is taking HIV medicines can lead to new, drug-resistant strains of HIV. With drug resistance, HIV medicines that used to suppress the person's HIV become ineffective. In other words, the person's HIV continues to multiply.

Once drug-resistant HIV develops, it remains in the body. Drug resistance limits the number of HIV medicines available to include in a current or future HIV regimen. Drug resistance also has a negative impact on the health system both economically and in management of other diseases in that instead attention and more resources are used in the quest to get a drug to combat the resistance, while at the same time other conditions are neglected. This poses a public health problem to a nation in particular and the world at large.

3.2.10 Conclusion

The purpose of the preliminary literature review was to inform the researcher and the reader on the main issues linked with the experience of drug adherence with regards to HIV infection. The following are some of the topics which were discussed in this chapter:

- Developmental challenges.
- Neuro-cognitive disorders.
- Psychiatric disorders.
- What is adherence?
- Measuring adherence.
- Adherence to antiretroviral therapy among HIV infected adolescents.
- Barriers to non-adherence.
- Adherence facilitators.
- Public health implications of non-adherence

In Chapter 4, the research design, data collection and analysis techniques, ethical considerations as well as measures to enhance the research quality are explained.

CHAPTER FOUR

RESEARCH DESIGN AND METHOD

4.1 INTRODUCTION

In the previous chapter, chapter three the researcher presented preliminary literature review pertinent to the study. This chapter will briefly explain the research problem, the study aim, as well as the grand tour question that guided the data collection. Qualitative research paradigm will be discussed with emphasis on its attribute that justified its selection in this particular study. The discussions are structured around the attributes of qualitative research, the phenomenological research method, research design, sample selection, data collection and analysis. The ethical considerations that were employed in the study will be explained as well. The centrality of this chapter is based on the fact that it articulates the specific methods adopted in the study and provides the framework for data collection and its quality.

4.1.1 Research problem

Adolescents face difficult and often confusing emotional pressures as they grow from being children to adults. The biological and psychosocial changes that take place during this period affect every aspect of adolescents' lives. This coupled with HIV infection brings a plethora of problems to the adolescent. HIV infection brings an extra burden to the already burdened adolescent. According to WHO (2013:1), adolescents are falling through gaps in HIV services, they need services and support tailored to their needs. They need to be equipped to manage their HIV infection and take ownership of their health care. In-depth understanding of the lived experiences of adolescents living with HIV is critical to determining the development of appropriate services aimed at improving the adolescents' psychosocial wellbeing, continued health and overall quality of life hence this study.

4.1.2 Research aim

The study aims to gain a clear understanding of how adolescents experience the phenomenon of adhering to ART, especially how they perceive HIV infection and what their reactions towards being HIV positive symbolise. The researcher aimed to

propose guidelines that health care providers, care givers and policy makers may use to address the aspects of ART adherence specific to adolescents in order to improve the therapeutic outcomes and quality of life in Zimbabwe in particular and Africa as a whole. The study explores the lived experiences regarding drug adherence of adolescents on ART.

4.1.3 Grand tour question

The researcher asked every participant two grand tour questions and negotiated the data to illuminate their lived experiences and perceptions. The grand tour questions were: ***What have been your experiences since finding out that you were infected with HIV and that you have to be on treatment every single day of your life? And what would you say are the most difficult issues which make drug adherence difficult?*** The two questions assisted in exploring the perceptions and the meanings adolescents assigned to their lived experiences. The perspectives related to other people's responses towards them were explored using cues and hints provided by them during the interviews in line with the tenets of phenomenological research investigations.

4.2 THE RESEARCH METHOD AND DESIGN

4.2.1 Research design

A research design is the blue print or overall plan of fulfilling the objectives which will be encountered during the research process (Burns and Grove 2011: 253). It guides the researcher in planning and implementing the study in a way that is likely to achieve the intended goal ibid (253). LoBiondo-Wood and Haber (2014:56) explain the research design as an organisation of elements in a masterful work of art which incorporates the processes and techniques used. The defining characteristics of qualitative research as stated by Denzin and Lincoln (2011:3) is that it involves using an interpretive, naturalistic approach where the qualitative researcher studies things (situations, phenomena) in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Patton (2014:116) and Creswell (2014: 48) contend that qualitative research begins with assumptions and uses interpretive/theoretical frameworks to inform the study of the identified research problems and focuses on addressing the meaning individuals or groups ascribe to such social or human

problems. The qualitative researcher uses an emerging approach to inquiry, collects data in a natural setting, sensitive to the people and places under study, and employs an analysis framework that is both inductive and deductive and establishes patterns or themes. The final product of qualitative inquiry incorporates the voices of participant, the reflexivity of the researcher, a complex description and interpretation of the problem and its contribution to the literature or a call for change (Creswell 2014:48). In affirmation, Polit and Beck (2012:259) state that the research design in qualitative researchis "emergent" because the final design that guides the researcher in data collection and analysis arises during the course of data collection in the field. Within the qualitative research paradigm are various research methodologies (better known as designs) which share several similarities in their overall goals and techniques, although they arise from different theoretical and philosophical backgrounds. The commonest methods used include phenomenology, ethnography, grounded theory and discourse analysis among others (Polit & Beck 2012:263; Creswell 2014:44).

This study utilised the phenomenological method which falls within the qualitative research tradition rooted in the works of philosophers Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) as discussed in section 2.4. The researcher chose aqualitative research approach using the phenomenological method because it allowsrich understanding and description of lived experiences related to ART adherence asexperienced by the adolescents. These experiences arose from various participant contexts (Polit and Beck 2012:260). This choice of the phenomenological method is further supported by Brewerton and Millward (2001:223) who say that its greatest advantage is allowing deep understanding of the *structure* or *essence* of people's experience in its rich immediacy and vibrancy (Manamela 2009:90). This is further supplemented by Cohen's (2004:402) declaration that the phenomenological method facilitates deep examination of the structures of an experience from many different angles, sides and perspectives.

4.2.2 Assumptions underlying the design

The design used is based on the following key methodological assumptions about the researcher and participants.

4.2.2.1 Assumptions related to the researcher

With regards to the researcher, it was assumed that:

- The researcher's consciousness and use of the open-ended questions are primary research instruments used during the data collection (Creswell 2014:45).

- The researcher is inseparable from the research process (Polit and Beck 2012:16).

- The reductive process (bracketing) should be integral (Polit and Beck 2012:270).

- The inquiry results in rich descriptive information which helps the researcher understand the meaning of lived experience (Streubert and Carpenter 2011:20).

- The outcome of qualitative inquiry is conveyed descriptively incorporating participant's words and from their contexts (Streubert and Carpenter (2011:22).

- The researcher best understands human experiences in their whole rather than as interdependent variables of a situation (Creswell 2014:47).

- The researcher best articulates participant's lived experiences in a natural setting were the phenomenon occurs (Streubert and Carpenter 2011:22).

4.2.2.2 Assumptions related to study participants

With regards to participants, it was assumed that:

- Participants are best suited to provide information about experiences regarding ART adherence and assigned meanings to the experience (Parahoo 2006:66).

- Participants do not need to understand the research process in order to contribute towards understanding of the experience (Witte 2007:102).

- The reality of a phenomenon exists as participants see it and inquirer records them as seen from participants' eyes (Streubert and Carpenter 2011:21).

- The inductive nature of qualitative research means the researcher builds knowledge from observations and understandings gained from the study participants' narratives during the research process (Creswell 2014:46).

- The meaning obtained from the investigation results from co-creation between both the researcher and the researched (Wimpenny and Gass 2000: 1485-1488).

4.3 THE NATURE OF QUALITATIVE RESEARCH

Qualitative inquiry is designed to understand and describe poorly understood phenomena and processes including people's lived experiences (Alston and Bowless 2003:290). The researcher's aim in qualitative research is to focus on learning the meaning participants hold about a problem not the meaning the researchers bring to the research or writers from the literature Creswell (2014:48). The qualitative inquirer focuses on understanding the phenomena from the perspective of those who have experienced it first-hand, Streubert and Carpenter (2011: 3) claim that qualitative research methods are best suited approaches to gaining knowledge about situations where there is human subjectivity and interpretation, especially where there need to describe complex human phenomena.

Qualitative research approach is preferred when a poorly conceptualized phenomenon needs to be explored to generate detailed understanding of the issue Creswell (2014:48). This is because the qualitative research approach allows in-depth explication of the phenomenon by providing the researcher to talk directly to those involved by going to their homes or places of work and allowing them to tell their stories unencumbered by what the researcher expects to find or what is articulated in literature (Creswell 2014: 48). This in-depth exploration is useful to study a group and to identify variables that cannot be easily measured including 'hearing silenced voices. A key aspect of this research approach is its capacity to empower vulnerable individuals to share their stories within own contexts or

settings that the choice. Creswell (2014:48 adds that the choice of qualitative research is also warranted to develop theories when partial or inadequate theories exist for certain populations and samples or when existing theories do not adequately capture the complexity of the phenomenon. The qualitative research approach fits within the current study because quantitative measures and the statistical analysis simply do not fit the problem of understanding the issues related to ART adherence by HIV infected adolescents.

In the following section, the defining characteristics that make qualitative research appropriate for investigating lived experience such as the lived experience of adolescents having to take ART every single day of their lives is articulated.

4.3.1 The nature of qualitative research

Qualitative research as explained by Patton (2015:45), Creswell (2014:56) and Streubert and Carpenter (2011:20) as:

- An interplay of inductive and deductive reasoning.

- Emphasis on the emic (insider) perspective.

- Reality as being subjective and multidimensional.

- Capturing and discovering meaning and essence.

- Developing concepts in the form of themes, categories and subcategories.

- Emphasis on understanding of human phenomena

- Reporting of findings in a literary style rich with participants' commentaries.

- Use of multiple methods and data sources.

- Flexible method to enrich deeper understanding

- Linguistic epistemology with unit of analysis as the words.

- Holistic analysis emphasising the relationships between elements.

- Openness to new perspectives that emerge from the field work.

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- Data collection occurring in natural settings.

- Reliance on outcomes that emerge from the data rather than as predetermined.

In view of this, a descriptive, exploratory and contextual qualitative research design was employed using phenomenological method since it allowed the researcher to:

- Describe the essence of the experience of having to takeantiretroviral drugs every day of the adolescent's life (Streubert and Carpenter 2011:21).

- Collect data in the natural environment in which the phenomenon related to drug adherence was experienced (Creswell 2014:45).

- Conduct the study in an unstructured manner allowing for flexibility during data collection.

- Produce thick and vivid descriptions so that the reader can relate to them, projecting them in the moment.

- Present data with an open mind, acknowledging that all data obtained from participants is valuable for the research outcome (Creswell 2014 48).

- Adjust to the new realities that emerged during data collection because of the inherent flexibility and elasticity.

- Exploring meanings HIV infected adolescents assign to their experience of drug adherence considering that reality is multiple and constructed by those who experience a given phenomenon in their own social world (Streubert and Carpenter 2011:20).

4.3.1.1 Descriptive nature of qualitative research

Qualitative research is useful to study phenomena about which little is known and provides the opportunity to define such phenomena through description. As explained by Streubert and Carpenter (2011:21), that the in-depth probing nature of qualitative research suites the task of answering questions such as what is the nature of this phenomenon? Thompson (2007:304) agrees that describing in

qualitative research is critical because it is through describing human experience as lived that we can understand the other. Qualitative inquiry describes the dimensions, variations and importance of a phenomenon thus helping to delineate, elucidate and classify the important aspects of a phenomenon (Polit and Beck 2012:22). Creswell (2014:47) adds that the qualitative researcher develops a complex picture of the phenomenon by reporting multiple perspectives, identifying factors involved in a situation and sketching the larger picture that emerges by identifying and explicating complex interactions of factors in the situation. The researcher used this descriptive attribute of qualitative research inquiry to classify the essential elements of the lived experiences to describe them in greater detail to facilitate deeper understanding.

4.3.1.2 The exploratory nature of qualitative research

According to Polit and Beck (2012:22), the exploratory nature of qualitative research is characterised by the researcher beginning with the phenomenon of interest and investigating its full breadth and depth including the manner in which it manifested including other factors that may influence the phenomenon. This view is also supported by Manamela's (2009:91) affirmation that qualitative research allows exploration of new areas in order to gain insight into the phenomenon. Qualitative research methods are useful for exploring the full nature of a poorly understood phenomenon (Polit and Beck 2012:22). Hence the exploratory nature of qualitative research allows researchers to shed light on various ways in which a phenomenon is manifested including underlying influences such as participants'cultural background. The researcher specifically explored the '*phenomenon of ART adherence of HIV infected adolescents'* including the meanings assigned to HIV.

4.3.1.3 Contextual nature of qualitative research

Human experience is best understood from the contexts of those who experience the phenomenon (Polit and Beck 2012:23). This current study was conducted within a socio-cultural context awash with strict sanctioning and stigmatisation. The qualitative research design thus allowed the researcher to explore HIV infected adolescents' experiences regarding drug adherence within this unique context for the reader to grasp essential elements and meanings of their lived experiences. The choice of the contextual aspect of qualitative research design was implored by

the desire to present these experiences in the natural environment in which the strict socio-cultural sanctioning occurred. As stated by Bogdan and Bilken (2003:44), the research questions were carefully chosen so that the areas addressed helped contextualize the study findings to the realities of adolescents living with HIV and on ART.

4.3.2 Limitations of qualitative research

Though qualitative research design has a number of advantages due to its inherent flexibility and spontaneous nature, the researcher still noted the following challenges:

- Compared to the structured quantitative inquiry, the openness and emergent design that defines qualitative study resulted in the researcher needing direction on how to proceed at different stages of the research process. As a result, the researcher had to rely mostly on their supervisor for guidance and direction.

- Undertaking a qualitative study is more difficult than what it appears at first sight especially at the level of data collection where the interviews are directed by the grand tour question. The requirement for the researcher to adjust subsequent questions depending on how participants respond is very complex.

- The detailed description of the data collection methods as well as the incorporation of verbatim quotes from participants to enhance research quality proved to be very taxing. This requirement far exceeds the expectations within the quantitative tradition where most research data is presented numerically.

- Conducting qualitative studies takes a long time. It took me several months to progress from identifying the focus of the study, to conducting a preliminary literature review, collecting data, analysing data and presenting the findings. I would have taken a shorter time had it been a quantitative research.

- The data generation process resulted in a huge amount of unstructured descriptive data of over 80 pages single spaced, that needed to be coded, organised into meaningful data units. The researcher had to read the verbatim transcriptions several times in order to come out with the themes, categories and significant statements. The process was very complex and tiring because it needed totalimmersion into the data to make sense of the vast amounts of descriptive data.

- The ethical and scientific requirement for trustworthiness puts me under a lot of pressure to ensure that the findings were presented in a manner that represented the true picture of the views of the adolescents. This requirement meant that the researcher had to adhere to all expected ethical and scientific standards of research. In the following section, the various steps of the actual research activity will be explained from the point of identifying the population up to the point of delineating how ethical considerations were met to ensure the research findings were authentic and congruent with scientific and ethical standards of qualitative research.

4.4 POPULATION AND SAMPLING TECHNIQUE

Polit and Beck (2012:534) define population as the entire set of individuals and objects that have the characteristic or attributes in which the researcher is interested, while Parahoo (2006:274 says that a population consists of units such as people, events, objects or institutions from which research can potentially be collected. It sometimes is defined as a target population. Sampling technique refers to how a sample is selected from within a target population. While many options for sample selection exist, in phenomenological studies, purposive sampling is often used to choose participants who have experienced the phenomenon first hand and are suited to answer questions related to the experience (Parahoo 2006:274).

4.4.1 Population

The population consisted of all adolescents who were HIV positive, had been on ART for at least six months and collected their medication from Mpilo Opportunistic Adolescent Clinic. However, for practicality, the investigation was limited to a smaller group of adolescents who Brink (2009:123) terms the study population,

which is a section of eligible population to be included into the study. In this case the study population comprised of adolescents:

- Aged between 18 to 21 years.

- Have been on treatment (ART) for at least 6 months.

- Have experienced some challenges regarding drug adherence.

- Are registered at Mpilo Opportunistic Clinic and come for regular reviews and drug supply from this centre.

4.4.2 Sampling technique

Sampling refers to selecting a portion of the population to represent the entire population (Streubert and Carpenter 2011:90). The purpose of sampling in qualitative research is to identify information rich cases and explore them in in-depth interviews. Polit and Beck (2010:319) maintain that sampling in qualitative research involves selecting people who are knowledgeable, articulate, reflective and willing to talk at length with the researcher to meet the study's informational needs. The researcher made a choice from the following applicable options: purposive sampling, network sampling, volunteer sampling, total population sampling, random sampling and convenience sampling whose salient characteristics are discussed in Table 4.1 below.

Table 4.1: Sampling techniques used in qualitative research studies

Sampling techniques used in qualitative research	
Technique	**Purpose and defining characteristics**
Purposive Sampling	To select information rich cases for in-depth study of a phenomenon. Subjects are selected individually according to knowledge of phenomenon and the study's informational needs. Several variations exist as presented below:
	Stakeholder sampling: is useful in evaluation research and policy analysis and involves identifying stakeholders involved in designing, giving or receiving or administering a product or service being evaluated and persons affected by it (Given 2008:697-698).

	Critical case sampling: is used when a decisive case is required to help make a decision about a particular phenomenon. It is used to conform to recommendation by experts and it allows for generalisations to larger target population (Given 2008:698).
	Extreme or deviant case sampling: chooses extreme cases which represent the clearest instance of a phenomenon by considering informants whose experience is beyond the norm (Given 2008:698).
	Typical case sampling: Used when researcher is interested in describing typical cases as opposed to making general statements about a phenomenon (Patton 2014:167). The researcher or informants identify typical cases regarding the phenomenon and explore it further (Given 2008:697-698).
	Politically important case sampling: occurs when the researcher selects high profile cases to increase visibility of a phenomenon (Norwood 2000:212). This sampling assumes that including prominent figures in a particular inquiry may help with adoption of the findings.
	Negative case sampling (disconfirming): used when the researcher is looking to extend the analysis by looking for cases that will disconfirm it, to arrive at the point where explanations are sensible. This technique is useful in theory testing and to find the point at which generalisability of findings stop (Given 2008:698).
	Theoretical sampling: is used by researchers following a more deductive of theory testing such as in grounded theory research to individuals or cases that embody theoretical constructs related to the phenomenon (Given 2008:698).
	Criterion sampling: is used when the researcher wants cases or individuals who meet a certain criterion, disease or experience. It is useful to assure quality of the study findings (Given 2008:697-698).
Purposive sampling	**Maximum variation sampling:** The technique is used to obtain cases or individuals who cover the spectrum of positions and perspectives in relation to the phenomenon. It involves all different categories of people who have undergone the experience so that the researcher is able to describe themes that cut across different groups (Patton 2014:182).
Purposive sampling	**Expert sampling:** This sampling approach is used when the researcher is looking for individuals or cases who have a particular expertise that is likely to advance the researcher's interest and to potentially open new doors of inquiry, hence creating more understanding of the phenomenon in question (Given 2008:698)

	Homogenous sampling: used when there is need to describe the experience of a particular group in detail (Morse 1991:128). Consideration for sampling and investigation is based on variables such as gender, age or ethnicity because the phenomenon may be experienced differently by different people.
	Random purposeful sampling: helps the researcher to reduce potential purposeful sample to a manageable number particularly if the potential sample is larger than what the researcher can handle. The researcher chooses randomly from a group of informants to increase the credibility (Mongwe 2009:86).
Network sampling	Network sampling: is where support of a single informant is used to assist in selecting additional informants. It assumes that members of a group can identify others who meet the same criteria. It is useful where informants are difficult to identify. The approach is also termed snowball sampling and is particularly helpful in the introductory phase of a study after the researcher gains participant' trust (Norwood 2000:212).
Volunteer sampling	Volunteer sampling: involves soliciting participants through advertisements. Its advantage is that it helps to include informants with broader understanding of the phenomenon (Morse 1991:131). As a quality measure, volunteer participants are pre-screened before enrolment to determine if they meet the inclusion criteria.
Total population sampling	Total population sampling: This sampling technique is used to identify potential informants with the attribute the researcher wishes to investigate. This strategy is reserved for situations where there is a relatively small number of potential informants and where excluding anyone would be rude and inappropriate (Norwood 2000:212).
Convenience sampling	Convenience sampling: this sampling technique is used to save time and money and the researcher targets those informants who are readily accessible that is easily available. It may lead to poor sources of information and low credibility of the study. It is considered poorest of the sampling techniques (Mongwe 2009:86).

This current study used purposive, convenience and criterion sampling techniques to get study participants, the rationale and the method of which are now explained.

Purposeful sampling

Purposive sampling technique was used to select study participants for this study. The choice agrees with Streubert and Carpenter's (2011:29) affirmation that

purposeful sampling supports the qualitative researcher's goal of developing a thick description of a given phenomenon. Purposive sampling involves consciously selecting certain participants from the target population whom the researcher believes will help them generate thick descriptions (Brink 2006:133). In this study, would be participants met the sampling criteria (section 4.4.2.1), a random purposive sampling was done in order to get a manageable number of participants. The researcher selected the actual participants from a list of qualified adolescents (Mongwe 2009:86).

Convenience sampling

Convenience sampling refers to the inclusion as study participants, people who are conveniently available at the time of data collection (Polit and Beck 2012:311). According to Norwood (2000:428), convenience sampling involves selecting readily available participants that meet the inclusion criterion. It involved starting with participants who were *"at the right place at the right time",* especially at the beginning. Although this sampling technique is often criticized for having low credibility, the research team made sure that all those who were sampled *"conveniently"* met the study's inclusion criteria (section 4.4.2.1). In the current study, convenient sampling was not a problem because the target population was rather large and as affirmed by Brink (2006:132), the conveniently sampled potential participant was an HIV infected adolescent on ART who met the study criteria.

Criterion sampling

According to Patton (2014:180), convenience sampling is where the researcher set criteria (section 4.4.2.1) and picks all cases that meet the inclusion criteria. Why this sampling method was chosen is because of its strong impression on quality assurance. The research team selected participants based on that they were HIV positive adolescents on ART. The researcher got to know of the adolescents through verification by health care providers at an adolescent opportunistic clinic before commencement of the study.

4.4.2.1 Sampling criteria

A key characteristic of qualitative research is that a variety of sampling methods are applicable (Polit and Beck 2011:321 and Christian 2009:291). This means that a researcher can employ a sampling technique that allows for careful selection of participants depending on the informational needs and the inclusion criteria. In the current study, eligibility to participate in the study was determined by:

- Being an HIV infected adolescent and aged between 18-21 years.

- Should have been on ART treatment for at least six months.

- Consenting to participate in the study as an informant.

- Granting permission to be tape recorded during and after the study interview.

- Be ready to share their lived experience regarding drug adherence with the researcher.

- Demonstrating the ability to competently describe their lived experience.

- Agreeing to validate themes and descriptions in other interviews if required.

- Showing no signs of complications of the infection such as neuro-psychotic behaviours, depression and restlessness.

Participants who satisfied these inclusion criteria were randomly chosen from a group of purposely chosen HIV infected adolescents on ART. Patton (1990:169) suggests the logic and power of purposive sampling lies in selecting information-rich cases; those who are on ART and have experienced the challenges of drug adherence.

4.4.2.2 Sample size

In qualitative research there is no rule regarding the sample size (Patton 2014:67), rather the size of the sample is determined based on the informational needs of the study (Polit and Beck 2012:321). However, Sandelowski (1995a:179-183) warns that the issue of sample size should not be misunderstood when dealing with qualitative

research because adequacy of sampling is important in both qualitative and quantitative inquiry. Parahoo (2006:277) agrees that the qualitative researcher needs to make judgments to ensure that the number of participants is adequate to support a particular enterprise, warning that the sample should not be too large, so as to sabotage the deep case oriented analysis of the phenomenon, nor should it be too small so that the researcher fails to delineate the "core" essence of the phenomenon.

This is further validated by Punch (2004:117) who asserts that when the research sample is too large, certain responses of the participants may not be considered or not respected. LoBiondo-Wood and Haber (2010:126) also warn that researchers should avoid using too few participants arguing that such very small samples tend to be unstable, especially for nomothetic analysis. This view is similarly shared by Giorgi (2008:36) when he points out that larger samples help the researcher to more easily distinguish or discriminate a single individual's particular way of living the phenomenon from a more general way that belongs to a type rather than to an individual. Hence, the number of participants should allow sufficient variation so that the researcher gets to "*general aspects*" of an experience and ably arrives at the "*essential elements*" of the phenomenon close to first-hand experienceas possible. Further, Polit and Beck (2012:321) point out that sample size in qualitative research is guided by the point at which data saturation and redundancy appear. In agreement, Streubert and Carpenter (2011:90) state that data generation in qualitative research should continue until the researcher notes that data saturation and when a sense of closure appears as additional interviews yield no new information and data are repeating.

Data collection continued until the researcher was satisfied that the point of redundancy and saturation were attained (Robinson 2000:208; Streubert and Carpenter (2011:91). This point of data saturation was noticed with relative ease, because initial data analysis (initial reading) occurred alongside data collection. In other words, the researcher was careful to ensure that the sample size was small enough to facilitate idiographic analysis of each of the salient features within the phenomenon of inquiry and large enough to ensure nomothetic analysis so that the findings are sufficiently clear to apply to other HIV infected adolescents on ART.

4.5 The Research Instrument

A research instrument is a tool or method that the researcher uses to collect data or to measure the concept or phenomenon being studied (Polit and Beck 2012:557). In qualitative inquiry, two types of tools are available: the researcher and the formal research instrument as an interview guide or observation checklist which guides the researcher in collecting the data required for answering the key research questions.

4.5.1 The researcher as an instrument

The process of conducting qualitative research using the phenomenological method is characterised by a series of transformative steps which focus on the researcher as a central entity (Barret 2007:417). Streubert and Carpenter (2011:22) point out that the "researcher as instrument" notion is an important aspect of qualitative research because the researcher is intimately involved in research activities of data collection through observation, interviewing and interpreting results. The intimate relationship between researcher and participants enables researchers to add to richness of data collection and analysis and improve data quality (Streubert and Carpenter 2011:22). As a research instrument, the researcher presents to the world what the experience means for those who undergo it. The researcher's role is thus to understand and evaluate the meanings participants attribute to their experience (Hoskins and Marino 2004:35). In order to present these views clearly, the researcher utilised a form of phenomenological reduction, also referred as bracketing (refer to section 2.3.6) which allowed the researcher to return to the original awareness of the phenomenon under investigation (Streubert and Carpenter 2011:76). This methodological process allowed the researcher to convey to the readers adolescents' lived experiences regarding ART adherence in a form untainted by prior undue influences (Gorgi 2008:42) This concept of researcher as instrument is further illustrated by Reinharz (1983:78), Barrett (2007:418) and Streubert and Carpenter (2011:46-47) who explain that the researcher is involved in the transformation process through the following five stages:

- The first transformation occurs as participants described their experiences, transforming them into language during data generation phase. This is an active creative and improvisational process that creates representations of the phenomenon so that this experience may be shared (Graue and Walsh1998:91). This transformation was enhanced by ensuring that the in-depth interviews took place in places recommended by the participants ensuring comfort, conduciveness and a non-threateningatmosphere (Barrett 2007:417).

- The second transformation occurs when the researcher transforms what is seen or heard into understanding of the original experience. Reinharz (1983:78) advises that since individuals can never experience what another person has experienced, researchers rely on participants' data to develop their understanding of the experience.   This second transformation occurs as the in-depth interviews are shaped into datarecords (Barrett 2007:418). This transformation occurred as raw data in form of interview notes and audio transcriptions were organised and reconstructed into permanent records as evidence of the data generation process (Graue and Walsh 1998:142). This phase of transformation was achieved in this current study by exercising great loyalty when incorporating the interview notes and transcriptions into the data.

- The third step of the transformation process according to Barrett (2007:41) occurs as the researcher turns personal understanding of the narratives into conceptual themes and categories which define the essence of phenomena. These themes were generated as the researcher immersed in the" raw" data, and after reading developed patterns from the data. The thematic areas covered the participants' experience related to ART adherence as expressed by the HIV positive adolescents (Graue and Walsh 1998:143).

- The fourth transformation occurs as the researcher turns the themes, symbolisingthe essence of the experience into an initial written document that portraystheresearcher's understanding of the experience (Reinharz 1983:78). This involvesinterpreting what the data means and relating the interpretations to other sources of insight about the phenomena in literature,

including findings from related research, theoretical frameworks andcommon experience (Barrett 2007:418).

- The fifth phenomenological transformation involves turning the initial written document into the final document, the exhaustive description, detailing the researcher's understanding of the phenomenon, from which all preceding steps can be clarified (Reinharz 1983:79). This final description as Graue and Walsh (1998:142-143) and Barrett (2007:414) explain reflects primary evidence of the phenomenon interwoven with the researcher' reasoned interpretation. In other words, the exhaustive description of the phenomenon relied upon the researcher's logical description and artistic presentation of the key findings   (Barrett 2007:418), with the aim to get the feeling of *"phenomenological node",* which evidences thereaders' affirmation that they could have had this very experience as well.

4.5.2 The formal research instrument

In qualitative research a variety of strategies can be used to generate data including interviews observations diaries narratives and focus groups among others (Streubert and Carpenter 2011: 33). In this current study in-depth interviews conducted with the aid of an interview guide were chosen as the formal research instrument (Robinson 2000:18) for the data generation because of the need to understand HIV positive adolescents' experiences regarding drug (ART) adherence in-depth. An interview as defined by Gillis and Jackson (2002:466) is a face to face verbal interaction in which the researcher elicits information directly from the participants through direct questioning. Interviews are highly regarded in qualitative research as substantiated by Creswell (2014:78), and Elmir, Schmied Jackson and Wilkes (2013:34) affirms that face to face in-depth interviews result in exchange of information that would otherwise be difficult to obtain through other methods of data collection such as questionnaires or even surveys given their personal nature. The choice of in-depth unstructured interviews using open ended questions was based on the understanding that it would provide participants the opportunity to fully describe their experience (Streubert and Carpenter 2011:35). In addition to providing a platform for participants an in-depth interview was chosen because it yielded rich and detailed information that enabled the researcher to understand the

meaning of the phenomenon from the view point of the adolescents (Streubert and Carpenter 2011:35). Flood observes that in-depth interviews within phenomenological inquiry usually start by the researcher asking a general question the grand tour question which is used to drive the conversation to deeper levels through the following three stages: first establishing the context of the experience then moving to construct the lived experience and then moving to reflect on the meanings interviewees assign to their experience the result of which is a detailed explanation of the essence and meaning of the livedexperience in question. A key aspect considered during the interviews was the level of trust that existed between the researcher and the participants. Perry Thurston and Green (2004:140) state that the nature and quality of communication and relationship between the researcher and interviewees greatly influence the richness of the data generated because interviewees are more likely to respond according to their perceptions of the interviewer. With this in mind, together with my research team, we ensured that a good relationship existed between the interviewing teams and the participants, facilitated by continually assuring the informants that the confidentiality of their information would be kept as advocated by Streubert and Carpenter (2011:35). Also employing unstructured in-depth interviews using open ended questions provided participants with an opportunity to respond to research questions, including probes and clarifying questions that the researcher asked as the participants navigated through their lived experiences. This allowed adolescents living with HIV and are on ART to share their experience and life stories and the meaning thereof in their own words thereby making them more authentic and believable by others (Rosen 2006:310-311).In order to facilitate the in-depth interviews, an interview guide was utilised (refer to annexures) as recommended by Robinson (2008:18) consisting of three sections namely: introduction, questions and conclusions as explained below:

Introductory section

This is the climate setting part aimed at creating an environment that facilitates data collection. In keeping with the recommendations of Qu and Duma (2011:239) and Perry *et al (*2004:140), a good relationship ensured successful interview outcomes by allowing the adolescents to share closely held information with the interviewers (Streubert and Carpenter 2011:35). The introduction part consisted of congenial

elements like greetings, welcome remarks, explaining the study objectives and ground rules for the interviews as detailed in the interview guide.

Questions section

The question section consisted of a single grand tour question explored through related thematic questions aimed at aiding the journey of exploring adolescents on ART's experiences in various contexts. The grand tour question was ***what have been your experiences since finding out that you were HIV infected and that you have to be on treatment every single day of your life? And what would you say are the most difficult issues which make drug adherence difficult?***The two grand tour questions were negotiated and explored with every participant to ensure the questions were well understood using applicable thematic questions:

- When did you first find out that you were infected with HIV?
- How did you find out?
- What have been your experiences since finding out about your status
- Have you ever had about medication adherence and what do you understand about it in your given situation?
- What have been your experiences regarding drug adherence?
- What would say are your most difficult issues which make drug adherence difficult?
- For how long have you been on this treatment?
- Have you had support from anyone regarding drug adherence?
- How often do you come to the clinic?
- What would you like done in order to improve issues around drug adherence?

These thematic questions facilitated deep exploration of perceptions and meanings of lived experiences and were enhanced by cues and hints that emerged during the interviews. Probing and clarifying questions were also used to explore unclear areas. The probing questions used included questions such as:

- "Could you say something more about that…...?"

- "Can you give a more detailed description…?"
- "Do you have further examples of this...?"

While clarifying questions used were:

- "What did you think then…?"
- "What did you actually do then…?"
- "What did you actually do when your body felt….?"
- "How did your body react…?"

The use of grand tour questions is supported by Fontana and Frey (1998:64) who infer that investigating experiences using unstructured interviews enables researchers to understand complex issues related to people's experiences without imposing strict categories that may limit the scope of the inquiry. The "thematic questions" and "emerging probes" facilitated navigation through participants' experiences which allowed deep exploration of their worlds (Qu and Dumay 2011:239).

4.5.3 Pretesting research questions

The formal research instrument was pre-tested prior to commencing data generation. (Polit and Beck 2014:75-76) consider a pre-test as a trial administration of a newly developed instrument to determine whether it meets the desired adequacy, including generating information. The pre-test involved administering the draft interview guides to two adolescents living with HIV and are on ART to determine the clarity of theinterview questions and whether the time allotted was adequate. After the pre-test theresearch team revised the thematic questions as *a quality control* intervention.

4.6 Data Collection

Data collection is defined by Gillis and Jackson (2002:424) as gathering information from identified subjects to answer a particular research question. In qualitative studies, the researcher is expected to describe in sufficient detail the data collection process for others to "see" how the research progressed, thereby serving to enhance the trustworthiness of the study findings. Another rationale for explicating the data collection process is that it helps the researcher show evidence that the data collection process occurred in a systematic manner in line with the chosen

research

paragidm and the associated epistemological assumptions (Solomon 2001:229).

4.6.1 Data collection using in-depth interviews

In line with the phenomenological research tradition, in-depth unstructured interviews were conducted using an interview guide that consisted of a single grand tour question, but navigated through several closely related thematic questions. This approach was chosen because of its inherent capacity to enable interviewers to gain entrance into the participants' world in order to have full access to their experiences. In the words of (Polit and Beck 2010:341), interview guides are helpful in ensuring that all main questions are covered during the interview and that no area gets missed out. McNamara (2009:2-3) points out that another strength of the interview guide is that it helps the researcher to ensure that similar general areas are covered or similar information is collected from each interviewee in addition to allowing the researcher some freedom to adapt the thematic questions to get desired research information. Each participant was allowed time to describe their experiences in the full without the researcher leading and interrupting them needlessly. However, whenever the need arose, probing and clarifying questions were used from the hints and the cues noticed during the interview to explore aspects of the lived experience much deeper.This approach permitted participants to describe their experiences freely until they felt they had exhausted their experiences. The interview was facilitated by navigating with each participant the thematic questions in an exploratory manner that did not limit participants' answers only to pre-established alternatives (Norwood 2000:247-248).

4.6.2 Motivation for selecting in-depth interviews

In-depth interviews were chosen as the primary data collection method because:

- Unstructured in-depth interviews allowed participants to describe their livedexperience in detail in a free and non-restrictive manner. This allowed the researcher to grasp the essence of each of their lived experiences (Parahoo 2006:66).

- The data collection approach provided the researcher with flexible, creative andpenetrative methods and a window for exploring each participant's lived experience in a manner unique to their situation (Polit and Beck 2010:220).

- The method also allowed the researcher to gain entrance into participants' personal (or inside) emic view, the intimate and private world, critical to explicate their lived experiences and associated meanings (Streubert and Carpenter 2011:22).

- The method allowed participants to share their experiences in their own wordsrather than through pre-established lines of thought, as would have been withstructured interviews as in quantitative research inquiry (Norwood 2000:247).

- The approach created the opportunity to intuitively follow participant's leads byasking probing and clarifying questions, leading to exploration of various cuesand themes into more complete lived experiences, thereby preventingmisinterpretation of their lived experience accounts (Qu and Dumay 2011:239).

4.6.3 Principles that guided in-depth interviews

The following principles were observed to ensure data quality during the interviews:

- The researcher remained open to the ideas that emerged from the interviews and remained focused on conceptualising them from each participant's eyes without undue influence from the researcher's pre-understandings and imposing any of their personal perspectives on them (Jonker and Pennik 2010:77) by exercising reflexivity.

- The researcher maintained the flow of participant's stories by avoiding unwarranted interruptions and only re-directing participants when they completed their sentences. The thematic questions were phrased in a simple way and as the interviews proceeded, unclear areas were clarified to ensure the interviews did not stall and remained freely open flowing, exploring thematic areas (Qu and Dumay 2011:248).

- Each interview was sustained by maintaining a positive relationship with the interviews by not offering opinions about responses and avoiding non-verbal indications of surprise or shock. Using non-verbal cues such as nodding to

indicate approval or a correct answer were kept minimal. The interviewers also desisted from leading questions, ensuring that all cues and new areas introduced during the interviews were followed through to the end (Qu and Dumay 2011:248-9).

4.6.4 Interviewing skills used during in-depth interviews

In addition to principles of phenomenological interviewing used, the research team followed interview skills recommended by Hannabus (1996:26), Field (1996:133) and Polit and Beck (2014:79) in order to avoid limitations inherent during data collection during face to face interviews by:

- Establishing and maintaining rapport with interviewees before and after commencement of data collection. The research team established rapport with

  participants by welcoming them and engaging them in a "small talk" prior to proceeding to the main interview as an ice "breaker" to start the process of building trust and to inform interviewees about the purpose of the interview and

  then to get them talking freely (Mellon 1990, as cited in Qu and Dumay 2011:250).

  Keeping the discussion going and easy flowing by encouraging each participant to talk freely without guiding their responses unnecessarily and avoiding close ended questions as well as jargons that would dampen the free flow of information, ideas or puzzle or even annoy them.

- Focusing and pacing the interview through tactful interruption and guidance of the interview sessions (Hannabus 1996:26). This was done by using structuring

  questions which helped the researcher to move from one part of an interview tothe next, especially after exhausting such previous areas. As Kvale (1996:134)advocates, the researcher incorporated questions such as "I would now like tointroduce...", and … "I would like us to talk a bit more on…" to pace the interview.

- Fostering patience and using the moments of silence during the interview to work positively towards the goal of the interview (Qu and Dumay 2011:248).

The pauses that arose during the interview were used to give interviewees time to reflect and gather energy for more disclosure. As Doyle (2001:11) advocates, the interviewers tolerated the silence that emerged and desisted from looking impatient, instead the researchers chose to give participants the time and chance to think about what they wanted to say without hurrying them. Giving participants time to think and recollect their views resulted in the interviewees filling the silence with more information and this kept the conversations" alive" and rewarding to both parties.

- Adopting a non-judgmental attitude and listening actively and empathetically to participants while avoiding being overtly involved with the topic (Field 1996:134). This potential pitfall was overcome by remaining calm and showing no direct involvement or association with the participant's experiences by maintaining balance and impartiality in the discussions. This impartiality allowed participants to spontaneously express their views without undue influence from the interviewers.

4.6.5 Initiation of the research process

Initiation of the research process consisted of three main phases: obtaining formal approval from relevant authorities, obtaining potential participants and preparing formal interviews in the community as described below:

4.6.5.1: Approval process

Approval to conduct the study was sought from the University of South Africa (UNISA) Department of Health Studies Ethics and Research Committees. This was followed by approval from Mpilo Central Hospital; a hospital based Institutional Review Board, and later, Medical Research Council of Zimbabwe (MRCZ). Scanned copies of these approval letters are enclosed (see Annexures).

4.6.5.2 Selection and training of research assistants

The researcher recruited and trained five (5) research assistants who were to be involved in the data generation. Three of them moved with the researcher during data collection. Two were used as transcriptionists. All the research assistants were professionals and familiar with the local languages predominant in Bulawayo such as isiNdebele and ChiShona though the interviews were held in English they were

times when the research participants could switch to their mother language in order to explain in detail what their experiences. They had experience in conducting qualitative interviews. In order to improve their capabilities, the researcher retrained them to ensure that:

- They talked to the local gate keepers to ensure that the researcher was accepted.

- Guided the researcher to the various adolescents.

- Participated in follow up interviews whenever there was a need.

4.6.5.3 Obtaining potential participants

- Selection of the participants was based on the sampling criteria (see section 4.4.2.1) following securing authorization letters from various departments.

- The potential participants were selected from the list of adolescents who regularly attended the clinic. A health worker from the adolescent clinic assisted in identifying the adolescents.

- The most credible potential participants were selected based on the understanding that they would be in the best position to describe their lived experience in-depth as required for qualitative investigations. These participants were selected using the set sampling criteria.

- The selected adolescents were contacted and appointments were made so that they could attend the interviews on their next review dates.

- This prior preparation was aimed at ensuring that the potential participants had been given sufficient time to reflect on their experiences so that they were better equipped to describe their lived experiences freely during in-depth interviews.

4.6.5.4 Physical environment for in-depth interviews

According to Elmir *et al (*2011:14, the researcher conducting in-depth interviews must give a thorough thought about the venue of interviews. A key consideration is

that both the researcher and the participant must feel safe in the venue. To reduce participants' sense of vulnerability each participant was asked to choose a suitable venue where they would feel comfortable. All the participants preferred to be interviewed at the clinic where they go for their reviews because qualitative research necessitates that participants should be interviewed in familiar settings where they feel comfortable. Better still; the interview venue should be the natural setting in which the experience occurred so as to generate rich data. However, the though the venue chosen by the participants was not where the experience occurred, they indicated that they felt more comfortable at this venue and that they got a lot of support from the staffers at the clinic. As Becker (1992:39) recommends, the interview venues were private, free from interruptions and where participants felt relaxed and comfortable. The justification for a comfortable venue lies in the observation that personal experiences such as lived experiences are best shared when a person feels safe and secure as provided by a homely environment. This notion is further supported by Streubert and Carpenter (2011:36) as they note that the more secure and comfortable a participant is, the more likely they will share important information about themselves such as lived experiences.

4.6.5.5 Obtaining consent from potential participants

The research team used a consent form to obtain written permission from potential participants. Polit and Beck (2012:127) explain that consent is an ethical requirement that researchers are required to secure before conducting a study, because it indicates the terms and conditions of a person's voluntary participation in a study.

Informed consent means participants have adequate information regarding the study, comprehend the information, and have the power of free choice, enabling them to consent to or decline participation. The research team implemented the informed consent process by ensuring every participant signed the consent form (refer to annexures). The research team prior to all interviews, provided ample information about the study to the participants, including purpose and scope of the study, the type of questions, how the results would be used including protection of their anonymity. The participants were also given time to consider their

participation and to ask clarifying questions before the formal interviews began. Consent was also obtained from participants to audio record the interviews to ensure that no data was lost during this data generation. This also helped to relieve the researcher and their assistants from writing large amounts of notes and instead the team concentrated on participant and the cues and leads in their interviews and only took field notes to support significant verbal cues that would not be captured by the digital audio recorder.

4.6.5.6 Seating arrangement during the interviews

The seating arrangement was such that the researcher, the research assistants and participants sat comfortably in a circular manner facing each other with a table between them. The digital recorders were placed on the table between the research team and participants to ensure that all proceedings were accurately recorded. This seating arrangement helped to create a comfortable environment for personal conversation with the informants and encouraged free communication between the participants and the interviewers. The seating arrangement further provided the research team the opportunity to maintain "*good"* eye contact and observe the non-verbal expressions of the participants as the interview progressed.

4.6.5.7 Recording of the in-depth interviews

To ensure good quality recording and data security, a high quality portable digital MP3 player was used to record the proceedings as suggested by Fernandez and Griffiths (2007:10). This technology is based on a patented audio-specific format that was designed by the Moving Picture Experts Group (MPEG). It combines excellent audio quality and small size enabling audio files to be shared easily including by email (Fernandez and Griffiths2007:11). The use of good quality recorders during qualitative interviews is supported yt Burns and Grove (2011:540) who infer that poor recording maybe so faint or so much distorted that the transcription becomes impossible. Aware of this expectation, high quality digital recorders were always at hand and this allowed the research team to concentrate on the interview process, asking questions appropriately and clarifying any unclear areas without having to worry too much about the recording, which would have been the case if tape recorders were used.The team was thus relieved of *"tape anxiety".* This allowed us to concentrate on the

interview instead of worrying about batteries and tapes running out. Besides, we had a third backup recorder, a Samsung (s-3) smart phone voice recording application. In addition to digital recording, field notes were taken to capture the context of the descriptions. This was used to describe participant's expressions, changes in their position and other observations such as emotions that could not be captured by the voice recordings.

Streubert and Carpenter (2011:43) assert that incorporating field notes during data analysis helps to achieve a more contextualised description of lived experience. These field notes became important additions during data analysis because they were used to validate important points made by the participants and they proved essential to lay emphasis of emerging thematic areas. Enhancing data safety is further recommended by Flood (2010:11) who maintains that extra care is required especially when the interview is the main source of data for the study.

4.6.5.8 In-depth unstructured interviews

The interview process was shaped by the views of Hannabus (1996:22-25), Field (1996:136) and Qu and Dumay (2011:245) who advocate for each interview to be adapted to the individual situation and context while ensuring participants comfort. Participants were made to feel at ease and a good sense of rapport was created by engaging them in a "*small talk*" before every interview. This helped to allay the participants' anxiety and readied them for the interview which proceeded as follows:

- The research team explained the purpose of the study, issues related to confidentiality and anonymity, requested participants' collaboration and obtained their formal consent. Permission was also requested to audio record the interview proceedings. Participants were asked if they had questions after assuring them of confidentiality, emphasising that no identifying information such as their names would be used, instead acronyms PAF (female adolescent) (PAM) male adolescent were used as identity markers. All the participants accepted to have their interviews recorded.

- The researcher started each interview by posing the grand tour questions. As Creswell (2014:54) notes, beginning a qualitative interview with exploration of a single idea allows the interviewer to first understand the

phenomenon in sufficient detail. As the interviews progressed, thematic and follow-up questions were tactfully introduced to further explore aspects of their lived experience which had not been relayed up to this point. The interview guide provided useful directions and focused the interview. The researcher assumed a stance of self-reflexivity, becoming aware that their pre-understandings about participant's experiences could influence interpretation of their experiences. This self-awareness readied the researcher for data generation (Streubert and Carpenter 2011:34).

- The researcher ensured that unnecessary interruptions were avoided during the interviews. Participants were asked to relay their lived experiences by elaborating on their feelings, memories, meanings and thought that have continued to linger in their minds as they reflected about the adherence issues. The responses were approached with an open mind obscure area were carefully probed (Patton 2014:324). Participants were asked to describe what the experience meant to them as Becker (1992:38) says that clarifications should be sought until participants' experiences are exhausted or when they say that they are not willing to explore the area any further.

- The researcher also adopted a flexible approach of "not using a preconceived framework but rather allowing to be led by the unique realities of the research situation. They either played a passive or active role during data collection. This flexibility was essential for entering participants' worlds and to adequately elicit their story to enable the researcher better the meanings of lived experience from the participants' perspectives. The researcher avoided leading questions and giving personal views during the interviews ensuring that all that was described were mostly participants' views.

- The researcher also remained centred on the data as participants' experiences were explored, listened attentively and followed each participant's story keenly. The researcher remained calm and focused. Interrogating participants was also avoided, instead participants were treated with the greatest respect and made to feel respected and valued by showing genuine interest in their life stories during the interviews.

- The research team encouraged participants to continue talking by using culturally acceptable affirmation sounds that encourage people to talk while taking care not to portray a sense of approval or disapproval of what was being said. Clarifying and probing questions helped to elicit more information in obscure situations. The interviews continued until data saturation was reached and participants exhausted their lived experiences. At this point the interview endedwith a request to follow up interview should any unclear areas emerged (Van der Wal 1992:115).

4.6.5.9 Follow up interviews

The research team listened to the recorded interviews immediately after every interview, checked whether the interview made sense and determined the need for follow-up with same participant. Paterson (1997:199) maintains that a follow-up interview is essential especially when participants are required to expound on some of their previous descriptions. In support Streubert and Carpenter (2011:91 declare that the second interview is required to give the researcher the opportunity to expand, verify and add more descriptions about the phenomenon being studied and assisting participants to clarify and expound on unclear areas.

4.7 Data Analysis

Details of data analysis highlighted in this chapter are presented in chapter five. As expected in qualitative research, the researcher immersed in the data and committed fully to the project with a significant degree of dedication to reading, intuiting, analysing, synthesizing and reporting the results (Streubert and Carpenter 2011:45). Data analysis was informed by Wertz's (1983, 1985, 2005, 2011) Empirical Psychological Reflection (EPR) research approach. Whilst this analytical approach is linked to the Duquesne tradition and inspired by Husserlian phenomenology, the method shares features with general interpretive phenomenological research inspired by Ricoeur's (1976) Hermeneutic-phenomenological philosophy (Van der Wal 2013:1-2). This analytical framework was chosen because it is detailed and flexible which allows the researcher to capture both 'unique individual' experiences and general aspects of adolescents' lived experiences. An important feature of this approach is the flexibility of not using a preconceived framework (Grbich 2013: Loc2278). At the same time, it allowed the

researcher to examine key elements of participants' lived experiences including embodied selfhood, emotionality, social relationships and temporality in order to better understand their unique life experiences Wertz (2100:133). Wertz's (1983/2011) data analysis framework consists of three specific phases of analysis and one phase of describing themes to obtain a holistic understanding of the phenomenon termed as phenomenological description or writing (Wertz 2011:131). To carry out the three stages of reflection well, specific attitudes or stances and methodological procedures of research activities are required (Wertz 2011:131) as further described in section 5.4. DeSantis and Ugarriza (2000:362) affirm that the theme is an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations and captures the nature of the experience into a meaningful whole. Themes enabled the researcher to decipher hidden meanings in the stories and were used during the phase of phenomenological writing to articulate the unique individual and general essences of the phenomenon including meanings and structures of adolescents' drug adherence lived experiences interspersed with verbatim expressions to enhance the study's credibility (Van Manen 2011:2) and also to help the reader get a near first hand feel of these experiences.

4.8 Ethical Considerations

Ethics is defined as a system of moral principles or rules of behaviour (Wehmeier 2000:395) while Regan (2011) defines it as anything that is about what is right, fair and obligatory. While ethics in research is defined by Polit and Beck (2012:553) as a system of moral values concerned with the degree to which a researcher adheres to professional, legal and social obligations during the research process. In the current study, the key ethical considerations lay within three broad areas participants, institutions and scientific integrity of the entire research enterprise. Norwood (2000:57 advocates that researchers should commit to addressing anticipated as well as emergent ethical issues from the time the research problem is identified up to the final stages of communicating the findings. As Streubert and Carpenter (2011:60) counsel, the researcher was conscious that ethical standards of qualitative research arise out of the dynamic and evolving nature of the research process, meaning that unanticipated ethical concerns could arise anytime. Hence, in addition to adhering to the ethical issues grounded in the ethical principles of
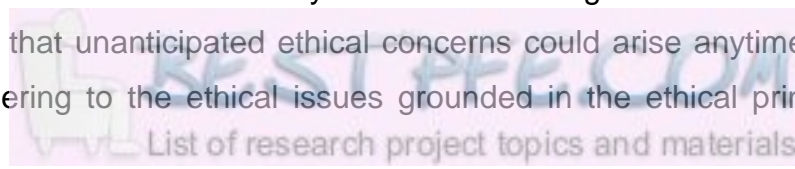
autonomy, beneficence and justice, the researcher remained open to the possibility of new and unexamined ethical concerns especially during data collection. The details of how ethical considerations were adhered to in regard to participants, institutions involved in the study as well as the scientific integrity of the study follow.

4.8.1 Ethical Issues Related to Participants

In qualitative research, participants are the researcher's primary concern in terms of ethical considerations. While it was clear that the participants would not suffer any physical injury, the researcher was very much aware that sharing of sensitive experiences may lead to experience of psychological and emotional trauma. Consequently, the researcher ensured informed decision making, observance of anonymity, privacy and confidentiality, prevention of harm and discomfort as well as fairness in treating participants as explained:

4.8.1.1 Informed consent

Informed consent is a critical part of research and signifies that the researcher upholds participants' right to self-determination. According to Streubert and Carpenter (2011:61) informed consent is a prerequisite for all research involving identifiable subjects and requires of participants to have adequate information about the study. Polit and Beck (2012:127) explain that informed consent means participants have been provided with ample information and have the power and freedom to voluntarily accept or refuse participation and signifies the researcher's efforts to establish and maintain participant's autonomy. In keeping with this requirement, the researchers always obtained informed consent at the start of the study (Hamersley and Atkinson 1995:264). The researchers addressed participants' right to self-determination by providing a written explanation along with an informed consent form to explain the study purpose, nature of participation including potential risks and benefits to participants as well as reasons for their participation. Participants were also informed that they had the right to terminate participation and to refuse to give information or seek clarification during the interview (Burns and Groove 2011:192-195). Methods and procedures to be used in the research were also explained and doubts arising thereof were clarified. The informed consent process also involved obtaining permission to digitally record the interviews. The role of the researcher was also clarified as being an independent personwith no

ulterior interests. Participants were also informed that the data would be usedfor scholarship purposes only and to recommend strategies to improve the wellbeingof those who other adolescents in future. This role clarification enabled participants tosee the researcher as a neutral person, reducing chances of obtaining biased or fabricated information which could have occurred if the researcher was seen as a representative of some organisation. The consent was authenticated by signing an official consent (See annexure) as depicted in figure 4.1 which details the various steps the research team took to arrive at a signed consent form. This process was essential for informed decision making as well as in preventing avoidable harm and discomfort.

The research team upheld the ethical principle of beneficence, ensuring that participants were free from physical or psychological harm by timely addressing any issues that would harm or cause discomfort during the interviews (Streubert and Carpenter 2011:61). Participant's dignity and autonomy was also maintained by ensuring voluntary participation after obtaining written consent. In addition, thematic and related questions were framed in a manner that would not threaten or corner participants, but rather encourage them to share their experiences with the inquirer.

4.8.1.2 Confidentiality

A critical component upheld throughout the research process was confidentiality. Politand Beck (2012:129) point out that confidentiality is a pledge that any informationparticipants provide will not be publicly reported in a manner that identifies them andwill not be made accessible to others. The researcher was acutely aware that the in-depth nature of qualitative inquiry meant that participant's privacy was critical and had to be protected throughout the research period. Participant's right to privacy is based on the ethical principle of justice which states that individuals have the right to determine the time extent and general circumstances under which personal information including beliefs, practices, opinions and records with or withheld from others (Burns and Groove201:186).The researcher secured participants' right to privacy by asking them to choosethe venue for the interviews. All the participants chose to be interviewed from theclinic. The researcher ensured that participant information was not made accessible to persons other than the research team by using password protection and by using

identification codes instead of actual names. Also direct quotes used in the final report would not reveal participant's identity, which were disguised in codes (Polit and Beck 2012:129).

4.8.1.3 Anonymity

Anonymity is closely related to confidentiality and is the most secure means of protecting confidentiality. Strict anonymity occurs when the researcher cannot link a participant with particular data (Polit and Beck 2012:129). As Burns and Grove (2012:194) maintain, confidentiality warrants that any information participants provides will not be made accessible to parties other than those involved in the research, whilst anonymity ensures that revealing information about participants' identities are not declared during presentations, reports and in ensuing publications. The research team constantly reminded and assured the participants as Norwood (2000:68) recommends that their personal information will not be handled carelessly.

The researcher was aware that if any worry of breach of confidentially lingered in participant's minds, they could advertently withhold vital information or could decide to provide inaccurate information deliberately. To allay their anxiety, participants were told that the findings would be reported from the nomothetic (generalised) perspective ratherthan from the idiographic (individualised) descriptions. This aggregation helped to ensure anonymity of participants and reduced the possibility of linking a particularindividual to a specific verbatim expression in the final report (Polit and Beck 2012:130).

4.8.1.4 Fair treatment of participants

Participants were treated fairly, aware that the close and private nature of relationship with participants raises peculiar ethical concerns. Streubert and Carpenter (2011:65) warn researchers to be aware that being the research instrument means the researchers come to know participants in a personal way, sometimes to the extent that a blurring of responsibilities arises. As Ramos (1989:57) advises, the researcher was conscious of this blur and so remained steadfast in the "*instrument*" role instead ofassuming the "*therapist*" role. Hence to be fair to participants, the researcher guided the interview process and maintained

the focus of the interview keeping clear that the interview was not a therapeutic event. We desisted from asking questions that would result in more answers than they originally agreed. At the end of each interview, the team reiterated issues that needed further clarification (Streubert and Carpenter 2011:65).

4.8.2 Ethical issues related to institutions

Van der Wal (2005:154) advices that research related institutions should be treated as though they were individuals. The implication of this declaration is that the researcher has to obtain informed consent from these institutions as well as ascertain a level of anonymity so that names and specific identifying information about them that may have ethical implications are left out to ensure privacy. The researcher protected the rights of institutions by adhering to their guidelines ensuring that data collection, analysis and reporting occurred in ethical and scientific manner (Norwood 2000:72).

4.8.2.1 Informed consent and permission

Data collection commenced only after permission was granted by various institutions, including the Department of Health Studies, UNISA; Mpilo Hospital, Zimbabwe; Medical Research Council of Zimbabwe. As an ethical requirement, the researcher dutifully followed the advice and guidelines and the recommendations of the various IRBs and related institutions during the data generation and dissemination phases of the research.

4.8.2.2 Anonymity and confidentiality

In order to comply with the principle of anonymity at the institutional level, names of health facilities linked to the adolescents who participated in the study were omitted. Similarly, names of adolescents and hospitals and health centres they were associatedwith were left out to further ensure anonymity and confidentiality (Norwood 2000:72).

4.8.3 Ethical issues related to research integrity

A high standard of scientific and personal honesty was upheld throughout the study. Scientific integrity refers to researcher's competence in all aspects of the research activity, particularly how well they adhere to the ethical and scientific expectations

of the study at every stage. The researcher demonstrated ethical and scientific integrity by respecting the rights and dignity of the participants and institutions involved in the study and avoided any form of malpractice. In observing ethical requirements and judiciousexecution of scientific rules, the scientific integrity was assured (Mongwe 2007:109).

4.8.3.1 Researcher competence

The researcher's capacity to conduct this research study was acknowledged by the Department of Health Studies Higher Degrees Committee, UNISA through their approval of the research proposal. This competence was also affirmed by other institutions that provided similar ethical clearance to conduct this study. The researcher's competence to assure the study's integrity was also bolstered through the guidance of my supervisor, himself a seasoned qualitative researcher who constantly supported ma at every step of the research process. As Van der Wal (2005:15-19) advises, the researchers were mindful that the study outcome needed to meet ethical standards required for education, clinical and scientific research if the findings were to be utilised in care.

4.8.3.2 Researcher integrity

The researcher demonstrated personal integrity by avoiding deception of participants and institutions involved, including the public who receive the results. Struwig and Stead (2001:69) describe deception as misrepresenting facts to intentionally mislead participants in such a way that if, they were aware of the nature of the study, they would have declined to participate. Polit and Beck (2012:123) add it may involve withholding information from or providing false information, to interfere with participant's right to make truly informed decisions about costs and benefits of participation, exposing them to situations different from what they earlier consented. The researcher avoided deception by providing accurate information to all those involved notably participants, institutions and the public. The researcher also desisted from fabrication, falsification and manipulation of data and data generation and analysis procedures as affirmed by Cohen and Ciocca (1993:95). The researcher also avoided all forms of plagiarism, which implies presenting as own ideas of others through inappropriate referencing as explained by Polit and Beck

(2012:134). As Struwig and Stead (2001:69) point out, the researcher avoided deception thereby preventing embarrassment, anger and humiliation for all those involved in the study and ensured the research report meets the highest standards.

4.9 Criteria to establish quality and trustworthiness

Standards of quality in research emphasise concepts of objectivity, validity, reliability, rigor, open mindedness and honesty through reporting of research findings (Focus 2005:1-2). Research quality as defined by Meulenberg- Buskerns (1997:111) refers to the degree to which the work conforms to methodological expectations of the study. Trustworthiness in research according to Lablanca (2010:1) is the demonstration that astudy and the argument based on its results are strong and verifiable. In order to ensure quality, Mauthner and Doucet (2003:413-415) advocate that researchers should show how they arrived at and interpreted the findings. It follows that in all studies, whether qualitative or quantitative, the central elements of reliability and validity need to be met. In qualitative studies, Morse, Barrett, Mayan, Olson and Spiers (2002:17) maintain that data reliability and validity can be achieved through anin-built verification process. This process entails checking, confirming, making sure, and being certain that the researcher can incrementally ensure reliability and validity and consequently rigor of the study. They argue that by incorporating verification strategies in the research process, reliability and validity are attained, rather than waiting for external reviewers to declare as such at the very end .According to the Randon House College Dictionary (1980:1114), reliability is being… "authentic,consistent and trustworthy and being able to depend upon with confident certainty". Reliability deals with accuracy and consistency of information obtained in a study (Polit and Beck (2012:373). The concept of validity refers to being sound, just and well founded (Randon House College Dictionary 1980:1453). Likewise, Polit and Beck (2010:377) refer to validity as the degree to which an instrument measures what it is designed to measure. An account is valid if it represents accurately features of a phenomenon it is intended to describe, explain or theorise (Hammersley 1987:69). The centrality of these concepts implies that a researcher should demonstrate how these concepts have been addressed in their study.In quantitative research that is underpinned on positivism, reliability is ascertained by ensuring the research tool is consistent, stable, predictable and

accurate (Kumar2005:156), implying that the greater the degree of consistency and stability of aninstrument, the greater its reliability. The opposite of reliability is a measurementprocess that yields erratic, unstable or inconsistent results (Neuman 2006:188). In aresearch study, the researcher is expected to ascertain the reliability of theinstrument by pre-testing the questionnaires in a pilot study and then making necessary adjustments to assure its consistency and stability over varying conditions. On the other hand, validity is achieved by ensuring that the study's instrument is valid and measures what it is supposed to measure (Gray 2004:206-210). Accordingly, the researcher assures the validity of the research instrument by ensuring that the contents covered; including that the questionnaire reflects variables to be measured. Mpisi(2010:196) advises researchers to test and improve the validity of their research instruments using pilot studies and then make required adjustments. In qualitative research that is underpinned on human science paradigm, the concepts of reliability and validity as overarching constructs are still relevant because as Kvale (1989, in Morse *et al* 2002:19) states, validation is an important element in all research, requiring checking and questioning various aspects to ensure quality. The goal of quality control or rigor in qualitative research is to accurately represent participants' experiences. To ensure that qualitative researches such as the present meet quality standards, Krefting (1991:215) advises use of models that appropriately measure rigor without sacrificing the relevance of qualitative research tradition. In view of this expectation, I settled for the "gold standard" quality criteria outlined by Lincoln and Guba (1985) and later augmented by Guba and Lincoln (1994) based on five aspects of trustworthiness relevant to both quantitative and qualitative studies namely truth value (credibility), applicability (transferability), consistency (dependability), neutrality (confirmability) and authenticity (Polit and Beck 2012:492). The rationale for these criteria is the fact that when meticulously observed, they result in achievement of quality control and trustworthiness of the research findings. A pertinent discussion on how these criteria were utilised for quality control now follows.

4.9.1 Credibility

Credibility refers to the confidence participants have in the truthfulness of the findings of a particular study (Polit and Beck 2012:492). Krefting (1991:218) argues that qualitative research study is considered credible when it portrays an accurate

description of the human experience that people who also share the same experience would immediately recognise and find believable. Credibility was established in this study through prolonged engagement with the study participants incorporation of method and data triangulation; consensus building with a research expert; and researcher authority and capacity for such inquiry, as explained below.

4.9.1.1 Prolonged engagement

In qualitative inquiry, prolonged engagement according to Polit and Beck (2012:495) isthe investment of sufficient time collecting data to have an in-depth understanding ofthe phenomenon so as to test for misinformation and distortions and to ensure saturation of important categories. In addition to being able to gather in-depth information, prolonged engagement also results in building of rapport and trust with study participants. The researcher spent sufficient time with each adolescent so that useful, accurate and rich data would be obtained from them to better understand the phenomenon. Prolonged engagement was fortified with some follow-up interviews.

4.9.1.2 Triangulation

Triangulation refers to use of multiple reference points to draw conclusions about what constitutes truth (Polit and Beck 2012:497) aimed at capturing a more complete and contextualised portrait of the phenomenon. Triangulation was achieved by the use of multiple methods and perspectives during data collection and interpretation. The impetus for triangulation lay on the desire to ensure a convergence point, where reality as manifested by participants would be accurately reflected in the researchers' representation of their lived experiences (Krefting 1991:219). Triangulation was achieved in the present study by engaging in both method and data triangulation:

- Method triangulation was achieved by using both the initial in-depth phenomenological interviews and follow-up interviews which are two different data gathering methods (Thomson and Jolley 1997:187). These two approaches ensured data gathering from two different viewpoints and prevented biases and deficiencies usually associated with using a single

data collection method. The preliminary literature review also helped to set guidelines for the entire interview process.

- Data triangulation was achieved through extensive review of relevant literaturebefore and after the study.

4.9.1.3 Consensus with expert reviewer

Using peer or expert evaluation is credited by early phenomenologists such as Van Kaam (1966, cited in Beck 1994:260) who justify the practice as providing an opportunity for critical comparison of results between at least two phenomenologists toensure data validity. The researcher passed all the raw data to the supervisor to carry out independent checking. The supervisor helped to ascertain the themes and categories the researcher had obtained and any discrepancies were subjected to thorough scrutiny and corrected after achieving what Mongwe (2007:115) terms as intraparticipative agreement with my supervisor. He thus served both as independent expert coder as well as an analyst to verify and authenticate the various themes and categories which then formed the basis of the research findings.

4.9.2Transferability

Transferability is the second criterion for establishing trustworthiness in qualitative research. According to Krefting (1991:216), transferability refers to the degree to which the findings of a study can be applied to other contexts. This according to Lincoln and Guba (1985:290) is equivalent to quantitative research's external validity and refers to whether a study's findings also apply in other settings. Polit and Beck (2012:492) are also of the view that transferability entails the extent to which findings of study may be "generalised" to other settings or groups. Streubert and Carpenter (2011:49) similarly consider transferability as referring to the probability that the findings have meanings to others in similar situations. Whereas the researcher was acutely aware that the expectation of determining whether the findings fit or are transferable rests with potential users, the researcher complied with Lincoln and Guba's (1985:316) criteria of providing the basis for making transferability judgment possible for potential users. Plans for transferability were enhanced by careful selection of participants and by providing sufficient descriptive

data in the final report so that the consumers of the study may ably evaluate applicability of the findings to other circumstances through:

4.9.2.1 Careful sample selection

The researcher ensured careful selection of participants by using only the approved sample criteria to select the best possible sample. Krefting (1991:220) defines a nominated sample as use of a panel judges to help in the selection of participants experienced in the phenomenon. Field and Morse (1985, cited in Krefting 1991:220) also refer to a nominated sample as using one or two long time members of a group to identify persons who are typical of the membership. In the current study, the charge nurse of the adolescent opportunistic infection clinic and some peer educators in consultation with the researcher and research assistants carefully selected the most eligible adolescents who had drug adherence experiences using purposive, convenience and criterion sampling techniques were applicable. The details of the sampling techniques are described in section 4.4.2.

4.9.2.2 Thick descriptions

The researcher enhanced transferability of the study findings by including in the final report as much of direct quotes from the participants as possible. The details of the thick descriptions that capture the vivid experiences using the adolescents' words are given in chapter six.In support Whittemore, Chase and Mandle (2001:531-533) explain that vivid description of participant's experiences enables consumers of research to have a *near-real mental* experience which enables them to better understand the experience as described. In the current study, in addition to using verbatim quotes, the researcher described the research setting as well as the transactions and processes that characterised the entire investigative process. This clarification aims to facilitate better understanding of the findings including users' decisions for transferability of the study findings to other practice settings (Sandelowski 1986:28).

4.9.3 Dependability

The third criterion for establishing trustworthiness in qualitative research is dependability which means data stability over time and over conditions (Polit and Beck2012:492). In the opinion of Thomas and Magilvy (2011:152), dependability
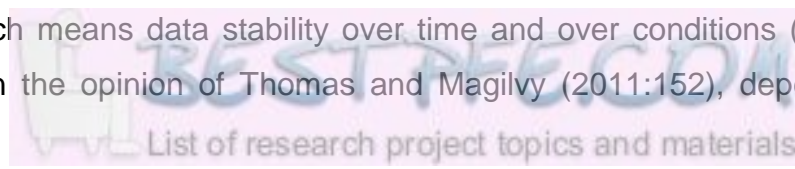
concerns with whether the study process is consistent and reasonably stable over time andacross researchers and methods. The researcher assured dependability of the study findings by ensuring that all the processes within the entire research process were consistent with the philosophical and methodological precepts of phenomenology (Rose, Beeby and Parker 1995:1126) and that methods of data gathering and analysis were explained clearly for others to verify (Lincoln and Guba 1985:290).

The first requirement of methodological consistence was boosted when the researcher first went through with general principles of qualitative research methodology and the phenomenological method prior to starting the project. The second strategy was to overcome inconsistencies in the research process by describing in detail the various steps of data generation, analysis and description. Importantly the details of data generation are contained in chapter four, data analysis in chapter five findings in chapter6 and interpretation in chapter seven and recommendations in chapter eight.   In each section, the researcher's role is articulated for others to make judgments. In specific terms, data collection occurred in settings and during times consistent with the study's design and the research question. Coding checks were made by both the researcher and the supervisor and they showed adequate agreement. Quality checks were made for any bias and misinformation in the data. These various processes led to a data trail that a reader wishing to conduct a data audit or secondary analysis or verify data consistency may use as recommended by Lincoln and Guba (1985:290). In view of these, the researcher assured them self that the findings could be similar if the study was repeated with similar participants in similar context by similarly trained researcher.

4.9.4 Confirmability

The fourth criterion for trustworthiness, confirmability refers to objectivity or neutrality of the research data. According to Polit and Beck (2012:492) objectivity refers to the potential for congruence between two or more independent people about the data's accuracy, relevance and meaning. A closely related concept of neutrality according to Lincoln and Guba (1985:290) is the criterion that the reader can use to ascertain the degree to which the findings of a study are determined by the actual views of participants and not that of the researcher's imaginations.

Consistent with Polit and Beck's (2012:492) position, the researcher was conscious that the findings had to reflectparticipants' true voice and conditions and not their uninformed biases and views. The researcher demonstrated full objectivity through reflexivity, auditability and flexible coding system

4.9.4.1 Reflexivity

The researcher was conscious of their role their pre-understandings about HIV would have on the findings. In remedy, the researcher remained open to mechanisms that would enhance the self-reflective stance required to enter the field with an open mind set (Streubert and Carpenter 2011:34). This openness was achieved through the process of reflexivity which Finlay (2008:15-17) compares to Husserl's reduction. Like Heidegger and Gadamer, Finlay (2009:12) maintains that the researcher's fore-structure cannot be fully bracketed out, but rather needs to be acknowledged and placed in the foreground to separate out what belongs to the researcher from that of the participants. This process described as a dialectic tension between "striving for reductive focus and reflective self-awareness; between bracketing out researcher pre-understandings and exploiting them as a source of insight" (Finlay 2008:17-18). Polit and Beck (2012:110) maintain that a researcher's reflexivity is critical in qualitative research because it is what qualitative researchers rely on to guard against personal bias in making judgments during the research process. They consider reflexivity as the process of reflecting critically on self and of analysing and making note of personal values and views that could affect data collection and interpretation. Jootun, McGhee and Marland (2009:42) explain that the process of reflecting on one's research and trying to understand how one's own values and views may influence the findings adds credibility to the study findings. In the present study, the researcher used the process of self-reflexivity to accurately portray the lived experiences and meanings the adolescents assigned to their experiences. Reflexivity was thus accomplished by recollecting and keeping in mind, what I already knew about lived experience of adolescents through preliminary literature review (refer to chapter 3). I enhanced self-reflection by consciously checking to ensure that my prior experiences andbiases did not skew the research data. This required me to be consciously aware and remain open to participants' views regardless of whether they were in agreement or divergent from all prior learning considering them authentic since they came from participants.

4.9.4.2 Auditability

Lincoln and Guba (1985:319) contend that a study may be considered objective by means of an audit trail, which refers to the way the researcher documents the findings. Polit and Beck (2012:547) consider an audit trail as systematic documentation of materials that allows an independent auditor of a qualitative study to draw conclusions about the trustworthiness of the findings. Glaser and Strauss (1967) and Guba and Lincoln (1989), as cited in Cutcliffe and McKenna (1999:377-78) recommend that to increase confirmability (objectivity) of the findings, the researcher should leave an audit trail or decision trail so that their pathway of the decisions made during data analysis can be checked or verified by other researchers. The researcher enhanced the auditability of the study by adopting Halpern's (1983) criteria as cited in Lincoln and Guba (1985:319) for creating an audit trail by keeping:

- Interview guide development information including amendments.

- Data reduction and analysis products such as codes or summaries.

- Review notes and mails from supervisor.

4.9.4.3 Flexible coding system

As a further procedure to ensure auditability, a flexible coding system was adopted as part of the consensus discussion between the researcher and the supervisor, who served as an independent expert. The supervisor and I agreed on all the codes as well as the categories and themes up to the present final product. The adoption of a flexible coding system meant that I remained open to new ideas, considering that themes and categories were tentative and open to re-coding and restructuring as and when the need arose. Hence, the *malleable* code and recode procedure enabled me as *researcher* and the supervisor as *check* to arrive at the most acceptable and complete description of the adolescents' lived experiences. This consensus process was in agreement with the recommendation of Krefting (1991:219) who declared that triangulation of investigators is critical because through consensus, the researcher is afforded a chance to clarify and improve findings.

4.9.5 Authenticity

The fifth criterion for establishing trustworthiness of a qualitative study espoused by Guba and Lincoln (1994) relates to authenticity. Polit and Beck (2012:493) refer to authenticity as the extent to which researchers fairly and faithfully show a range of different realities about the phenomenon being investigated. An account becomes authentic if it conveys the feeling tone of the participants‟ lives as they are lived (Polit and Beck 2012:493). A phenomenological account is thus authentic if it enables the reader to re-live the experience being described. This is what Van Manen (1990:27) terms as "phenomenological nod", when a person after reading a lived experience account says… "this is the experience I could have had…" This supports the claim that a good phenomenological description is validated by lived experience, as much as it validates lived experience (Van Manen 1990:27). As Polit and Beck (2012:493) posit, a truly authentic text invites readers to develop a heightened sensitivity to the issues portrayed in the research narratives through appropriately incorporating aspects of mood, feelings, experiences and contexts to allow better understanding. By documenting the "hard facts" about the adolescent drug adherence experience in a language that is evocative, expressive, transcendent and poetic. I allowed the emotional aspects of the lived experiences to create in the reader a phenomenological reverberation or resonance. This enables the reader to experience HIV and drug adherence of the adolescents through the eye, skin and heart (Van der Zalm and Bergum 2000:212). As Van Manen (2011:1) posits, the expressive manner with which the findings were reported hopefully allows readers to better feel and deeply understand the adolescents' everyday life.

4.10 CONCLUSION

In Chapter 4, operationalisation of a qualitative research design using the phenomenological method was explained. This chapter discussed in detail the sampling procedure, data collection method and the researcher's adherence to the ethical requirements. Strategies of ensuring data trustworthiness were discussed. In the following chapter (chapter 5) steps and various processes involved in data analysis will be explained.

CHAPTER FIVE

DATA ANALYSIS

5.1. INTRODUCTION

In the previous chapter, chapter four a detailed description of the research methodology was presented. The purpose of data analysis is to organise, provide structure and to elicit concrete meaning from narrative data. It is a *data reduction* and *sense making* effort that takes qualitative material and attempts to identify core consistencies and meanings therein (Patton 2014:453, Wertz 2011:161). Qualitative data analysis is an analytical process designed to condense raw data into categories or themes based on valid references (Zhang and Wildemuth 2010:2). This process relies on inductive reasoning and entails the enquirer creating generalisations from specific observations, beginning from specifics and then moving to general aspects of the experience (Polit and Beck 2012:10, Streubert and Carpenter 2011:10). The need for meaning making from qualitative materials is corroborated by Polit and Beck (2012:464) who declare that qualitative data analysis is an active and interactive process that results in search for meanings and deeper understandings from conversations following a very careful classification and analysis process (Jonker and Pennink 2010:87). Data analysis is an important part of qualitative research process because it allows the researcher to fit data together, make the invisible obvious and draw general conclusions about a phenomenon (Morse and Field 1996:126, Polit and Beck 2012:79). Qualitative data analysis helped the researcher describe and explain the essence of adolescence and ART adherence experience. A key notion of qualitative data analysis is dwelling with and becoming fully immersed in the data through prolonged engagement and deep reflection (Polit and Beck 2012:464 & Streubert and Carpenter 2011:92) In this current study, the desire to obtain a comprehensive picture of the experiences necessitated data analysis from the descriptive perspective. This allowed the researcher to capture the essence of adherence experience including the contextual features and meanings assigned to the experiences.

5.2 General Principles of Qualitative Data Analysis

In qualitative research, although initial data analysis occurs simultaneously with data collection to help the researcher determine when to stop data generation, real in-depth analysis begins when the researcher starts listening to the recordings and reads through the verbatim transcriptions to get a sense of what the data says. This process is then followed by a thorough reduction of data into units whose contents convey specific information about the lived experience and lend themselves well to meaningful analytical reflection to answer the research questions posed (Burns and Grove 2011:548, Wertz 2011:131). According to Streubert and Carpenter (2011:45), this process of reducing data into meaning units begins immersing in and dwelling with the data and repeatedly reading the transcripts alongside field notes and recalling the observations and occurrences recorded during interviews. This process helps the researcher identify and extract significant statements from the data. As recommended by Burns and Grove (2011:547), immersion was enhanced by underlining key phrases, highlighting words, sections and paragraphs and inserting comments next to the data sets or texts that triggered them to ensure that the researcher's psychological processes that identified them would not get lost during further readings of the transcripts and this proved critical in helping the researcher to arrive at evidence based conclusions (Wertz 2011:160). In order to achieve quality data analysis, one principle used was committing to a structured analytical process to achieve in-depth understanding of what the data communicated (Basil 2003:143). Wertz (2011:132) observe that structured analysis requires prolonged in-depth reading, intuiting, analysing and ordering to enable the structure and meaning of lived experiences to be portrayed accurately to create new knowledge and signal call for action (Creswell 2014:37). A second principle adhered to during data analysis was embracing a form of phenomenological attitude, a vital methodological procedure by engaging in two methodological processes termed "epochés" by Husserl and described and by Wertz (2011:125) as abstentions; the first being the "epoche" of the natural sciences and the second the "epoche" of the natural attitude. The epoche of the natural sciences according to Husserl (1901/1970) as explained in Wertz (2011:125) involves putting aside the natural scientific and other knowledge including theories, hypothesis, prior research information about the phenomenon to return to the things themselves. The epoche

of the natural attitude also referred to as phenomenological reduction by Husserl required researchers to abstain from the natural tendency of consciousness to unreflectively posit and focus on the existence of objects independent of experience while emphasising transcendence as in most philosophical inquiry Husserl 1936/1954 in Wertz (2011:125). In addition of "bracketing" prior knowledge of adolescents ART adherence and emphasising transcendence by focusing on the existence of objects independent of lived experience; the researcher also deliberately embraced methodological procedure of openness, empathetic immersement and reflexivity (Van Manen 2011:1-2, Wertz 2005:172-173, Finlay 2003: 108 (2008:41) and Finlay and Eatough (2012:70-71) advocate.

5.3. Fundamentals of Phenomenological Data Analysis

The phenomenological data analysis framework of Wertz (1983/2011) was used because of its description of things or events as they appear in peoples' lived experiences (Finlay 2016:2; Wertz 2011132), essential to arrive at unique individual and universal essence of lived experience. This chosen approach shares features with works of Duquesne scholars among them Van Kaam (1996), Giorgi (1975) and Colaizzi (1978) all grounded on Husserl's (1962) descriptive phenomenology at the core of which is arriving at a description of the universal essence of the lived experience. In order to arrive at the general aspect of the lived experience, the researcher started by elucidating the individual instances of the phenomenon before delving into features that cut across participants experiences (Wertz 2011:151). As observed by Kvale (1996:52) and Laverty (2003:23), this data analysis method helped the researcher to structure the lived experience accounts, organizing them to give form and meaning to the life-worlds elucidating their essences and unearthing HIV infected adolescents' invisible drug adherence experiences. Using Wertz's (1983/2011) framework allowed the researcher to capture both the "unique individual" and the "general aspects" of participant's lived experiences (Wojnar and Swanson 2007:177). This also enabled the examination of the features of these unique lived experiences in an embodied, relational as well as in temporal and contextual manner. This feature further allowed the researcher to elucidate deeper meaning and structure of HIV infected adolescents' ART adherence's lived experiences resulting in a broader understanding and better conceptualization of the unique and general aspects of their personal experiences

(Koch 1999:21; Benner 2001:40; Wertz 2011:40). In keeping with the descriptive hermeneutic and existential traditions of philosophers Husserl, Heidegger, Gadamer and Recoeur data analysis within Wertz's (1998/2011) analytical framework answered the phenomenological question: How can we let that which shows itself be seen in the very way that it shows itself? As Van Manen (2011:2) points out the researcher was primarily interested in gleaning HIV infected adolescents on ART modes of "being-in-in-the-world", including how their "life worlds" of being children, students, future husbands and wives and partners changed as a result of the need to adhere to their ART regimen. Wertz's (1998/2011) with its features consistent with general hermeneutic method was chosen because it allows understandings related to meanings adolescents assigned to the phenomenon of having to adhere to their ART drugs for life. Wertz's (1998/2011) method was also chosen because as Ricoeur argues meanings in human experience are not given directly given to us and for one to understand them, there is a need to make a *hermeneutic exploration* through the person's narrative of the live experience. Cognisant of this assertion, the meanings embedded in the narratives were examined by exploring the socio-cultural perspectives, notably aspects notably of local myths and expressive language within the context of being an adolescent, being HIV positive and on ART. This analysis aided in unearthing of how adolescents' interpretation of the meaning of "being self" and "others" changed due to the need to remain adherent to the drug regimen. Wertz's (1998/2011) framework was selected because it helped the researcher to better understand and describe the meanings of HIV infected adolescents' lived experiences within the socio-cultural and related contexts in which the experience is encountered.

The analytical framework also shares features with other works within the phenomenological-hermeneutical tradition among them the methods of Diekelmann, Allen and Tanner (1989); Van Manen (1990) who themselves appear to have been influenced by the existential and hermeneutic thoughts of Husserl, Heidegger, Gadamer and Ricoeur. At the core of these frameworks influenced by transcendental, hermeneutic and existentialist thought, is the researcher arriving at both the structure and meaning of the event from the perspective of those who have experienced it first-hand, investigated from the socio-cultural and related contexts

within which the experience was lived. The thesis of this process was arriving at the convergence of adolescents' drug adherence lived experiences, the researcher's understandings and other sources including literature and expert opinions Wertz (2011:151).

5.4 Wertz's (1983/2011) Empirical Psychological Reflection

Empirical psychological reflection which informed the data analysis of this current study is grounded on Wertz's (1983, 1985, 2005, 2010 and 2011) work supported by other related works. The inclusion of other views is consistent with the dynamic nature of qualitative research including its emergent design and different researchers handling of aspects of the research in unique ways. Klopper (2008:63) agree that qualitative research procedures are neither rigid nor mechanistic and its emergent nature allows inclusion of approaches that illumine aspects of the research process. The main motivation for choosing Wertz's (1983/2011) approach is that among the many modern-day proponents of the phenomenological method, Wertz has continued to clarify and amplify his method through an array of various publications and explications (Wertz 1984, 1985, 1986, 2005, 2010, 2011). Although revised and updated regularly, Wertz's works still follow closely on that of his predecessors; Husserl (1913/1962), Van Kaam (1966), Giorgio (1975/2009) and Colaizzi (1978), incorporating trends in interpretive phenomenological inquiry (see section 5.3). These revisions make Wertz's (1983/2011) approach a preferred research framework to arrive at both unique individual aspects of the experience and general features of the phenomenon, including meanings and structure of the experience. A key aspect of the method is that it allows articulation of these experiences from within unique and invariant contexts of those who lived it. Wertz's (1983/2011) framework consists of three specific phenomenological phases of reflection, implemented through adopting specific phenomenological attitudes including engaging in several specific methodological research procedures, while the fourth phase consists of phenomenological descriptions and the specifics of the four analytical steps are described below.

5.4.1 Phases of Empirical Psychological Reflection (EPR)

Wertz's (1983/2011) four methodological steps Empirical Psychological Reflection framework is supported by fifteen research procedures and five basic phenomenological attitudes shown diagrammatically in figure 5.1
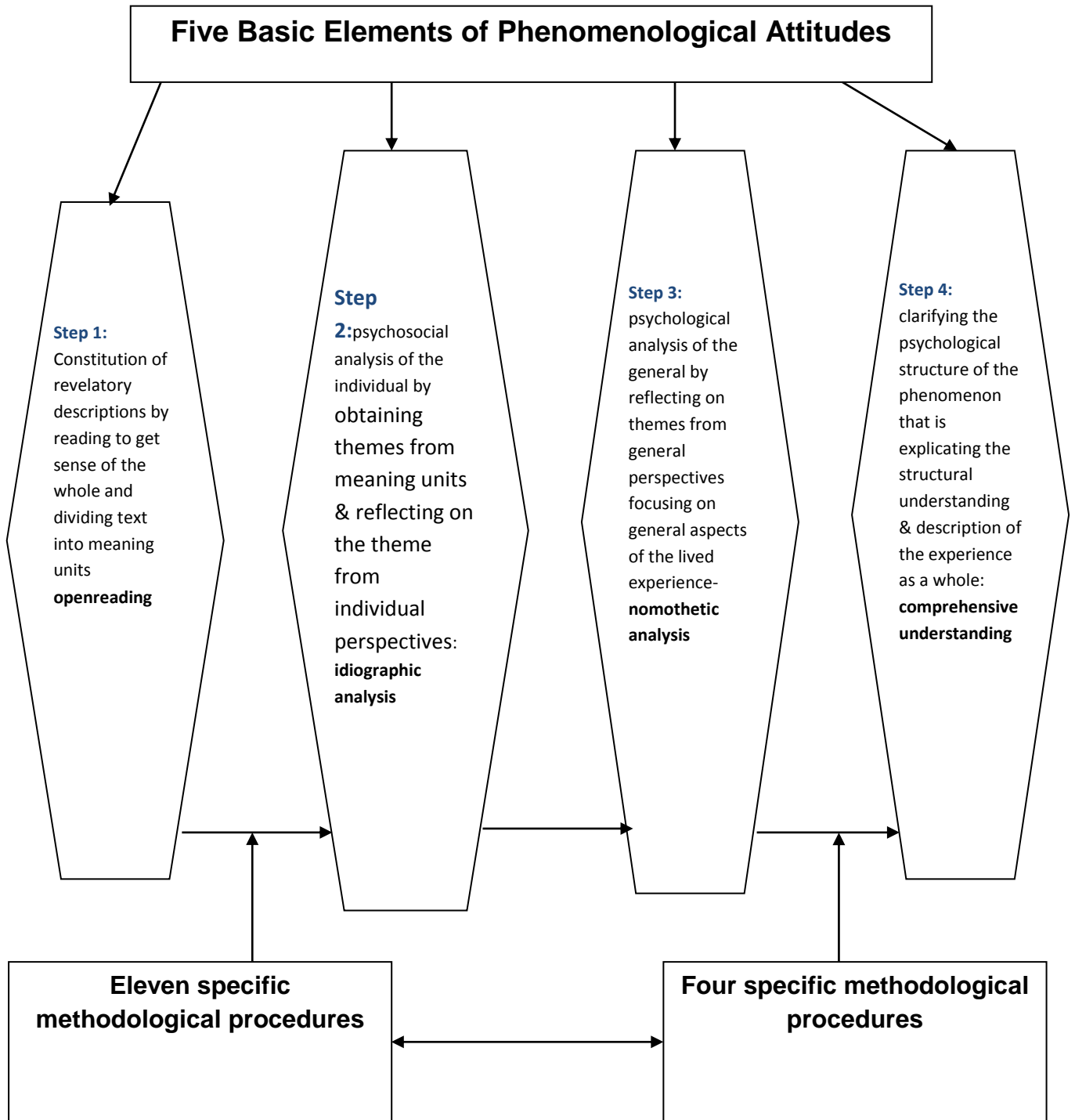
Figure 5.1: *Diagrammatic presentation of Wertz's analytical approach*

Wertz (1985:161, 2010:270, and 2011:131) explains that EPR occurs after the research data are well digitally audio-recorded during interviews and transcribed verbatim. The lived experience accounts consist of several descriptions of the everyday life experiences that adolescents experience before during, after and in-between the drug adherence. EPR proceeded through the following four phases:

- Constitution of Revelatory Descriptions (Open reading).

- Psychological Analysis of the Individual (Idiographic Analysis).

- Psychological Analysis of the General (Nomothetic Analysis).

- Structural understanding and description (comprehensive understanding).

5.4.1.1 Constitution of revelatory descriptions

This phase according to Wertz (1985:164, 2011:131), generates organised descriptions of the lived experience expressed in the first-person language of participants, one for each interview. This data cleaning phase characterised by open reading, involved removing form each transcript all the irrelevant data from the interview and ensuring all statements that reveal the experience as it occurred were left intact. The descriptions depicted how the adolescents infected with HIV experienced the drug adherence process. This preparatory phase that precedes in-depth data analysis is characterised by the researcher reading each interview text as a whole several times to gain an impression of the whole, followed by formulation of the researcher's thoughts about its meaning for further analysis (Streubert and Carpenter 2011:85, Wertz's 1985:164,2011:131). This initial step which documents the researcher's impression of the text is consistent with data analysis within general hermeneutic phenomenological research framework. In this phase, all interview transcripts were individually reviewed to gain a good sense of the phenomena of drug adherence experiences of HIV infected adolescents. This initial reading of transcripts is described by Wertz (2011:131) as open reading while interpretive scholars (Lindseth and Norberg 2004:149) refer to it as naïve reading focused on how HIV infected adolescents perceived drug adherence, what they thought symbolised people's reaction towards them and other adolescents

suspected to be HIV positive and on ART, including how it affected their everyday lives in the aftermath. As a quality measure, my initial impressions of the various aspects of adolescents and drug adherence were documented and discussed with my supervisor who served as an external expect and quality checker. As previously explained, discussions were held until a general agreement about their meanings was reached before proceeding. In line with Wertz's (2010:271, 2011:131-136) views, I constituted each revelatory description by engaging in the following five methodological steps:

- Reading the interviews carefully and openly.

- Demarcating meaning units in the interview data.

- Judging which data constituents are revelatory for the research question.

- Regrouping the relevant constituents into appropriate patterns.

- Discarding redundant statements and re-describing events.

5.4.1.1.1 Reading the interviews carefully and openly

Each transcript was read carefully without any special attitude in order to have a general understanding of each participant's lived experience. This was done by putting myself in the shoes of each adolescent and trying to empathically live their experiences from inside, not just as an idle spectator, asking such questions as how might this aspect have felt? This necessitated deep involvement with each lived experience and helping in grasping the meanings (Wertz 1985:164, 2010:271).

5.4.1.1.2 Demarcating meaning units in the interview data

The meaning units were demarcated from the interview data by focusing on and thematising sections with meanings embedded to facilitate in-depth analysis. This prevented chunks of data being left unattended, which could have actually happened if apprehension of entire description occurred in a single glance (Wertz 1985:165, 2011:131). This involved re-organising entire transcripts into small meaningful chunks to work with comfortably; apprehended within the context of the whole experience and consisted of parts whose phrases required each other to

stand as a distinguishable moment of a specific lived experience Wertz (1985:165, 2011:131).

5.4.1.1.3 Judging revelatory constituents for each research question

This stage involved making crucial decisions and judging which constituents would reveal relevant information about particular aspects of participants' lived experiences in accordance with the research questions. It involved discriminating data to inform the researcher's understanding of particular aspects of the participants' experiences. The revelatory nature of the sections of data were determined by the researcher's perception of what a description conveys in regard to the different research questions before and during the drug adherence phase.

5.4.1.1.4 Re-grouping relevant constituents into patterns

In keeping with Wertz (1985:167; 2005:172), this step entailed re-grouping together relevant constituents (data chunks) according to their meanings and then placing them in a temporal order so that the patterns accurately expressed the sequence of the events in each story. It involved bringing together related statements so that the original temporality of the experience as lived, was re-constructed especially where order of events were not reflected, to facilitate analysis (Wertz 1985:168; 2011:138).

5.4.1.1.5 Discarding redundant statements and re-describing events

The step gives rise to the final product of this phase, "revelatory descriptions". As Wertz (1985:168; 2011:139-140) states, it involves discarding all redundant statements and re-describing the events from the first-person perspective, more or less in participant's language. This final product is the "*Individual Description of the Phenomenon*", the basis for the in-depth data analysis (refer to section 5.4.1.2).

5.4.1.2 Psychological analysis of the individual experience

This idiographic phase of empirical psychological analysis, Wertz (1983:204; 2011:138; Grbich 2013:Loc2278) clarify, involves carefully reading and reflecting upon the meaning units in each Individual Phenomenal Description (IPD), that is,

participants' "*clean*" description of their experiences with all irrelevant statements removed, but having left all revealing details intact; to attain a deeper understanding of what is embedded in each of the meaning units regarding adolescents' psychological life in relation to drug adherence.

This analytical step is consistent with the structural or thematic analysis phase of general hermeneutics method (Lindseth and Norberg 2004:150). It involves identifyingpatterns of meaningful connections through "interpretive reading" (Streubert andCarpenter 2011:85; Grbich 2013:61). This is what Wertz (2011:131) describes as discriminating meaning units, which lend themselves well to analytical reflection to answer the research questions and upon further psychological reflection, may resultin themes which ground the study (Lindseth and Norberg 2004:150; Wertz 2011:132). As Wertz (2011:132) declares, I systematically posed to each meaning unit the various research questions and reflected upon each of them to answer the questions. This allowed identification and documentation of unique aspects of the lived experience. In an empathic manner and using deep reflection, the unique experiences detailed in each of the IPDs were examined to grasp the psychological sense in each meaning unit in their unique contexts, in relation to other meaning units and the whole phenomenon. This resulted in conceptualisation of what each meaning unit revealed the role it played and its contribution to adolescents' psychological processes in relation drug adherence experience Wertz (2005:172, 2011:126).

In Wertz's (2005:172; 2011:126) words, this phase of data analysis constituted the procedure of "intentional analysis", described as a reflective process characterised by the researcher describing and gaining insight into the "how" and "what" of lived experience; that is how experiential processes proceed and what is experienced (Husserl 1913/1962, in Wertz 2011:126). Through intentional analysis, I deciphered *"various kinds of intentionality";* that is, the different ways participants meaningfully experienced the phenomenon. These reflections reveal that lived experiences are embodied, emotional, spatial, social as well as temporal (Wertz 2005:167; 2011:126).

The end result of the psychological reflection on each participant's phenomenal description is an integrative summary of the findings. It involves pulling all

reflections about each phenomenal description together; eliminating any redundancies and then concisely expressing the findings into the most revelatory aspects of each participant's lived experience. This "*synthesised*" description, which symbolises the end product of idiographic level of analysis, is what Wertz (1985:173; 2011:142) terms "Individual Psychological Structure" (IPS) of the phenomenon, and consists of both facts of lived experience and their psychological significance. This procedure of explicating the IPS helped me to focus thematically on the research questions within the perspective of a single "individual", albeit with the potential to exhibit "generally essential" features of the phenomenon to other study participants (Wertz 2011:142). To effectively apprehend the meanings in each lived experience account during this phase, I adhered to five basic "stances" or "attitudes" (refer to section 5.4.2) and eleven "active operations" (refer to section 5.4.3). These "methodological processes" enabled me to achieve the cardinal role: being the main research instrument, specially to grasp the "essential features" of each lived experience (Wertz 1985:174; 2010:272; Wertz 2011:142). Details of Individual Psychological Structures (IPSs) are highlighted in Chapter 6, to fulfil the quality control requirements of the audit trail.

5.4.1.3 Psychological analysis of the experience in general

This phase of psychological reflection, termed "nomothetic level" of analysis by Wertz (1983:227; 2011:150) attempts to learn and effectively portray the lived experience being investigated in general terms. It involves moving from the psychology of the individual experience to psychology of the experience in general; that is, the nuances of the experience across individuals and circumstances. This generated "general knowledge" about the phenomenon from individual examples, described as "General Psychological Structure" (GPS) of a lived experience (Wertz 1985:188; 2011:150). To arrive at general or eidetic aspects of the lived experience, the researcher starts with the "unique" individual psychological descriptions', which Van der Wal (2013) describes as "empirical description" and Wertz (2011:142) "individual psychological structure" and compares them for similarities and differences through the process of empirical or imaginative variation, where the experiences are varied and compared across different situations and contexts of participants. As Wertz (2011:150) explains, arriving at general elements (invariant features) of an experience, occurs through the process of "eidetic seeing",

characterised by identification of unique features that cut across different idiographic descriptions. Whilst focusing on the different individual experiences in narratives, numerous rich and varied examples of how participants experienced the drug adherence appeared and as reflections upon the IPSs continued, general insights about these experiences surfaced (Wertz 2011:151). The *"empirical variation"* process allowed unique empirical "*voices*" in the descriptions to be analysed to arrive at the essential meanings and structures of the participants' lived experience, which is objective psychological knowledge (Wertz 2010:271) and isessential to understand participant's unique lived experiences. This eidetic process started with looking at each participant's unique description of their lived experience and then re-constructing these individual profiles of lived experiences to make sense in the *"general sense"* of the lived experience (Wertz 2011:151; Van der Wal 2013:1). This move from "individual" to "general" aspects is critical since the individual psychological structure only reflects an "individual instance" of the phenomenon (Wertz 1985:188; 2011:150). Yet, with nomothetic analysis, the researcher transcends from individual expression of the drug adherence experience to the general natureand meanings of the experience of anticipating, experiencing and living with a condition that cannot be cured as a whole. This could have been projected to reflect humanity as a whole as affirmed in the data, in the literature, in the life world, in the reader's experience, through empirical variation process (Wertz 2011:135),allowing the findings to be "*extrapolated*" to illumine other situations (Finlay 2009:9). Articulating the GPS of lived experience requires understanding diverse individual cases (IPS) as instances of something more general and then articulating that generality of which they are particular instances (Wertz 1985:189), by articulating the "rich and varied examples of the phenomenon (Wertz 2011:151), that is the commonalities of the unique individual instances of their experiences. This transformation from "idiographic" to "nomothetic" analysis was facilitated by mulling over the question, *"What has been learned in general from each description about experiencing drug adherence as an adolescentliving with HIV?"* This "eidetic questioning" permitted movement from "unique individual" instances to "universal features" of anticipating, experiencing and surviving life threatening situations with similar physical, psychological, social, spiritual and economic consequences (Wertz 1985:188; 2011:126). This transition from "individual" to "general" helped me in identifying psychological processes and

meanings invariantly present in the lived experience accounts of all infected adolescents on ART; akin to empirical examples of anticipating, experiencing and surviving life threatening and life-limiting conditions in literature (Giorgi 2009, in Wertz 2011:151; Wertz 2011:151). This analysis phase was bolstered by five "phenomenological attitudes" articulated in section 5.4.2 in addition to eleven "active operations" or "procedures" of empirical reflection, as described in section 5.4.3, which enabled me to apprehend the different moments and perceived meanings and structures during idiographic analysis.In addition to "phenomenological attitudes" and "active operations," nomothetic analysis also incorporated four "active operations" described in section 5.4.4. Details of the psychological reflection employed during the nomothetic analysis follow in Chapter 6.

5.4.1.4 Structural understanding and comprehensive description

Structural understanding and description phase are the phenomenological description which involves integrating and describing insights gleaned from reflections upon the meaning units (Wertz 2011:132). The researcher summarises and reflected upon themes and sub-themes in relation to the research questions and entire study and revealed various possible ways of experiencing the world as an adolescent infected with HIV and on ART Lindseth and (Norberg 2004:150). Structural understanding was done by articulating participant's lived experiences as a "structural whole" through comprehensive understanding of their unique and shared experiences. To portray the in-depth understanding of these experiences, the researcher reflected deeply upon the unique individual themes, general themes and my pre-understandings about adolescent ART adherence. This *fusion of horizons*was then carefully articulated as comprehensive understanding of the meaning and structure of participant's lived experience regarding ART adherence Wertz (2011:132-133). This comprehensive description of lived experience was facilitated deep reflection including use of empirical and imaginative variation techniques to glean further insight from different aspects of participant's individual experiences. It also drew insight from associating the final themes with existing and relevant literature Wertz (2011:160). Lindseth and Norberg (2004) agree that these final descriptions arising from deep reflections, empirical variations and associations with literature, revised, widened and deepened understanding of

structures and meanings of adolescents' drug adherence experiences. The comprehensive understanding of the phenomenon was represented as unique individual experiences and as common instances within individual experiences and highlighted the different contexts of participants' experiences. This step of the final phase leaned on Cauley's (2008:425) and Van Manen's (2011:2) recommendation that lived experience accounts should be presented in an evocative, expressive, transcendent and poetic manner to enable the reader grasp both hard facts and emotions related to the experience. According to Van der Zalm and Bergum (2000:212), the facts of the lived experience act as building blocks for new knowledge, while the emotions help create phenomenological reverberation to connect readers to the text. In addition, this style was also intended to ensure the final account of adolescents' lived experiences resonated with and is easily recognizable by participants Creswell 1998:289-290). To boost the vividness of the experiential accounts, some bits of raw interview data are included into the final descriptions by incorporating participants' verbatim expressions to enable readers follow aspects of their lived experience (Wertz 2011:161; Van Manen 2011:2). These concrete situations, including different contexts of lived experience open windows into participants' life worlds, providing readers with intuitive understanding of participant's world lived experience; by allowing access to the original experiences (Wertz 2011:161). The "*comprehensive*" understandings of the lived experiences were documented using everyday language (Lindseth and Norberg 2004:151) so that readers could *see, hear, touch, smell or taste* these experiences. The use of everyday language is supported by Klemm (1983) who affirms that '*when we try to express the meaning of lived experience, we need to use everyday language' (*Klemm 1983, in Lindsethand Norberg 2004:151), lest we obscure the messages in lived experience accounts. In explicating "*comprehensive*" understanding of the lived experience, verbs instead of nouns were used to tell participant's stories since the former are better at revealing lived experience than nouns. In addition, poetic expressions were utilised to make thenarratives lively and able to carry the emotive sense of the lived experiences. As Vanden Hengel (1982) proclaims, poetic language makes words mean as much as theycan and creates mood, which reveals possible ways of being in the world and "showsa deeper mode of belonging to reality" (Van den Hengel 1982, as explained in Lindseth and Norberg 2004:151), while the scientific language reduces the capacity

to generate multiple meanings of language used (Ricoeur 1991:448-462. As Caulley (2008:424-430) advices, the researcher tried to ensure that the descriptions were as vivid and captured various experience scenes to involve readers and to make them fell as if they were there.

5.4.2 Attitudes of empirical psychological reflection

According to Wertz (1983:204; 2011:132), effective engagement in psychological reflection requires researchers to adopt five basic stances of phenomenological attitudes during the idiographic and nomothetic level of analysis among them:

- Empathetic immersement in the situations described.

- Slowing down and dwelling in each moment of the data.

- Magnification and amplification of the situation as experienced.

- Suspension of belief and employment of intense interest in experiential detail.

- Turning from objects to their personal/ relational meanings and significance.

5.4.2.1 Empathetic immersement in the situations described

This attitude requires the use of transcriptions as a point of access from which to make adolescents' lived experiences as the researcher's own, as if to put on the shoes of each participant, as reading and immersement into descriptions of their encounters occurs. This conforms to Wertz's (1983:204) declaration that the spirit of true phenomenology means the researcher cannot simply remain a passive spectator, but must experience the joys and pains of participants in full detail and in-depth to faithfully know them well. This attitude facilitated thoughtful entry into adolescents' situations and through careful reflection upon each phenomenal description; each of their lived experience situations were reconstructed Wertz (1985:174; 2011:131). This flexible approach became vital in understanding the individual adolescents' views about drug adherence experience.

5.4.2.2 Slowing down and dwelling in each moment of the data

This phenomenological attitude cautions against glossing over details of the individual phenomenological descriptions as if they are already known (Wertz 1983:204). The researcher remained alert and made sufficient room and time to clearly understand participants' descriptions of their lived experience. This was done by slowing down, lingering and dwelling with each moment of the data until such time that it made sense. This was to heed Wertz's (1985:174) warning that if one simply glosses over incidences in participants' descriptions, their meanings would remain largely implicit and this would defeat the central purpose of the investigation. This slow and thoughtful dwelling permitted comprehension and apprehension of the different sections of the data by seeing what each act or section of the narratives meant to each participant in their various contexts, what difference it made in their lives, including how various meaning units fitted in each adolescent's entire lived experience account in relation to ART adherence (Wertz 1983:205).

5.4.2.3 Magnification and amplification of the situation as experienced

This stance involves magnifying and amplifying various sections of the data to manifest their hidden meaning. This process was premised upon Wertz's (1983:205: 1985:174) affirmation that when one stops and lingers in the moment of an experience, its significance and meanings are magnified. What to the adolescent or a naïve reader seems unimportant and mundane then becomes significant and a big deal to the researcher. The core elements in participant's situations were grasped by magnifying various aspects of the raw data, however mundane the data unit appeared at first. This opened the researcher's mental *eyes* and *ears* to the things hidden in each participant's lived experience account.

5.4.2.4 Suspension of belief and employment of interest in the experience

According to Wertz (1983:205), this stance is a modification of the natural attitude and naivety with which the researcher originally entered the participant's situation. To ensure better understanding, Wertz (1983:205) recommends, that rather than

remaining immersed in the data persistently, the researcher needs to regularly stop, take a leap backwards, abstain from continued absorption and then "wonder" afresh, what a particular way of "living" the experience means, what it is all about, including how it affects individuals and their relationships with others and other existential components including interpretation of time and space (Wertz 1985:174; 2011:132). This "suspension of belief" compares with "bracketing" as discussed in section 2.3.6 and "reflexivity" as articulated in section 2.3.10. the researcher reflected and critically examined the various structure and meanings of each moment in the lived experiences accounts as seen through the *"existential lenses"* of time, space and others, by alternatelybreaking the initial "*fusion*" with the data and stepping aside. Hence, by momentarilygaining "*freedom*" from the naïve understandings of the lived experience accounts, I was then delivered to a "*position*" where I could clearly "see" the origins, relations andthe structures of each adolescent's lived experience Wertz (2011:132).

5.4.2.5 Turning from objects to their meanings and significance

This phenomenological stance is underpinned on Wertz's (1983:206; 2011:131) caution that during data analysis the researcher should not be concerned about "reality" or "falsity" of the objects or state of affairs in participant's descriptions; as a judge would in a court proceeding (Wertz 1985:175). This caution is based on the basic assumption of phenomenological research that reality is multiple and varies from one person to another (Guba and Lincoln 1989:105). Cognisant of this tenet, I was careful in apprehending the various situations that were meaningful to the participant, that is, the researcher focused more on what particular aspects of the lived experience meant to adolescents through their existentially meaningful contexts. Informed by these assumptions, the researcher focused firmly on how the phenomenon of drug adherence appeared to adolescents including the meanings of various events and how these meanings arise and get transformed through the three temporal zones of before, during and after drug adherence process. This stance delivered the researcher to each participant's unique situation of how the need of drug adherence affected them, thereby enabling articulation of their peculiar meanings and significance of their situations (Wertz 1983:206; 2011:131-2).

5.4.3 Procedures of Empirical Psychological Reflection

These are 15 active methodological procedures through individual and general levels of analysis; 11 of which are utilised during idiographic analysis while the remaining 4 are used during nomothetic analysis. Whilst discussed herein in a linear form, these specialised procedures according to Wertz (1985:175) constitute an extricable unit during actual reflection. The research process was guide by Wertz's (1983:206; 1985:174) assertion that both idiographic and nomothetic analysis, these research activities (section 5.4.3) and the attitudes (section 5.4.2) may come into play either successively in combinations or in an all-in once stroke, in every statement in each participant's individual phenomenal description. This means that these stances and procedures should be considered mutually implicative and inseparable throughout data analysis. Consistent with Wertz (1985:175; 2011:132), the following 11 research procedures were employed during idiographic level of data analysis of participants' experiences:

- Identification of the existential baseline of the experience.

- Reflecting on relevance of what is revealed about the phenomenon.

- Explicating implicit meanings that are not thematically clear in the descriptions.

- Distinguishing the various constituents that make up the entire experience.

- Understanding relations among constituents and their roles to the whole.

- Thematising recurrent modes of experience, meanings and motifs.

- Interrogating opacity-extending and acknowledging limits of comprehension.

- Imaginatively varying constituents to identify mutual implications and invariants.

- Formulating descriptive language for psychological knowledge using every day phrasing, received scientific terms or philosophical discourse.

- Verifying, modifying and reformulating findings after returning to the data.

- Using existential concepts as heuristic (basis) to guide description reflection.

A detailed articulation of how each of the research procedures occurred now follows:

5.4.3.1 Identification of the existential baseline of the experience

Wertz (1983:207) points out that implicit in the researcher's frame of reference are the norms of psychological existence, typical day-to-day life in which the phenomenon is not profoundly present or where other phenomena predominate. The chosen existential baseline or temporal background becomes the ground upon which the phenomenon stands out and is identified by the inquirer Wertz (1985:175). In the current study, the experience of HIV infection and drug adherence experienced by adolescents was contrasted against the ground of no HIV infection and no drug adherence. The existential baselines and the temporal dimensions provided the basis for intense contrast between the grounds of "experiencing" and "not experiencing". This comparison helped in delineating the precise lines of the lived experience of ART adherence. As Wertz (1983:207) says, the contrast between the between the "before" and "after" of the lived experience allowed the researcher to arrive at deeper understanding of these moments by using the baseline to discern how HIV and ART adherence has affected the adolescents.

5.4.3.2 Reflecting on the relevance of each moment of lived experience

The reflection and decision-making occur constantly as the researcher analyses each lived experience Wertz (1983:207). The existential baseline and the temporal dimensions provided the researcher with the basis for judging the statements in the IPDs for their relevance to each adolescent's lived experience. The researcher reflected on the relevance of each moment of the lived experience by asking questions such as "*how do I understand the adolescents' experience of drug adherence?" "What does this statement reveal about their experiences?" "How is it relevant to their situation?"* By reflecting upon the various key moments in each individual phenomenal description, I then abstracted the essential structures and

meanings in each lived experience account of every HIV positive adolescent on ART (Wertz 1983:175).

5.4.3.3 Explicating implicit meanings that are not thematically clear

As explained by Wertz (1983:207), the researcher was aware that the interview transcripts are not the ultimate objects of reflection, despite the necessity in helping the researcher understand the person's lived reality. Wertz (1985:176) further explains that once the situated in the participant's world through their description, the researcher should reflect on the things not explicitly mentioned in the description, but are demonstrably present, albeit implicitly in the participant's situation. By "penetrating" the implicit grounds in the descriptions, the researcher validated how HIV infected adolescents' horizons of normalcy were distorted by the experience of drug adherence.

5.4.3.4 Distinguishing constituents that make up the entire experience

Wertz (1983:208; 2011:132) recommends that once the inquirer is involved in participant's situation, they should make distinctions between different aspects of the key moments within the lived experience. This sensitivity to different aspects of a single reality enables the researcher to see hidden patterns, themes and categories related to participant's reality in terms of personal, spatial, temporal or relational dimensions. As declared by Wertz (1985:176), differentiating between different aspects of the lived experience were facilitated by distilling extracting from each statement what it expressed that was different from others using a combination of empirical and imaginative variation techniques of narrative (qualitative) data analysis.

5.4.3.5 Understanding relations among constituents and their roles to the whole

Wertz (1983:208; 2011:132) advises that in order to clearly understand how various constituents relate to the entire experience, the researcher should reflect on each constituent, focusing on what it has to do with other elements and aspects of the phenomenal description. Various constituent questions such as: *how does this constituent relate to the whole experience? What part does it occupy?,* were used

to realise the methodological procedure . This interrogation technique also facilitated the process of determining salient aspects of the phenomenon that depended upon or presupposed others. It further assisted the researcher in decoding how different aspects of each person's experience related to and augmented each other Wertz (1983:208-209; 1985:176).

5.4.3.6 Thematising recurrent modes of experience, meanings and motifs

In addition to identifying the relationships between various constituents within the experience and affirming what each of them occupies in each adolescent's life, the researcher began to search for uniting and consistent elements within the diverse experiences related to the drug adherence experience Wertz (1985:176). As the researcher decoded what each of the constituents stood for, the themes crucial to understanding the essential aspects of participants' unique lived realities unfolded in conformity to Wertz's (1983:209; 2011:132) declaration moving the study forward.

5.4.3.7 Interrogating opacity: acknowledging comprehension limits

This methodological procedure involves interrogating and dwelling with the data to understand their contexts and clarify vague areas that surprise the inquirer during psychological reflection Wertz (1983:209; 2011:132). When unclear areas emerged, the researcher continued to seek guidance from the supervisor. Interrogating unclear areas allowed the researcher to navigate through the various opaque areas and to reveal the meanings and attain deeper understanding of lived experiences Wertz (1985:176).

5.4.3.8 Varying to identify mutual implications and invariant structures

This analytical procedure according to Wertz (1983:209; 2011:133), requires the researcher to ask whether any of the constituents, distinctions, phases, relations and the themes could be different or even absent while still presenting an individual's unique reality. I questioned: "would an HIV infected adolescent experience drug adherence differently if they had no previous information about HIV?" By questioning what these lived experiences would be in the different scenarios and then imaginatively or empirically varying aspects of the descriptions

enabled the researcher to clarify the different contours of adolescents' lived experiences (Streubert and Carpenter 2011:48; Wertz 1985:176).

5.4.3.9 Formulating descriptive language for the psychological knowledge

This is the researcher's attempt to express the sense made during both the idiographic and nomothetic stages of analysis using descriptive language which may take the form of everyday phrasing, received scientific terms or engaging in a philosophical dialogue (Wertz 2011:133). The transformation of the experience into psychological language is not simply a translation of the description, but rather original speaking of the defining elements of the experience delineated from contact with HIV infected adolescents on ART. Consistent with Wertz's (1985:177; 2011:133) affirmation, the words used to describe the new knowledge were chosen from everyday language, scientific vocabulary and from philosophical discourse.

5.4.3.10 Verifying, modifying, and reformulating the findings

Whenever the researcher speaks in psychological terms (Wertz 1985:177), there is a distance between what is said and the participant's original description, implying the presence of an inherent danger of losing contact with participant's lived situations. This shortcoming was overcome by constantly returning to the original descriptions to verify, modify or negate new reflections about moments in the participant's lived experience. This verification was facilitated by constantly comparing with coded individual psychological structures. This validation exercise was guided by questions such as: "*is everything said borne out?", "is everything in the participant's lived experience accurately reflected in the final description of the experience?".* This verification resulted in unison between what the participant said and what the researcher described (Wertz 1985:177; 2011:133).

5.4.3.11 Using existential concepts as a heuristic to guide reflection

According to Wertz (1985:177) this last active procedure is secondary and is built upon the other specialised operations aforementioned, especially the stages that involved verification, modification and reformulation of themes. This deep level reflection may be guided by using received concepts which included existential structures related to the "self", "world" and "others" that are prevalent in participant's everyday psychological reality. Whenever an adolescent described their lived

experience within a particular existential framework, I would carefully think over how other existential concepts were involved as well Wertz (1983:211; 1985:177). In addition to the "self-world-others" existential concepts, I also used other concepts such as "life-world", "being-in-the-world", "*temporality*", "*corporeality*" and "*spatiality*" to guide deeper level reflection and for interrogating unclear aspects of participant's lived experiences. Incorporating life world existential and other received concepts to guide deeper level reflection illuminated in a radically descriptive way, what was already given in the narratives, but had not yet been "discovered" in earlier reflection. These existential concepts bolstered my "descriptive reflection" and empowered me "see" and "grasp" what had been initially overlooked (Wertz 1983:211; 2011:133).

5.5 CONCLUSION

In this chapter, the descriptive aspects of data analysis processes were discussed in detail. The analytical processes described is based mainly on the works of Wertz (1983; 1985; 2005; 2010; 2011) which shares features with the hermeneutic phenomenological research approach of Ricoeur (1976/1978). These analyses were conducted at both idiographic (individual) and nomothetic (general) levels. The following chapter (6) the salient outcomes of the analytical processes and discussions will be outlined.

CHAPTER SIX

DATA ANALYSIS WITH LITERATURE SUPPORT

6.1 Introduction

In the previous chapter, chapter five, the researcher presented the descriptive and interpretive aspects of data analysis based mainly on the works of Wertz (1983, 1985, 2005, 2010 &2011). In this chapter the researcher presents the synthesised data in form of themes and categories supported by meaning units to enhance audit trail and credibility. The main aim of the study was to explore and describe the drug adherence lived experiences of HIV infected adolescents in Zimbabwe in order to improve their therapeutic outcomes. The nomothetic analysis phase resulted in six themes as shown in Table one below.

6.2 Fieldwork Experience of The Researcher

After passing through a rigorous ethical clearance, I was very excited to start interviewing research participants. The major learning experience in this phase was how emotional an interview could get. I had in no way anticipated how emotionally involving some of the interviews could become, it was more like a reality shock. On a number of occasions, I experienced severe emotional reaction, often torn between being a researcher and being a counsellor, let alone being carried away by their stories of pain and suffering. This was a true test of scholarship; in no way intended for the fainthearted!! I had to learn to deal with severe emotional reaction, especially when an interviewee broke down and cried loudly and sobbed endlessly. On three occasions, I caught myself almost being carried away; I nearly cried...my eyes were teary. After the interviews, it became apparent to me that phenomenological research can truly be an emotion draining event. While I had a gut feeling that this might happen, the extent of the reactions of some participant especially the emotion weight this levied on me was unimaginable. Indeed, a journey of a thousand miles had begun.

6.3 Demographic Profiles of Respondents

The demographic profiles of the study participants are presented in Table 6.1 below.

Table 6.1: Demographic profiles of the study participants N=13

Variable	Frequency	Percentage %
Gender		
Female	6	46.15
Male	7	53.84
Level of education		
Primary School	1	7.69
Secondary	10	76.92
Tertiary	2	15.38
Occupation		
Student	6	46.15
Unemployed	7	53.84
Place of residence		
Urban area	10	76.92
Rural area	3	23.07
Marital status		
Single	12	92.30
Cohabiting	1	7.69
Age when told about own HIV status		
Five years	2	15.38
Nine years	1	7.69
Ten years	3	23.07
Eleven years	3	23.07
Twelve years	4	30.76
Support system		
Grandmother	6	46.15
Clinic	1	7.69
Siblings	1	7.69
Parents	4	30.76
Non	1	7.69
Duration on Antiretroviral drugs		

5 to 6 years	2	15.38
7 to 8 years	4	30.76
11 to 12 years	7	53.84

6.4 Central story line, themes and categories.

In presenting the findings, a data display containing verbatim quotes of the interview data is displayed in order to enhance clarity of the themes and categories. The findings are discussed with literature support. **Since HIV drug management is lifelong and the experience of the individuals starting ART from infancy is a new phenomenon, adolescents' lived experiences regarding ART adherence is a lifelong process and ongoing. It involves the person in totality. The lived experiences so far could be different in a decade or two.** The central story line, themes and categories are presented in Table 6.2 below.

Table 6.2 Central Story line, themes and categories

Since HIV drug management is lifelong and the experience of individuals starting ART treatment from infancy is a new phenomenon, adolescents' lived experiences regarding ART adherence is a lifelong process and ongoing. It involves the person in totality. The lived experiences so far could be different in a decade or two	
Theme	**Categories**
Theme 1: Treatment fatigue	i) Frequent hospital visits. ii)Pill burden (iii) Adolescent self determination (iv) Feeling well; treatment holidays (v) Being away from home
Theme 2: Delay in getting to know own HIV Status	i) Delay in disclosure of status by caregivers ii)Impact of knowing own status iii) Blame game
Theme 3: Stigma	i) Desire in keeping diagnosis secret; fear of rejection ii)Self stigma. iii)Health care stigma iv)Stigma at boarding schools v) Stigma at home
Theme 4: Disability (visual Impairment)	i)Unable to read instructions on drug containers ii)Difficult to determine correct drug to take iii) Dependency on a friend or relative
Theme 5: Lack of support	i)Poor family support ii)Healthcare support iii) Labelling (being labelled defaulters) (iv) Poverty-transport money, food

Theme 6: Religious beliefs(church)	i)Belief in faith healing ii) Religious praying months such as Ramadan

6.5 Descriptive overview of treatment fatigue

The concept "fatigue" is explained by the Oxford Mini Dictionary and Thesaurus (2008:246) to mean tiredness, listlessness, lethargy and weakness caused by stress. While Clarborn, Meier, Miller and Leffingwell (2015:1) define treatment fatigue as a decrease in desire and motivation to maintain vigilance in adhering to a treatment regimen among patient's prescribed long-term protocols. They further indicate that the cause and course of treatment fatigue appear to vary by developmental stage. The participants expressed both implicitly and explicitly that they experienced treatment fatigue at some stage because of the fact that the treatment was lifelong and that their condition was not curable. The categories which emerged under this theme are described below.

6.5.1 Frequent Hospital visits

Most participants in this study did not stay near the hospital where they were registered for treatment. However, they preferred coming to this hospital because according to them, they experienced no discrimination as everyone who came to this institution was known to be on ART. The statistics availed at the hospital showed that most of the adolescents aged between 18 to 21 years had very high viral loads of above 40 000 copies which is considered very high and the health workers linked this to non-adherence to the treatment regimen. Because of this problem, the adolescents' review appointments were more frequent. Most adolescents were from poor families and because of the economic challenges, most adolescents failed to turn up for their monthly reviews. Frequent hospital visits were also seen by some participants as a way of indirectly disclosing one's status.

> *"...I am an orphan, and stay with my grandmother who is disabled.*
> *She does not work we have no food and no money for transport to*
> *come and collect my monthly medication so I only come when I*
> *get someone who feels sorry for me like today. I last had my pills*

three months ago. At times I walk to the hospital which at times takes about three hours". (female participant 20 years old).

"…I have asked the doctor to give me more pills like for three months so that I do not miss my drugs since I do not have money to come regularly at the clinic but they refused saying that I needed to be seen regularly but I know I will not come"

"…I cannot give others my card to come and collect my drugs for me because they will tell others that I am sick. I am not ready for anyone to know my status so I do not come to collect for some time because I will be having no money for transport" (19-year-old male participant).

"...Having to come to the hospital at the same time every month and being required to take my pills at the same time makes me somehow different from others. I do not want to be different". (19-year-old female participant).

In this study, many adolescents missed hospital appointments and their treatments because they could not raise enough money for transport fares. This is consistent with literature that patients on higher incomes have less difficulty with adherence compared to patients in low income or no income at all (Azia, Mukumbang and van Wyk 2016:5). Though ART programmes are made more affordable to users by providing them free of charge at the points of delivery, in Zimbabwe, transport costs and the general economic hardships experienced especially by orphans are major concerns that hinder adolescents from optimal adherence to their treatments (Madiba 2017:3 and Errey et al, 2015:3).Besides the economic hardships, literature also reports that frequent visits to health facilities can also prompt (indirect) disclosure of HIV status which can be one of the reasons why adolescents opt to miss their hospital appointments (Kyaddondo, Wanyenze, Kinsman and Hardon 2013:S38). Adolescents do not want to be seen as different from their peers whether sick or not therefore for those on ART to keep up with hospital appointments makes them feel that they are different from others hence the

skipping of these appointments (Aurpibul, Oberdorfer, Choeyprasert and Louthrenoo 2016:232).

6.5.2 Pill Burden

Adherence to therapy among HIV infected individuals is the primary determinant of virologic suppression, disease progression and death. However, treatment adherence is seen as a major challenge for adolescents owing to numerous changes occurring during this developmental stage (Hornschuh, Dietrich, Tshabalala and Laher 2017:2).

> *"…These pills are too big and they need to have a nice flavour. Sometimes I just do not want to take them; they are too big" (18-year-old female participant).*

> *"…. This thing of nurses telling me to drink the pills every day … and every day is just too much. It's because they do not know how difficult it is to drink these big and many pills" (18-year-old male participant).*

Pill fatigue occurs over time to chronically ill people on regular medication. The individual stops taking medication because of stress and monotony of constant swallowing of pills (Levin 2012:33). In a meta-analysis of 19 randomised controlled trials of clients on ART the results indicated that the higher pill burden was associated with both lower adherence and worse virologic suppressions in both once and twice daily sub-groups (Nachega, Parient, Uthman et al, 2014:1303). In another randomized controlledtrial study done in the United States, the cohort with single tablet regimen had better viral suppression than the one with multiple tablet regimen (Scott, Magagnoli and Hardin 2016:385). Research has shown that lower pill burden leads to improved antiretroviral therapy adherence among HIV patients (Cohen, Meyer and Davies 2013:4; Nachega 2014:5).

6.5.3 Adolescent self determination

Self-determination is basically a fundamental principle of human rights law which explains that it is an individual's right to freely determine and freely pursue social, cultural and economic development (Parker 2000:1). The following are some of the

responses given by the participants after being asked whether they had disclosed that they have HIV positive status to friends and other family members:

> "…. It is my secret; I am not supposed to tell my friends" (19-year-old male participant).

> "…. My status is my secret until I am old enough. The only people who need to know are my close family" (21-year-old female participant).

> "…. Why should I tell anyone about my condition? It is not of their business". (21-year-old female participant

A study done using the Self Determination Theory (SDT) to understand the adolescents' motivations to disclose their HIV status indicated that these adolescents were motivated to disclose because of fear of stigma and previous experiences of others disclosing for them without their consent (Gillard and Roark 2013:672). Adolescents also feel that this is a way of information control and also a desire to avoid pity from significant others (Mutumba 2015:88).

> "…. Aah! my friend told her brother's wife about her HIV status and the brother's wife told everyone in the neighbourhood and my friend was discriminated. She ended up committing suicide. I will not tell anyone about my status. Those who matter in my life already know" (20-year-old female participant).

> "…My grandmother said I should not tell anyone because people will talk and would not like to be associated with you". (19-year-old male participant).

> "…When my auntie told me that my mother had told her about my HIV status, I was very sad. My mother had no business in telling my auntie about my status. Now when she looks at me it is like she is saying you are dirty". (20-year-old male participant).

> ".. I have not told my girlfriend about my HIV status because she will leave me once she knows". (19-year-old male participant).

Research has shown that self-disclosure among adolescents is a very complex and difficult decision (Madiba & Mokgatle: 2016:3; Naswa &Marfatia: 2010: 6). According to Gillard and Rock (2012:3), the accumulation of negative experiences experienced by adolescences over time seem to make them become motivated to disclose their statuses to anyone outside the close family. In a Brazilian study (Galan *et al 2015:3*), the results indicated that the adolescents said it was normal not to disclose of their HIV statuses as long as they took care of their own health. As a result, adolescents put a lot of effort into maintaining the secrecy of their status and one of the ways they use is forgoing their treatment and hence poor or non-adherence to ART results Madiba (2016:3).

6.5.4 Treatment holidays

According to Gupta and Gupta Medical Dictionary (2012:282), a treatment holiday is an interval when a patient on long-term medication temporarily stops taking the prescribed medication. However, in the case of adolescents on ART, their treatment holiday is unstructured; they decide to stop in order to experience a drug free life or to understand the effects of being on drugs (Inzaule *et al 2016*:2). In this study, treatment holidays occur in two ways, namely :(1) when one is feeling well and (2) when one is away from home due to a holiday or school trip.

6.5.4.1 Feeling well

HIV management requires strict adherence remembering to take medications throughout the client's life and lifestyle changes, coping with side effects and remembering to attend medical appointments as and when is necessary (Mburu *et al 2014*:3). However, there is a reduced stigma which follows ART use because of weight gain and reduction of episodes of illness which is interpreted as a sign of having been cured from AIDS by some patients so they stop taking their drugs (Gilbert *et al 2009*). In this study some of the adolescents indicated that they stopped taking their drugs because they felt that they were not sick but were well.

> *"...I have been taking drugs since I was five years old. I was feeling well so there was no need for me to continue. I stopped my treatment". (18-year-old female participant).*

". I did not see why I should continue taking the drugs since I had not had any problem for the past year so I stopped taking my treatment. I thought I did not need to be on treatment at all" (19-year-old male participant).

".... Why should I continue taking these drugs when I am not sick?" (21 year old female participant).

Medication adherence for chronic illnesses is a major problem not only for HIV infection. It has been estimated that about 50% of patients do not take their long-term therapy for chronic conditions as prescribed (Karda, Lewek and Matyjaszczyk 2013:5). In a study of some chronic conditions such as hypertension and diabetes mellitus done in Ghana, about 53% of patients who were on antihypertensive and diabetic drugs stopped their treatment saying that they were now feeling well Kretchy, Owusu-Daaku and Danquah (2014: 4). In another retrospective study done in Tanzania on women post-delivery the results indicated that the women had stopped taking their antiretroviral drugs because they felt well (Ngarima, Popenoe, Kilewo, Biberfeld and Ekstrom 2013:450).

6.5.4.2 Being away from home

The results of a study done in Uganda and Zimbabwe (Bernays, Seeley, Rhodes and Mupambireyi 2015:275) indicated that children and adolescents invested heavily in concealing and disguising their HIV status in order to be indistinguishable from their peers and considered normal. One of the ways the adolescents use is not to take their drugs as long as they are away from home.

"...Whenever I am away from home, I do not take my drugs. I do not want my friends or anyone else to know that I am on treatment. It is not their business" (19-year-old male participant).

".... When we go for school trips, I do not carry my drugs" (20-year-old male participant).

"...if you have gone for a journey and you are sure to come back that same day, there is no need to carry your drugs. So, when you get there something happens and you are not able to go back

home then you can miss your drugs for two days or more" (19-year-old female).

"Some studies have found an association between changes of residence and ART non-adherence (Haberer et al 2011:4). In a study done in Kenya, adolescents described a context of negative societal beliefs about HIV necessitating a lifestyle of secrecy hence they would not take their ART drugs anywhere else except when they are at home" (Kunapareddy, Nyandiko, Inui, Ayaya, Marrero and Vreeman 2014:1).

6.6 Delay in Getting to Know Own HIV Status

While maintaining open communication is fundamental in the management of the HIV epidemic, disclosure of HIV status among family members has remained a significant challenge. Disclosure of HIV status within families has been documented as essential for adherence to treatment regimes, mobilization of social support and prevention of further transmission of HIV (Kyaddondo, Wanyenze, Kinsman and Hardon 2013:3). According to the American Academy of Paediatrics, adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health including sexual behaviour (Naeen-Sheik & Gray 2005: 3). While Article 17 of the United Nations Convention of the Rights of the Child states that every child should have access to information and material from a diversity of national and international sources especially those aimed at the promotion of their social, spiritual and moral well-being and physical and mental health (WHO 2011:5). Research has shown that apart from parental illness and death, becoming aware of their HIV status is perhaps the most difficult life event the young people have experienced (Mavhu *et al 2013*:4). According to literature, the average age of getting to know own HIV status is 10 to 12 years (Mumburi *et al 2014*, Arun *et al 2009*& Biadgilign *et al 2011*) while the mean age for disclosure in this study was 10 years with a range of 5-12 years.

6.6.1. Delay in disclosure of HIV status by care givers

The defining features of late disclosure of HIV status by care givers were described by almost all the participants as shocking, very painful, traumatic and led to non-

adherence of treatment. Most participants got to know their HIV status after they had enquired from their care givers why they continued taking so many tablets while other family members were not. One female adolescent said that she asked her grandmother why she had to continue to continue taking "the asthma drugs" (the illness she had been informed she suffered from since childhood) when she was not having attacks. She said she was not given a satisfactory answer but when she threatened to stop taking the drugs that is when the grandmother informed her of what she was really suffering from. In a Ugandan study (Kyaddondo, Wanyenze, Kinsman and Hardon 2013: S13), it was found out that the common response by parents who had not yet disclosed to their children said that they were waiting for the child to mature. Because of the misinformation about the drugs they were taking, most adolescents became non-adherent to their antiretroviral drugs.

> *"…I was devastated; my world had just crumbled down. I did not know what to do. I felt that I was tired of life. I just wanted to die. I decided to stop taking the pills because already I was tired and would not see myself continuing to take these drugs daily for the rest of my life. I stopped taking my treatment". (18-year-old female participant).*

> *".. I cried… I was very hurt, I was heartbroken. I was hurting and crying for five days. My aunt was trying to comfort me, but it was too painful. She kept talking to me. She was aware that I was hurting". During this period, I threw away my tablets" (female participant; 19 years old)*

> *".. I was angry… crying…. I wanted to know why they did not tell me all this time, saying that I am still a child and I won't understand. This hurt me for a long time and I would lie to them that I had taken my treatment and yet I had flushed all the tablets down the toilet" (male participant; 18 years old).*

> *"...I felt like there is no one who loves me. It's like the world had turned on me and then I felt angry deep inside my heart. (Female participant".; 18 years old)*

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Most research participants had similar experiences, they stopped taking their treatment after getting to know their HIV statuses and they indicated that they just felt tired of continuing. This resulted in non-adherence to the lifelong treatment. Madiba (2016:2) notes that delay or non-disclosure is one of the barriers to ART adherence among adolescents mostly in resource limited settings. World Health Organization (WHO) also recognizes that delayed or lack of disclosure ultimately affects ART adherence. In a study done in Uganda the results indicated that implicating other diseases could however impact on adherence of the adolescents as it foils the understanding of the importance of adherence and subsequent consequences which are specific to HIV management (Inzaule, Hamers, Kityo, Rinke de Wit and Roura 2016:3). This could also result in anger and depression when the adolescents become aware of their condition (Inzaule *et al 2016:3*).

6.6.2 Impact on knowing status

The adolescents who visited this particular site regularly engaged in various activities and also were asked to write about their journey from the time they were informed about their HIV status. This book was named "My Hero Book". All research participants who completed their "Hero Book" described the phase of getting to know their HIV status as the biggest obstacle which cannot be removed from their journey and this was shown by a drawing of a very steep mountain. The participants reported that learning of their HIV status resulted in feelings of despair, hopelessness and a sense of total loss of control of one's life. These feelings were best summarised using the Stages of Grief by Elisabeth Kubler Ross. Kubler-Ross's theory can also be applied to individuals' own grief in response to a differing expectation of their life. These stages postulate a series of emotions experienced by terminally ill patients or by someone who has lost a loved one. The five stages are denial, anger, bargaining, depression and acceptance. Grief according to the Oxford Mini Dictionary and Thesaurus (2008:298) is lamentation, anguish, desolation, mourning and misery while Neimeyer (2001:3) defines it as sorrow and the emotional suffering caused by loss. In this case it is the loss of the HIV negative status acquiring a positive status. This is what Zeligman and Wood (2017:20) refer to as chronic sorrow. This allows for conceptualisation of chronic sorrow as grief, the one that follows an HIV diagnosis. The emotional responses of these adolescents revolved around anger and bargaining stages.

Denial

When the adolescents got to know that they were HIV positive, they reacted in different ways.

I could not believe it.....

Why me? I am only a child. What have I done to deserve this?

It was hard...

Denial was evident in response to the diagnosis as one adolescent said....*it was the first time I heard that I have HIV,* while another adolescent said *I felt happy like I did not have a problem.* By so doing the adolescents were erasing reality, the reality that they were infected with HIV.

Anger

Adolescents in this study revealed considerable anger and that they stopped taking their drugs because of the reasons they had been told before by their care givers such as asthma, heart problems and many others. These emotions are understandable considering that all those interviewed in the study, they got to know their about their HIV status when they were still very young (around 11 to 12 years old) and had not yet had any sexual relations nor were they involved in drug injection activities.

I was angry, angry at everyone.

I did not want anyone to treat me like I was different from the others.

I did not want pity from anyone so I closed myself away and in the process stopped taking my drugs.

Bargaining

Most adolescents in the study associated HIV with a death sentence. They bargained with God that if only their condition could be changed.

Please God I am only a child I have done nothing wrong.

I do not want to die can I please have another chance. I want to continue with school and I do not want to die.

Depression

After the initial denial of their HIV positive status had worn off, most of the adolescents in this study said they experienced depressive feelings after the realisation that it was true that they were infected with HIV. Because currently there is no treatment for HIV, adolescents said that they felt that death was imminent. They became depressed and stopped taking their drugs.

I was scared because I was going to be sick so I just stopped taking my pills so that I just die.

How am I going to look like? It's better to die

It's so shameful. What are people going to say if they know I have HIV?

Acceptance

In the end all the research participants interviewed seemed to accept their condition.

I have to learn to accept it and try and take care of myself.

It has happened I have to accept it.
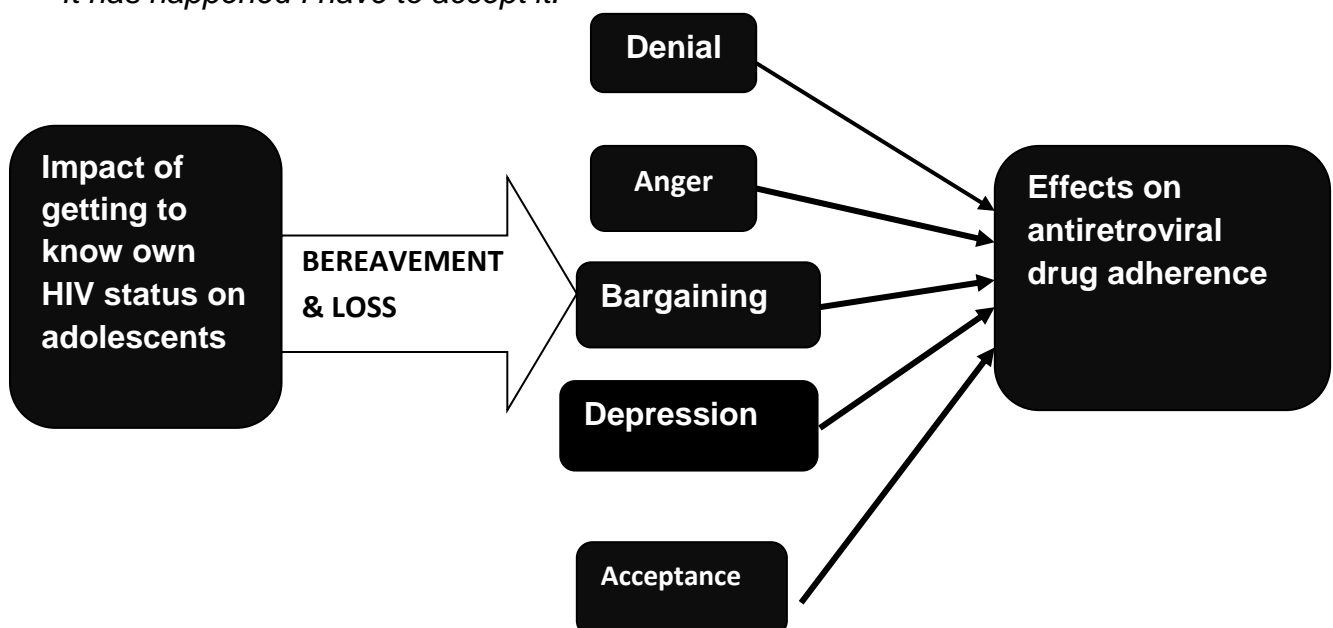
Figure 6.1: *Impact of getting to know own HIV status on adolescents (adapted from Kubler-Ross's stages of grief)*

The effects of getting to know own status also results in withdrawal from people and treatment as indicated by one study participant. According to Mavhu *et al (*2013:3), their adolescent research participants indicated that they at times stop taking their treatment because they are depressed and that they just wanted to die since HIV is not treatable. One study found increased problems among adolescents who knew their HIV status. They said there were significant scores on the internalizing behaviour problems such as anxiety, depression and withdrawal (Pantelic, Boyes, Cluver and Meinck 2017:6). Though the adolescents want to be informed about their status, they prefer to control self-disclosure of their HIV status (Madiba and Mokgatle 2016:1).

6.6.3 Blame game

According to the Penguin English reference dictionary (2002:137), blame is defined as placing responsibility on someone for a wrong doing. Inaccurate understanding about HIV transmission, misinformation and misperception has led to stigmatizing attitudes with regard to HIV and AIDS. Literature has it that fear of stigma, fuels the HIV and AIDS pandemic by creating a culture of secrecy, silence, ignorance, blame and victimization (Pantelic, Boyes, Cluver and Meinck 2017:6). HIV and AIDS are perceived as conditions of shame and PLHIV are seen to be solely responsible for their misfortune (Akande *et al* 2011:3). Because most adolescents in this current study were born infected, they blamed someone for finding themselves in this predicament. However, some of these adolescents were involved in reckless behaviours such as unprotected sexual activities which could lead to them infecting other people but still they continued to blame others except themselves. Besides blaming someone for infecting them, the adolescents also blamed other people for such issues as poor drug adherence and missing their clinic visits.

> *"..Why should I continue taking the pills? What did I do to get this infection? It was my father's fault. He had many wives and was a womanizer and now look at me …I am suffering because of him"* *(21 year old male participant).*

> *".When my mother reminded me to take my medication, I snapped at her, It was her fault that I was born positive and now suffering"* *(19 year old female participant).*

"….I asked my mother why I was the only child who had HIV in the family and the only one whose father had died. It was her fault that I was in this predicament" (19 year old participant).

According to Satpathy (2003:69), the blame game perpetuates internal stigma and internal stigma results in one not taking responsibility of their own health. In this case the participants did indicate that since they felt that it was not their fault that they got infected, they at times forgo taking their drugs resulting in poor adherence of the drugs. The effects of blame and not taking drugs as prescribed could be seen on one of the participants (21years old) stunted growth, had a slur in his speech and poor gait. The participant indicated that he has been in and out of hospital because of poor adherence. Internalized stigma which (comes as a result of the blame game) according to (Pantelic *et al* 2017:2) is a key risk factor for negative outcomes among HIV infected adolescents including non-adherence to antiretroviral treatment, morbidity and mortality.

6.7 Stigma

Stigma has been defined as the phenomenon whereby an individual with an attribute which is deeply discredited by their society is rejected (Mac Henry, Nyandiko, Scanlon, Fischer, McAteer, Aluoch, Naanyo and Vreeman: 2017:2) while Earnshaw and Chaudoir (2009:2) define it as the social discrediting and devaluation of HIV infected people. The concept of stigma has been studied before in relation to other diseases such as leprosy before the advent of HIV and AIDS. According to Mac Henry *et al* (2017:2), stigma acts as a barrier to prevention, treatment and care because of the feelings of shame, blame, guilt and social isolation. Stigmatising attitudes whether experienced or perceived or internalized are important issues of concern to people who have chronic incurable diseases such as HIV. In this current study, participants indicated that stigma and stigmatising acts and attitudes played a major role in their lives and resulting in poor drug adherence experiences. McHenry *et al* (2017:1) concurs that stigma not only impacts on adolescents' psychological well-being and mental health but also on non adherence to ART and nondisclosure of status.

6.7*.1 Self Stigma*

Stigma has adverse effects on the disease progression as it can lead to non-adherence (Close 2013:322) and non-disclosure (Levin 2012:43) especially when there is a need to disclose to sexual partners. According to McHenry *et al* (2017: 3) stigma shapes all aspects of prevention and treatment. Self stigma according to Woolett (2013:23) is when individuals take on perceived stigma of others and begin to stigmatise themselves. This is very common in adolescents as they are also struggling with self image and identity issues. Self stigma can cause lasting effects on the adolescent's socio-psychological functioning, including denial of their diagnosis which in turn will affect drug adherence.

> *"…I feel sad because I am different from others; I cannot do what they do and cannot play with them" (20 year old female participant).*

> *"….I always think that people know my status so whenever they look at me I always assume they are feeling sorry for me"(19 year old male participant).*

Woolett (2013:23) asserts that as adolescents concentrate on non-disclosure, they are perpetuating self-stigma by constantly being paranoid of what the unknowing people think of their status. Mutumba (2015:87) also says that adolescents use self stigma as a coping mechanism and this has different implications to their well-being. Literature says stigma was closely related loss of social and economic support and it also includes internalised negative feelings about oneself (McHenry 2017:4). In the same study the study participants identified treatment related impact of stigma including non-adherence, nondisclosure and increased mental health problems.

6.7.1.1 Desire to keep diagnosis secret

With self-stigma comes the notion of not wanting to disclose own HIV status. Disclosure of own HIV status in adolescents has been seen to increase condom

negotiation and use, improves ART adherence and reduces levels of unprotected sexual activities (Madiba and Mokgatle 2016:1). The following are some of the responses from the participants regarding the need to keep their HIV status a secret:

> *"...You must only tell your family members who will not tell other people outside because others are gossipers and will tell other people that this child is HIV positive"* (female participant, 19 years old).

> *".It must be a secret. It is not something that you can just tell everyone. People outside my immediate family do not know. (male participant" 18 years old).*

> *" … It's my own secret. I am not supposed to tell my friends. (male participant" 20 years old)*

> *"…My status is my secret and will remain my secret until I am older. In most cases, it is a secret; the only people who need to know are your family". (male participation; 19years).*

> *"…I asked myself that if I'm going to tell them about my status, what's going to happen, so I decided to keep quiet. (male participant" 19 years old)*

Disclosure of one's HIV status is considered an important health promoting support strategy that can avert further HIV transmission(Arrey, Bilsen, Lacor and Deschepper 2015:3).In adolescents ,disclosure is seen to impact positively on self care behaviour and psychosocial well being (Okawa, Mwanza-Kabaghe, Mwiya, Kikuchi, Jimba, Kanaksa and Ishikawa 2017:326). Negotiating when and how to disclose chronic in life threatening diseases is never easy neither for the health care professional nor for the diagnosed patient and this situation becomes even more complicated if that patient is an adolescent(Arrey*et al* 2015:3). In the case of HIV, the disclosure of a positive diagnosis is even more than any other chronic diseases, problematic because of its discredited and discrediting aspect (Madiba and Mokgatle 2016:2). Adolescents maintained secrecy in order to be accepted by their

peers but also to protect themselves from stigma and isolation. In a study done in Kenya, the results showed that most adolescents were reluctant to disclose of their status because they considered it to be their secret (Abubaker *et al* 2016: 2).

6.7.2 Health Care Stigma

Health care systems are crucial in HIV management and health care providers play an important role in HIV management. In Zimbabwe, specialist clinics have been set aside at tertiary hospitals and treatment zones are found at local clinics for HIV infected people who are on ART. In addition to the zones and specialist clinics, a special booklet (card) with a different colour from the normal booklets (card) which are used by all other clients with different conditions was designed specifically for the HIV management (see figure 2 below). According to the research participants, they viewed this different coloured booklet as a discriminatory tool which made it very easy for other people to identify them and in turn stigmatise them because of their HIV status. As a result of this identifying mark, the specialist clinics and the special zones the respondents said they often missed their clinic appointments because of fear of being identified by friends as HIV sufferers. A study in Uganda reported stigma and discrimination at health care facilities as the main deterrent to drug adherence for adolescents(Nabukeera-Barungi*et al* 2015:2).

The National Policy on HIV and AIDS's guiding principle 2 states that human rights and dignity of people living with HIV should be promoted and protected; discrimination and stigmatisation should be avoided as far as is consistent with the rights of society. At the same time, the constitution of the country protects the right to health for everyone, section 76(2) provides for specific protection of the right to have access to health care for vulnerable groups. These include people living with chronic conditions including HIV. The government must facilitate access to or create an enabling environment for everyone to access the service. It must remove all barriers that are capable of impairing the enjoyment of the right to health care.
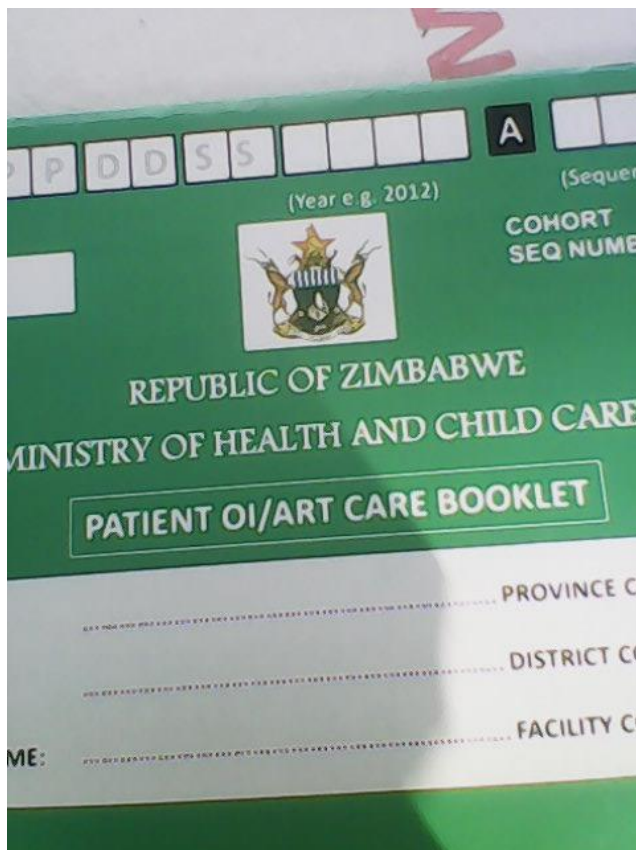
Figure 6. 2: Booklet (card) used by HIV infected clients on ART in Zimbabwe

6.7.3 Stigma at Boarding Schools

The advent of HIV has caused a challenge to the education sector (Kelly 2003). In response, the governments have moved to develop education sector HIV policies whose scope of application covers all the students and employees. However, the policies have predominately revolved around legal issues and HIV in general (Mutumba 2015:88). Little attention is paid to the needs of pupils living with HIV, a problem compounded by the fact that their special needs are largely unknown because of non disclosure of their HIV status. In the current study, some of the study participants expressed the following sentiments about stigma at boarding schools;

> *"…At my school we were sharing double beds so as a result everyone would see what one would be doing. As a result, it was difficult for me to take my pills because I was afraid my classmates*

would think that I had AIDS and that I was dying since it is how we were taught by our science teacher. I stopped taking my pills and became sick" (18 year old male participant).

"….My grandmother told our hostel matron about my condition and from then she treated me differently. She would shout at me in front of my friends if I forgot to take my pills and would say that I would die. Because of this my friends disserted me and I had to leave school because it was too much for me" (21 year old female participant).

"….At our school there was no place to keep my pills so I moved around with them in my bag. One day someone stole my bag in the hostel and they threw my pills on the floor. I could not pick them up because some knew what those pills were. I stopped taking my pills and went home and never came back to school again" (19 year old male participant).

"…..I was supposed to go to a boarding school but I refused. I told my aunt that they would be no space to hide myself when taking my medication" (20 year old male participant).

Stigma has been shown to impact on ART adherence especially among adolescents in boarding schools (Mutwa et al; 2103:1, Adejumo *et al* 2015:2 and Wolf *et al* 2014:2). These findings are similar to other studies which have reported the challenges faced by adolescents living with HIV in schools including discrimination, taunting, bullying or gossiping from their peers, and educators suggesting that there is an urgent need to sensitize and train educators about the special needs and rights of these children in school settings. In addition, there is a need for a balanced approach in the designing of prevention messages as such current messages as "AIDS Kills" are discriminatory. According to Mutumba (2015:88) adolescents at boarding schools went to great lengths to avoid acts that could arouse suspicions about their status such as avoiding noisy pill bottles, not taking their medication in-front of peers and by not associating with known HIV positive peers who had disclosed their statuses.

6.7.4 Stigma at home

"…When I got sick, I asked my sister to go and collect my refills from the hospital but she refused because she said that people would think that she was HIV infected" (18 year old female participant)

"...I stay with my grandmother and my nephews whose parents are in South Africa. Because my nephews know that I have to eat before I take my pills, they hide the food and tell me to go and get from the graves were my parents are. If my grandmother is not around, I do not take the pills because I will not have food. I told the nurses who in turn talked to my grandmother about what I go through during her absence at home" (18 year old female participant).

"….Both my parents died but they left me a house. My uncles have taken the house from me saying I will die soon so I have no need of the house. Because of the ill treatment, I wish God would just take me. Yes I collect my pills every month but I do not take them most of the time because of the situation at home" (20 year old male participant)

"...My aunt tells me to go away....your mother died of it and now you want to bring it to me, you are disturbing me. I felt like she was being harsh on me because of this disease so I just stopped the drugs so that I can also die because of my disease"

The family environment has been noted that it can influence adherence. Supportive family environments according to Mburu *et al* (2014:3) help the adolescents to deal with stigma and improve drug adherence while those families not so supportive perpetuate internal stigma. A study done in Uganda revealed that acts of stigma and discrimination included separation of plates, utensils and taunts by other children about their HIV status (Mutumba *et al* 2015:6). Some studies have reported that stigma at home has forced some adolescents to stop taking their

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drugs because of lack of support from the home environment (Kunapareddy *et al* 2014: 6).

6.8 Disability (visual Impairment)

The visual impairment is a term experts use to describe any kind of vision loss, whether it is someone who cannot see at all or someone who has partial vision loss. Visual impairment in this current context will be taken to mean someone who cannot see at all. The visually impaired have limited access to health care services and related information which can result in serious setbacks against properly taking medications.

6.8.1 Unable to read instructions on drug containers

From the observations made by the researcher, all the private pharmacies , private hospitals and public hospitals visited dispense drugs in envelops or bottles with instructions which can only be read by people with no visual impairment regardless of whether the patient was visually impaired or not. Literature has reported that many visually impaired clients failed to read instructions on the drug containers resulting in them either stopping to take the drugs completely or either under or overdosing themselves (Koo *et al* 2016; Zhi-Han, Hui-Yin and Makmor-Bakry 2017).

> *"...At times I could not remember the number of pills I was to take from each bottle but I could not read the instructions on the medicine bottles" (21 year old male visually impaired participant).*

> *"....I just ended up not taking the pills because I did not want to kill myself by taking too many of them" (21 year old male participant).*

> *"....I wish the instructions were written in Braille so that I could read on my own. I cannot ask someone to always read for me, I need to be independent" (21 year old male participant).*

6.8.2 Difficult to determine the correct dose to take

> *"....Since I could not read the instructions written on the bottle, it was difficult for me to know if I was taking the right doses. One day*
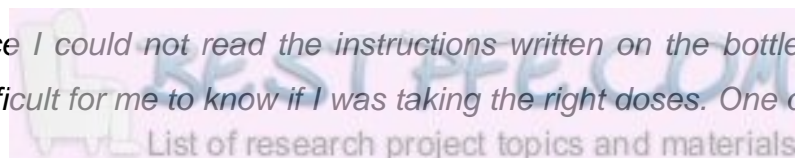
a small pill fell from my hands and I could not find it so I just drank what was in my hands" (21 year old male participant).

".....I am at a boarding school so I cannot ask anyone to read for me. HIV is my secret so no one should know" (21 year old male participant)

In a study done in Saudi Arabia, the most common challenges encountered by visually impaired clients were linked to drug identification (75%), dose recognition (82%) and identification of expiration date (92%) (Kentab, Al-Rowiali, Al- Harbi, Al-Shammari, Balhareth and Al-Yazeed 2014:3). In another study done in India (Naik, Cacodcar and Dhupdale 2018:4), in addition to the above challenges the following challenges were also identified: spillage of medication, difficulty in using liquid medications, consumption of wrong medication and wrong dosages.

6.9 Lack of support

Social support is the help that a person receives from their social networks. Family members and peers can provide support to people living with different types of chronic illnesses including HIV. Chronically ill adults who have good family support have been seen to have better medication adherence (Rosalind, Heisler, Janevic *et al* 2013:3). Family members have been shown to give support by reminding the clients to take their drugs and accompanying them to get refills from the clinics (Mavhu *et al* 2013: 5). However, it was also discovered in the same study that some family members found it difficult to assist the adolescents living with HIV because they will not have disclosed their status.

6.9.1 Poor family support

Many of the research participants were orphans and were staying with grandparents or other significant relatives. They reported that they had poor support from their families. In a study done in Zimbabwe involving adolescence living with HIV (Mavhu *et al* 2013:4), the results showed that most of the research participants indicated that they were being treated differently in their households. They indicated that they were being discriminated upon because of their HIV status, were given a lot of work to and barely had time to do their school work. In another study done in

South Africa, the results showed that adolescents living with HIV and stayed with their parents had better ART adherence than those who stayed with relatives (Eyassu, Mothiba and Mbambo-Kekana 2016:693).

> *"...I used to stay with my maternal grandparents but had to run away to go and stay with my paternal grandparents. I was given a lot of work to do, was not allowed to share utensils with other children because they said I would infect them. Most of the times I would be so tired that I would not remember to take my drugs. I had to run away" (20 year old male research participant).*

> *"... I dread going home; my support is among my friends at the clinic. The situation at home forces me not to take my drugs so that I just die. It is tough at home" (19 year old female participant).*

> *"...When I ask for more food because the drugs make me hungry, I am denied and I just do not take my drugs because I will be hungry" (18 year old female participant).*

6.9.2 Health care support

Health care system support to its clients is fundamental to better therapeutic outcomes. However, at times the health care systems become barriers to better therapeutic outcomes. Some of the factors which have been found to obstruct medication adherence include poor treatment literacy, lack of follow-up of patients, dissatisfaction about the quality of the ART services provided, lack of confidentiality and long waiting queues.

> *"... At times I was not sure how I was supposed to take my pills. The nurse just said I will get instructions from the one who was going to give me drugs which did not happen. My grandmother had to go to the clinic to get more information and I realised I had not been taking my drugs well because I did not have the correct information" (19 year old male participant).*

Lack of confidentiality has been sighted as one health care impediment to drug adherence. This was sighted in the current research by study participants who

particularly did not like the colour coded booklet for use by people on ART and the specialised treatment zones.

> *"...I cannot come to the clinic as frequently as is required because once people from my community see me they will know I have AIDS. I wish we could all be consulted as individuals not to be segregated" (18 year old male participant).*

> *"...I hate going to the clinic. Once people see me carrying this green book they know I am on ART. So I miss my appointments most of the time because I feel the nurses are not worried about our health. If they were we could all be having the same book despite our illness" (18 year old female respondent).*

6.9.3 Labelling

Language is at the core of the network of resources that we draw on in describing the world and relating to others and as such HIV and AIDS cannot be separated from the ways in which we think about it, talk about it and act on it. The earliest television campaigns about HIV in SSA included an illustration of a coffin in addition the caption "the new killer disease is here" (Joffe 1995:3).In SSA, HIV is mainly associated with sexual immorality. Consequently from early on in the epidemic the language used in the SSA region to talk about HIV and AIDS to the public was that of warning people about the killing disease and hence had a label of 'immorality' and 'kills'. This left people confused and have since associated HIV infection with immorality. In Zimbabwe some euphemism include the term 'boarding pass' and this implies that HIV is a boarding pass to death. The Oxford Mini Dictionary and Thesaurus (2008:376) define labelling as putting in a specified category while the online dictionary defines labelling as tagging, classifying and grouping. In this current study the adolescents feel that they are being labelled by both the health care workers and *the community at large.*

> *"…Nurses always say that adolescents are difficult, they do not listen so already they have labelled us. As a result everyone thinks we are all difficult and yet some are not" (21 year old female).*

"...One of my friends I used to come to the clinic with has since stopped coming because a red sticker was put on their file indicating that they were not taking their drugs well. He tried to explain to the nurses what problems he was facing but no one listened to him. He was told adolescents always have stories so yours is not different from the others. Now he has stopped taking the drugs because his supplies have run out and he cannot come to the clinic because no one listens to him" (18 year old male).

"...First and foremost, people should know that I am a person. Yes I am not well but calling me names because of illness.... haaa no"!(18 year old male participant).

6.9.4 Poverty

According to the Oxford Mini Dictionary and Thesaurus (2011:508), poverty is defined as destitution, hardship and neediness while the online dictionary defines poverty as a state or condition of having little or no money or means to support. According to FAO, "*HIV and AIDS like all communicable diseases are linked to poverty. The complex relationship between poverty and HIV and AIDS is central to an understanding of the impact of the epidemic. The relationship is bidirectional in that poverty is a key factor in transmission and HIV and AIDS can impoverish in such a way as to intensify the epidemic itself*"

Most of the respondents in this study were orphans and they reported that they sometimes failed to take their medication because they are poor, are being looked after by their grandparents or relatives who were themselves struggling economically. The respondents also indicated that they at times had no food to eat hence they could not take their medication.

"... I do not work, my grandparents are not employed either and the pension they get is barely enough to support all of us. At times

we only have one meal per day so as a result I cannot take my pills" (20 year old female respondent).

Lack of money for transport to the clinic was also reported as a barrier to get to the clinic. Literature has it that transportation costs can also compromise both ART adherence and access to care (Tuller, Senkungu and Weiser 2014:3, Schlenker and Gilbert 2014:2 and Ross Watson 2015:5).Other researchers in urban Ethiopia described difficult with access and cost of transport as a barrier to ART adherence.

"...At times I have to walk to clinic so that I do not stay for too long without taking my drugs and the clinic is very far. I cannot afford the taxi fare; I need something close to R80 per visit. I last had my drugs some two months ago" (18 year old male respondent).

Food insecurity has emerged as a major and important barrier to ART adherence according to Weiser *et al* (2014). Their research found out that food insecurity has contributed to ARV non-adherence or intermittent treatment episodes because; ARVs increased appetite and led to intolerable hunger in the absence of food, side effects of ART were more pronounced in the absence of food, competing demands between costs of food and medical expenses led most people to default in their treatment. Jimmy-Gama *et al* (2014:135-136) reported that challenges to youths uptake of ART in Malawi included the unavailability of food a factor also identified in the Democratic Republic of Congo. In the study, one respondent indicated that she took her medication well when the grandparents are around but once they are away, she is denied food by her cousins hence she foregoes her treatment.

"..Istay with my grandmother and cousins so when my grandmother is around, I take my ART every day. When she goes away, the cousins hide the food from me because they know I need to eat before taking my drugs and after. If I ask they tell me to go to the graves were my parents are and get the food there" (18 year old female participant).

6.10 Religious beliefs

Religion according to the Oxford Mini Dictionary and Thesaurus (2008:554) is a cause, principle or system of beliefs held to with great enthusiasm or zeal and faith. While the online dictionary defines religion as a shared collection of transcendental beliefs that have been passed on from believes to converts that are held by adherents to be either based on formally documented doctrine or established cultural practices. Higher levels of religion have been associated with less psychological distress, less pain, greater energy and better social functioning especially after a terminal condition diagnosis such as HIV. However, religion can also worsen outcomes because of potential reliance on God and rejection of antiretroviral therapy and also of the view that HIV is a punishment from God for sinful lifestyles (Szaflarski 2013:325).

6.10.1 Belief in faith healing

Some participants in the study indicated that they had believed that since God had created them, He would not turn against them but would heal them.

> ……*I am a strong Christian, so at one time I went to my pastor and told him my problem. My pastor said he would pray for me because I was demon possessed and there was no need for me to continue taking the tablets because after the prayer, I would be healed. I believed him and after he had prayed for me, I stopped taking my tablets and did not even come for my review. After two months I became very sick, my mother had to force me to come to the hospital. I was admitted for a month and I received a lot of counselling during that period. I will never stop taking my pills again. I think some of the pastors have no knowledge about how HIV affects the body.*

Religion may intersect with antiretroviral drugs in ways that may challenge adherence. PLHIV from San Diego exhibited poor adherence because they believed that since God created everything, God will not turn His back on them so they participated regularly in religious rituals such as prayer and meditation at the same time not taking their antiretroviral drugs (Vasquez 2015:3). The results of a

study on hypertensive patients indicated that spiritual attachments of patients with a supreme being potentially increased their trust in the expectation of divine healing instead of adhering adequately with their anti-hypertensive medications(Kretchy, Owusu-Daaku and Danquah 2013: 2). A study done in Zimbabwe (UNAIDS 2016), the results noted that people who were on treatment, stopped taking their drugs because of advice from their faith healers. One woman in this study had this to say: "*I trusted my pastor, and after he prayed for me, I truly believed God had healed me so I stopped taking my treatment. I became very sick after a month. I went back to the hospital and stayed for about a month in hospital. Yes I continue going to church but will never stop taking my drugs again. It is about my health and life*".

6.11 Conclusion

Descriptive phenomenology was used to explore and describe the lived experiences of HIV infected adolescents regarding drug adherence. Through this exploration and description, knew knowledge of the resultant phenomena was generated resulting in the following themes:

- Treatment fatigue.

- Delay in getting to know own HIV status.

- Stigma.

- Disability (visual impairment).

- Lack of support.

- Religious beliefs.

These six themes led to a deeper understanding of the phenomenon of lived experiences of HIV infected adolescents regarding drug adherence. In chapter seven the concept of wholeness that emerged from the themes and supporting categories are discussed in relation to nursing and non-nursing theories.

CHAPTER 7

RELATING EMERGENT CONSTRUCTS TO EXISTING THEORIES

7.1 Introduction

In the previous chapter, chapter six, the researcher presented the data analysis of the study. In this chapter as recommended by Wertz (2011: 160) "wholeness" is discussed as the single most encompassing and general structure of the lived experiences of ART adherence by HIV infected adolescents. The concept of "wholeness" arose from the interpretation of the themes and categories derived in chapter six in line with recommendations from Wertz (2011:160).

The Oxford Mini Dictionary and Thesaurus (2008:674) define wholeness as a complete system made up of parts. Neuman and Fawcet (2011:10) explain that wholism or wholeness is both a philosophical and a biological concept implying relationships and processes arising from wholeness of dynamic freedom and creativity in adjusting to stressors in the internal and external environments. While the Penguin English Dictionary (2002:1609) further explains a whole as a coherent system or organisation of parts. In other words wholeness in the context of the adolescents and drug adherence is an arrangement that the adolescents hopes to achieve despite the stresses brought about by being HIV positive by continuing taking drugs as prescribed and maintaining a healthy lifestyle.. However this understanding of wholeness should not be taken to imply that nothing has been lost as a result of the adolescents getting to know their HIV status, but rather that the adolescents are able to bounce back by using the systems provided and adhering to their ART drugs as indicated after a traumatic experience. In other words embracing wholeness should be perceived to involve adjustments or transformations a person or group makes in response to actual undesirable changes and their consequences on their ways of life. I suggest that the wholeness should be understood as on-going transformations the adolescents underwent that enabled them to cope and live their changed realities following the HIV diagnosis.

Understanding wholeness is critical to recommend appropriate interventions that may address the unmet needs of individuals who may encounter similar lifelong conditions. The researcher arrived at wholeness after working through several

layers of individual aspects of the experiences of research participants (data) during both idiographic and nomothetic phases of data analysis. Wholeness, the unifying concept threads through various categories and main themes as explained in chapter six. In this chapter, the research findings will be discussed in terms of Betty Neuman's Systems Model (NSM) (Neuman 1970; Neuman and Fawcett 2011) an established theoretical framework in nursing. This discussion and integration are consistent with the "theory generating and development" aims of qualitative research which according to Creswell (2014:65) begins with the researcher gathering data, categorising the data into themes and eventually coming up with generalisations that are compared with existing knowledge in literature through a reflective and interpretive approach. This largely inductive approach results in general explanations which the researcher can use to challenge existing theories and inspire new theory development (Creswell 2014:65). Relating study findings to existing knowledge also helps to demonstrate transferability of results which again is an indication of the trustworthiness of the study results (Creswell 2014:206).

The concept "wholeness" is thus intended to serve as a point of reference through which the study findings can be supported and further articulated to increase understanding of the ART adherence experience and to promote transferability of the study findings. The notion of wholeness is central to adolescents' very existence and wellbeing. Adolescents responded in various ways (refer to data displays chapter 6) with some battling to overcome associated stigma of being HIV infected, while others learned to cope with the realities of the illness and recovered from the negative effects of the of the community around them. In addition to the structure that the NSM provided, the different stimuli demanding the individual to becoming whole as revealed by the current research, are also theoretically illuminated using other relevant frameworks from the disciplines of social-psychology and psychology.

7.2 Relating wholeness to existing theories

Relating the data to existing theories is consistent with the views of Creswell (2014:65-66) who says that in qualitative studies such as this current one, where the aim is to arrive at broad description and explanation of a particular phenomenon relating the study findings to existing models helps the researcher to arrive at some

point of coherence; interconnecting thoughts and linking parts to the whole. To further explain the findings the all-encompassing concept of wholeness is discussed in relation to three theoretical constructs: Betty Neuman's Systems Model, Berker's Labelling theory and Elisabeth Kubler-Ross's Stages of Grief. A discussion of the prominent features of each theoretical framework and how they contribute to a better understanding of the wholeness process in the context of drug adherence of HIV infected adolescents follows.

7.2.1 The Neuman's Systems Model (NSM)

As said before, the NSM is a well- researched and utilised model in the discipline and practice of nursing. The broad nature of the model accommodates all the themes and categories arrived at during data analysis.

7.2.1.1 Introduction and overview

The Neuman Systems Model is a unique open systems based perspective that utilises a holistic approach to client care (Miner 1995:3). Being universal in nature, the Model is open to creative interpretation and is widely used throughout the world as a multidisciplinary, wholistic and comprehensive structure as a guide for excellence in nursing practice (George 2014:344). The central focus of the Neuman Systems Model is basic survival. The key components are the client system composed of the physiological, psychological, socio-cultural, developmental and spiritual variables that interact with the internal and external environments and the three prevention-as-intervention levels (primary, secondary and tertiary) with the purpose of achieving optimal wellness (George 2014:363). The client in the NSM is viewed as an open system in which repeated cycles of input, process, output and feedback constitute a dynamic organisational pattern (George 2014:363).

The lines of resistance protect the basic structure and become activated when the normal line of defence is invaded by environmental stressors (George 2014:364). The lines of resistance are the last boundary to protect the basic structure (Reyes, Rico, Rimas and Rosales 2008). If the lines of resistance are effective, the system will rebuild but if the lines of resistance prove ineffective, death may occur (George 2014:366). The normal lines of defence represent the client's typical wellness level. The normal lines of defence indicate the system's stability over time whereas the

flexible lines of defence represent the initial response system to stressors (George 2014:366). Any stressor may invade the normal line of defence when the flexible line of defence offers inadequate protection (George 2014:365). Therefore, since Neuman believes that nursing is concerned with the wholeness of a person, any invasion of the system affects this wholeness hence the effort to try and bring back this completeness of the affected being. In this research, NSM is used because of its appropriateness of the condition under discussion that of HIV infected adolescents' lived experience regarding ART adherence.

7.2.1.2 The NSM longevity and currency

In 1997, the NSM guided Mill, study in addressing the prevention of stress related problems in HIV infected women attending an HIV clinic in Canada (Mill1997:13-26). The researcher concluded that the NSM provided a good framework upon which to test the interventions. Tobacco smoking according to Rayan (2016:3) is one of the greatest health threats in the world and in Jordan in particular. The researcher demonstrated that the NSM provided a useful framework to systematically assess the risk factors for smoking and providing appropriate preventive interventions among adolescents in the Jordanian community.

In 2017, Ahmadi and Sadeghi explored the feeling of wholeness of clients with multiple sclerosis in Iran using the NSM. The researchers concluded that the NSM provides a credible framework through which the delivery of care and information can be organised for multiple sclerosis patients; a chronic disorder with no definite cure (Ahmadi & Sadeghi 2017:5). In a study done in Brazil on men with Laryngeal cancer (Peres, Gimenez, Bezerra, Ribeiro, Carvaiho& Araujo 2017:3-7), the researchers indicated that the NSM model helped them to manage the condition through dialogue. The men according to the researchers were dejected and had lost the purpose of life but through dialogue advocated for by the NSM, they slowly began to feel whole.

Pierce and Hutton (1992:5) used a case study to demonstrate the application of the NSM with HIV positive clients. In another study involving HIV infected clients, Flaskerud (1992:1-5) used the model of primary, secondary and tertiary prevention to plan for the care of these clients so that they could feel whole again.

These examples demonstrate the applicability of the NSM in practice settings including its ability to cross various populations and settings as well as its usefulness in both quantitative and qualitative research. The NSM has the capability of embracing the emerging concepts in health care and has the potential to provide a strong basis for health care practice in the next century (Mill 1997:14).

7.2.1.3 Assumptions of the Neuman System Model

Polit and Beck (2017:413) explain assumptions as principles considered as being true that a researcher uses to ground conceptualisation, conduct analysis and document a study. Assumptions are also considered 'truths' foundational to theory and research and which are accepted as such by members of these communities without having to proof their 'truth'. The NSM is considered a systems model and the main focus on a systems model is on the interactions of the parts or subsystems (Potter and Perry 2012:40). According to Hannon-Engel (2008:126-127), systems theory allows for the conceptualisation of complex human systems to be described more simply to offer a foundation from which to examine the intricate multi-faceted and non-linear processes of being a human being. The assumptions of the NSM are as follows:

- Each client system is unique, a composite of factors and characteristics within a given range of responses contained within a basic structure.
- Many known, unknown and universal stressors exist. Each differs in its potential for disturbing a client's usual stability level.
- Stressors disturb the normal equilibrium.
- Man is a composite of the interrelationship of the four variables (biological, psychological, socio-cultural and developmental) which are at all times present.
- Each client system has evolved a normal range of responses to the environment that is referred to as a normal line of defence. The normal line of defence can be used as a standard from which to measure health deviation.
- When the flexible line of defence is no longer capable of protecting the client system against an environmental stressor, the stressor breaks through the normal line of defence.

- Primary prevention relates to the general knowledge applied to client's assessment to identify stressors before they occur.
- Secondary prevention relates to symptomatology. These are interventions generally initiated after an encounter with a stressor.
- Tertiary prevention relates to the adaptive process as reconstitution begins and moves back towards primary prevention. These are interventions initiated after treatment.

The participants interviewed in this current study were all unique in their different ways; each reacted to stressors in their unique ways and would bounce back to full health as expected given their conditions. Hence the assumptions of the NSM were relevant.

7.2.1.4 Metaparadigmatic concepts of nursing in relation to the NSM

According to Masters (2012:3), a metaparadigm is the most global perspective of a discipline while Parker (2001:5 and Fawcet (2005:4) define the concept as a framework for a discipline including the discipline of nursing that sets forth the global phenomena of interest and the propositions, concepts, principles as well as methods of a discipline. The Metaparadigmatic concepts are very broad and general and are intended to reflect agreement among members of a discipline about what constitutes the field of study of that particular discipline. It offers a platform upon which practitioners can develop theories and conceptual models to explain phenomena central to their practice (Alligood &Marriner-Tomey 1997:224, Parker 2005:5). While debates continue as to what should be included as being central to the discipline of nursing, most scholars agree that the central concepts of the discipline deals with are person, environment, health and nursing (Parker 2001:6; Fawcet 2005:6; Masters 2012:3). In the subsequent section these four concepts are discussed within the assumptions underlying the NSM, thus providing for the congruent structuring of the current study findings using the tenets of the NSM.

Neuman regarded the concept of a person as an individual, family, community or a society. The client is seen as an open system that works together with other parts

of its body as it interacts with the environment (Neuman and Fawcet 2011:9). The client system according to the model composes of five variables namely; physiological, psychological, socio-cultural, developmental and spiritual (George 2014:34, Knight 1990:2). These five variables function harmoniously and are stable in relation to internal and external environmental stressor influences (Fawcet 2011:5). The five client systems variables are within the basis structure as well as within the flexible line of defence, the normal line of defence and the lines of resistance (Fawcet 2011:5). By assessing the effects of all client system variables in interaction with the environment, the client system's health status becomes known and clarifies for the care giver appropriate use of the three prevention strategies as intervention modalities to facilitate an optimal client wellness condition (George 2014:34, Knight 1990:2). In the context of the current study, the person refers to the HIV infected adolescents, the local community including the health care providers who were present as the adolescents struggle with ART adherence.

The environment in the NSM includes internal and external factors that impact the client (George 2014:346). The environment has the potential to be positive or negative and can affect the client's reaction. The environment is seen as a crucial aspect in the NSM (Neuman and Fawcet 2011:14, George 2014: 346). The internal environment is seen as the intrapersonal stressors that affect the person and can occur if the person acquires an infection. External environment exist outside the person and is all the forces that are external or existing outside the defined client system (George 2014:345). This is also known as the interpersonal which occurs between individuals and outside forces that affect the individual stressors. The created environment is developed unconsciously by the person and is symbolic of the system of wholeness as it supersedes the internal and external environment (Neuman and Fawcet 2011:15). It works as a safety mechanism that blocks the person from reality. It is a defence mechanism. In the context of the current study, environment implies the physical environment including adolescents who are living with HIV and are on treatment, the drugs, the societal reactions of stigma and discrimination and the socio-cultural expressions and beliefs with regards to HIV infection.

Neuman identifies health as complete system stability or "harmony among the five variables" (George 2014:345). As the client moves towards illness a need for more energy occurs. As the client moves towards wellness excess energy, occurs. Reaction can be positive or negative (George 2014: 345). There are three forms of prevention-as-intervention: primary, secondary, and tertiary. Primary prevention occurs prior to the system's reaction to a stressor (health promotion and wellness maintenance). Secondary prevention occurs after the system reacts to a stressor (provided based upon existing symptoms). Tertiary prevention begins after the system is treated (George, 2014:345). Reconstitution is initiated after the treatment for stressors begins. It can be viewed as "the return to and maintenance of system stability" (George, 2014:346). Reconstitution may improve, return to, or decrease the previous level of wellness (George, 2014:346). In the context of this study I propose that health should be understood to mean the ability of HIV infected adolescents to accept their HIV status and deal effectively with their physical and associated psycho-social challenges of living positively with HIV. Therefore the health of HIV infected adolescents means their ability to deal with the psycho-social challenges that arose from being HIV infected. The health of the community in this study implies the freedom from HIV and ability to maintain a negative status and remaining whole in a manner that is non-stigmatising, non-labelling and non-ostracising to affected persons.

The Neuman Systems Model addresses nursing as a means to "help the client system attain, maintain, or retain system stability" (George, 2014:346). This can be done by adjusting the prevention -as-intervention methods (primary, secondary, and tertiary) to fit the needs of the client. The nurse is the link between "client system, environment, health, and nursing" (George, 2014: 346). In this study nursing will be understood as health care in its broadest sense as it helps the person in this case the HIV infected adolescents attain, maintain and retain their system stability hence remaining whole.

In summary, the NSM views humans, both individually and in groups, as wholistic open systems, with coping abilities that act together to maintain wholeness and to promote effective person and environmental transformations with the ultimate aim to promote health.

7.2.1.5 Major concepts in Neuman System Model

According to Neuman, a human being is a basic structure surrounded by successive rings as a system. The successive rings in the model constitute the lines of defence (Neuman & Fawcett 2011:6). The lines of defence are defined as flexible lines of defence, normal lines of defence and the lines of resistance (Fawcett 2005:10); and each line involves physical, psychological, socio-cultural, developmental and spiritual variables. The basic structure or the central core is made up of the basic survival factors namely normal body temperature, genetics, ego structure, organ strength or weakness (Neuman & Fawcett 2011:8). Flexible line of defence keeps an individual's normal balance, keeps the system away from stressors and prevents stressors from affecting the client system (Neuman and Fawcett 2002:13). The normal line of defence reflects the individual's normal or general state of wellness. This develops as a result of environmental stressors and the individual's previous experiences. When the system is not sufficiently protected by the flexible rings of defence, any stressor can pass through the normal ring of defence and create a reaction in the individual (Neuman and Fawcett 2011:10). The lines of resistance are the lines that surround the basic structure of the client system. When damaging the normal line of defence, stressors activate and protect the basic structure (Neuman and Fawcett 2005:15).

Stressors according to Neuman (2002:14) are defined as the potential warnings which cause the stress that may disrupt the system's balance. Every individual is exposed to various stressors that threaten their system throughout their life (Neuman and Fawcett 2002:14). Stress has the potential of creating a disturbance or imbalance in one's harmony and requires a solution. Defense mechanisms respond to stressors in order to prevent them from reaching the central energy source. Life is threatened if defence mechanisms are affected (McEwen and Wills 2002:369). The lines of defence specified in the Neuman's systems model prevent stressors from reaching the basic structure. Many stressors are universal and sometimes they disrupt the individual's system and lead to physical illness or emotional and social crises (Alligood and Tomey 2002:10). In this model family is defined as an open system that includes the subsystem of family members (Neuman and Fawcett 2002:16). The family system tries to maintain its state of

balance against the effects of internal and external environmental stressors that threaten the state of wellness (Neuman and Fawcet 2002:16).
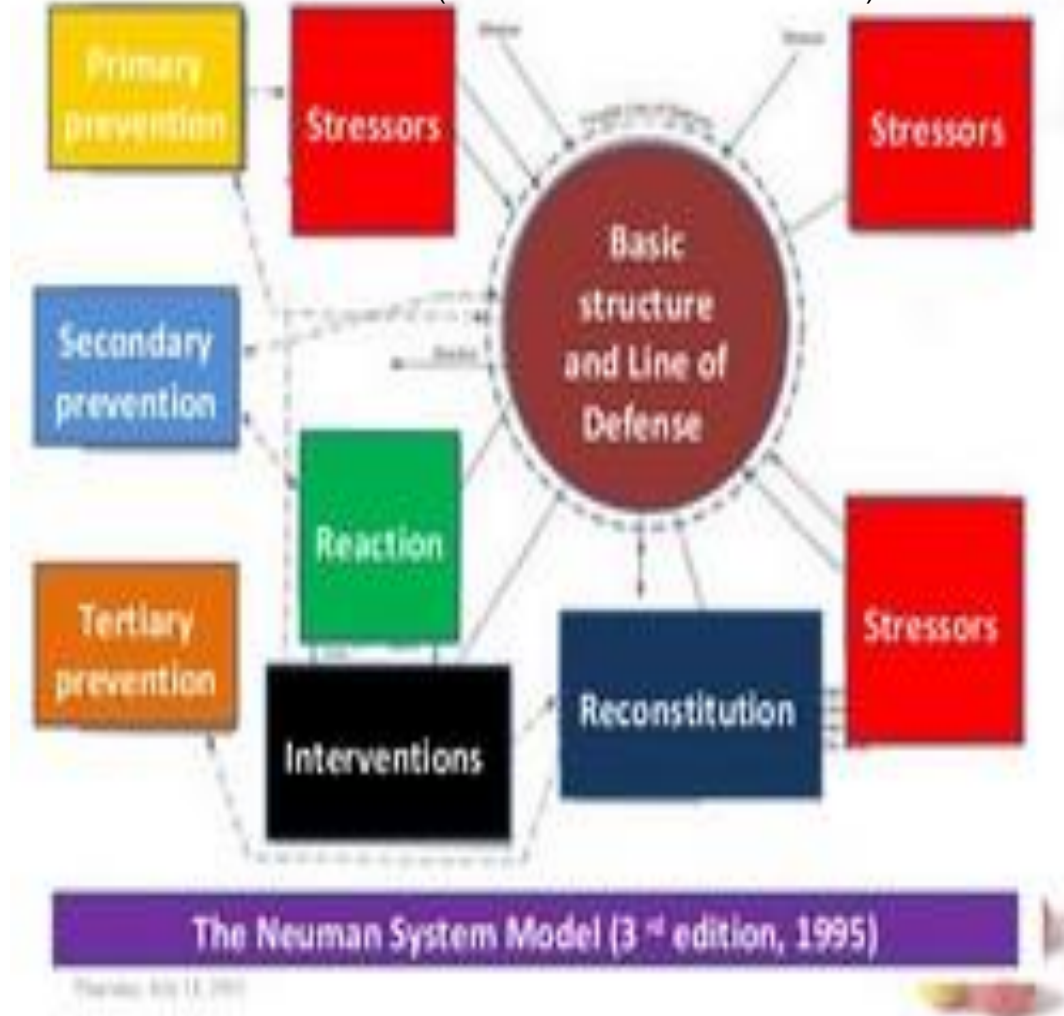
Figure 7.1: Major concepts in Neuman System Model (Accessed 12/08/2018)

7.2.1.6 The process of being whole

The NSM is predominantly wellness oriented and holistic. When the person or the community receives an environmental stimulus, which can either be interpersonal, intrapersonal or extra personal, this serves as an input process and it switches on the defence mechanism. The coping process that follows allows individuals and groups to fight the environmental stressor mentally, physically, socio-culturally and emotionally within the given lines of defence. The defence mechanism guided by the lines of defence which prevent the stressor from getting to the core will be

primary, secondary or tertiary in nature. This is all the process of maintaining wholeness of the individual or community.

7.2.1.7 Relating the study findings to the Neuman System Model

In this section salient features related to the study findings are explained in terms of the main goal of the NSM that of maintaining the individual and community as a whole. This will be done using the tenets of primary, secondary and tertiary prevention through the use of intrapersonal, interpersonal and extra personal stressors.

Primary prevention in most cases is taken to mean that there is no infection which has occurred, however primary prevention in the NSM model is dynamic and embraces the currency of health care in the 21st century hence its use in HIV care in this current study. The stimuli that triggered the desire to remain whole despite the HIV infection were multifaceted. The realisation by the health care provider that the HIV diagnosis is a source of stressor to the adolescent triggers them to offer counselling or any form of health promoting act before the adolescent gets stressed. This can be through counselling before the adolescents get to know their HIV status and is continued after informing them of their status for several sessions. This was revealed by some of the participants during interviews that they received many sessions of counselling before they were informed about their HIV status. Some of the participants got to know of their positive HIV status through friends and guardians who did not have the skills to handle disclosure issues. As a result, most of the participants reacted differently (see data display 6.4, 6.5, 6.8). Most of them stopped their treatment and in the process got ill and, in their quest, to become whole, they went back to health care facilities to be recommenced on their management drugs. This is known as secondary prevention were the stressor has affected the individual (see data display 6.4, 6.5, 6.8). In this current study, the participants described varying degrees of their stressors including even flushing drugs down the toilets but eventually went back to the health care providers in their quest of becoming whole again.

Because of the nature of the HIV infection, there is a constant need to adjust so that further re-infections can be avoided and wholeness can be achieved and maintained. Having realised that the only way they could remain healthy and whole

was through adherence to their drug regimens and changing their life styles; the adolescents formed peer to peer counselling groups so that they encourage one another to remain whole. They also documented their experiences in books which were known as their 'hero books' and each time they felt discouraged they were encouraged to share their stories with their peers so that they could get re-motivated.

7.2.2 The Labelling theory

Labelling theory is an explanatory framework that accounts for the effects of stigma associated with devalued standings such as being delinquent, homeless, and mentally ill or having an infectious disease. The Labelling theory attempts to explain individual experiences of maltreatment, violence and negative attitudes that arise out of interaction between a marginalised group and a marginalising group (Link, Cullen, Frank &Wozniak 1987:1461, Stuber, Meyer & Link 2008:351 and Pasman 2011:122-3).

7.2.2.1 Basic principles of the Labelling Theory

Originating in Sociology the Labelling theory was developed to explain how individual's self-identity and behaviour may be determined or influenced by the way the society in which they live classifies them (Kroska & Harkness 2008:193; Pasman 2011:122).

As an offshoot of the sociological concept of social interactionism, the Labelling theory support that reality as seen in the world by individuals is socially constructed implying that understanding, significance and meaning are developed not separately within the individual, but with others within the larger community (Jenkins & Carpenter-Song 2008:382; Leeds-Hurwitz 2009:892). The theory asserts that social processes like identity formation, cooperation, conflict and perceptions are products of human interaction (Jenkins & Carpenter-Song 2008:382; Leeds-Hurwitz 2009:892). The theory further declares that social construction of reality is a creative on-going process characterised by dynamic human to human interactions with intersubjective negotiation of reality (Kroska & Harkness 2008:193; Macionis & Gerber 2010:131-2).

An important aspect of such intersubjective creation of reality relates to how communities create labels that eventually come to define how individuals within the community are referred to and even get treated because of possessing a particular attribute. These labels often come either with positive or negative attributes. As Link and others (1987:1461) substantiate, labels play an important role in how those considered belonging to 'unfavourable' or 'inferior' group are perceived by members of the 'favourable' or 'dominant' group. In fact, Jenkins and Carpenter-Song (2008:382) are of the opinion that this negative labelling is what motivates members of the dominant group to negatively label and subject members of the minority (undesirable) group to ridicule, social rejection, stigmatisation and discrimination.

7.2.2.2 Relating the study findings to the Labelling Theory

In this current study, the labelled group consisted of HIV infected adolescents on ART, who needed to stand strong against the dominant group's (community's) negative labelling (Edgerton 1993:131, in Jenkins & Carpenter-Song 2008:382). The stigma associated with such labelling requires resilience efforts to counter the threat it has on the individual's self-concept, mental image, and their perception of themselves and their social identity (Edgerton 1993:131; Pasman 2011:122; Markowitz, Angell & Greenberg 2011:144).

When individuals have weak defences, the Labelling Theory argues that being labelled, for instance as mentally sick or delinquent, may actually cause a person to become mentally ill or delinquent due to self-fulfilling prophecy and self-stereotyping (Darley &Farzio 1980, in Markowitz *et al* 2011:147; Pasman 2011:122). HIV infected adolescents with a weak self-concept risked being negatively affected by this 'prophecy' of self-stereotyping and self-discrimination (Yang *et al* 2007:1527; Markowitz *et al* 2011:147). While substantiating on this affirmation, Link, Cullen, Struening, Shrout and Dohrenwend (1989:400-402) declare that thedanger associated with the negative labelling is that it erodes one's self-concept and makes the stereotypical attitudes about a person personally relevant to the individual, making them adopt self-stereotyping and self-discriminatory stances in the face of continued labelling. The findings revealed that some 'weak' adolescents indeed adopted dysfunctional (non-adaptive) coping styles among them secrecy, non-disclosure or social withdrawal from others. This further narrowed their social

networks leading to deeper isolation thus affecting their health and wellbeing (Kroska & Harkness 2008:193; Markowitz *et al* 2011:146).

Another outcome of personalising stigmatising beliefs 'imposed' on the labelled persons is that they may begin to expect devaluation and discrimination by the dominant group which demoralises them, lowers their self-esteem and self-efficacy and increases their chances of developing depressive disorders (Markowitz *et al* 2011:146; Pasman 2011:122). Although depression was not the focus of the study, I deduced that living through the widespread negative labelling, was partly possible by adolescents being resilient and embracing effective coping strategies like seeking support from others and adopting optimistic and positive attitudes. I further propose that this is what aided adolescents to transcend the various challenges without becoming overtly depressed.

7.2.3 Kubler-Ross's Theory of Grief

Sometimes known as the five stages of grief, the Kubler-Ross (1969) is an often discussed and applied theory of people's experiences of grief (Zeligman and Wood 2016:19). What is unique about this model is that previous theories of grief such as Freud (1917/1997) related to the experiences of grieving others while this particular model relates to the grieving individual (Zeligman and Wood 2016:21). Kubler-Ross's model can be applied to those who are grieving the loss of a loved one as well as to individuals' own grief in response to their impeding death or differing expectations of their life (Boer *et al* 2014:4). In the current study this model was found to be appropriate taking into consideration that the adolescents went through the bereavement process after losing their HIV negative status and acquiring a positive status.

7.2.3.1 Stages of Kubler-Ross's theory

The five stages of grief in Kubler-Ross's model are denial, anger, bargaining, depression and acceptance. These stages are briefly explained below:

Denial

One goes numb, denies the news and is in a state of shock. According to Kubler-Ross this is a stage were one wonders how life will go on in this different state.

Anger

Once one starts to live in the actual reality, anger sets in. Such statements as " Why me?", " life is not fair" are said. The blame game begins and anger can be redirected to friends and family.

Bargaining

This is the stage were one tries to bargain with God such statements as "if only I can have another chance". This is a stage of false hope were one might make themselves falsely believe that they can avoid the grief through negotiation.

Depression

Depression is a commonly accepted form of grief. It represents the emptiness one feels when living in reality. The world becomes overwhelming; one isolates themselves from others and might even experience suicidal thoughts.

Acceptance

This is the last stage in which one's emotions begin to stabilize and reality sets in.

Figure 7.2 Kubler-Ross Grief Cycle (Christina Gregory 2015) (accessed 30/08/2018)

7.2.3.2 Relating Kubler-Ross Stages of Grief Model to the study

Grief according to the Oxford Mini Dictionary and Thesaurus (2008:298) is lamentation anguish, desolation, mourning and misery while Neimeyer (2001:3) defines it as sorrow and the emotional suffering caused by loss. In the current study, it is equated to the loss of the HIV negative status acquiring a positive status. This is what Zeligman and Wood (2017:20) refer to as chronic sorrow. In this study, the adolescents went through all the stages of grief and some are still grieving.

7.3 Outcomes of the Adolescents with regards to wholeness

The concept wholeness means full quantity while the Miriam Webster online dictionary defines wholeness as a condition of being sound in body. An individual becomes whole by both innate and acquired capabilities. The innate capacity refers to physiological responses (such as production of white blood cells to fight infection) that are inborn and genetically programmed while acquired are those learnt over time (Masters 2012:139-140). The outcomes of being whole and the processes involved in Neuman System model are comparable to those in the Labelling Theory and the Kubler-Ross' Grief model which explains that how individuals react maybe influenced by the environment around them. The participants in the current study despite going through a lot of stressful situations, being labelled and going through the grieving process, they still managed to strive to become whole again.

7.4 Conclusion

Various themes and categories were related to a central concept of wholeness to promote deeper understanding of participants' experiences as recommended by Wertz (1985:213; 2011:160) and Creswell (2014:65). This explication allowed comparison to the key findings with existing models to facilitate generalisations which represent interconnection of thoughts as the person strives to remain whole. This further fulfils the expectation of qualitative research; that of bolstering existing scientific and nursing knowledge. In the next chapter, the study is summarised and guidelines to nurture adolescents are proposed.

CHAPTER 8

SUMMARY OF FINDINGS, CONCLUSIONS, RECOMMENDATIONS, PROPOSED GUIDELINES AND LIMITATIONS

8.1 Introduction

In this chapter, the research process is summarised, key findings highlighted, conclusions and recommendations. Discussions on various themes and categories as explained in chapter six are highlighted within selected theoretical models and frameworks to demonstrate their trustworthiness.

8.2 Purpose of The Study

The purpose of this current study was to describe the drug adherence lived experiences of HIV infected adolescents in Bulawayo, Zimbabwe.

8.3 Guiding research question

This current research was guided by the following research question: What are the lived experiences regarding drug adherence of adolescents on ART?

8.4 Research Design and Method

A phenomenological method was chosen to implement Wertz's 1983 & 2011 phenomenological data analysis framework. The research method served as both philosophical and methodological basis of the study and allowed description of "things" as they appear in participants' lived experiences (Finlay 2009:6; Wertz 2011:132) and this helped to arrive at unique individual and universal essence of experience with a socio cultural context.

8.4.1 Sampling

The research utilised purposive, convenience and criterion sampling techniques to draw thirteen participants (six females and seven males).

8.4.2 Data generation

In-depth qualitative interviews were conducted with thirteen participants who had been sampled based on the inclusion criteria and the interviews continued until data

redundancy occurred. The interviews were semi-structured, contextual and digitally recorded. In addition relevant field notes were also generated during the interviews.

8.4.3 Data analysis

Data analysis was done at both idiographic and nomothetic levels in accordance with Wertz's (1983/2011) phenomenological data analysis framework based upon six selected themes and this eventually led to emergence of categories supportive of the themes. Data analysis was based on the assumptions that adolescents' lived experiences would be expressed in a manner that would provide reality sufficiently unique to allow in-depth understanding of personal experiences. As Wertz (1983/2011) recommends, a single super category, one that supports or gives credence to all themes and categories was eventually selected after final synthesis of findings. The central and encompassing concept is wholeness which is well explained in chapter seven.

8.4.4 Literature support

A preliminary literature review was undertaken to guide the researcher to the complexities involved in studying the lived experiences of ART adherence. This review was intended to introduce the researcher to the context of the phenomenon and the socio-cultural perspectives that would eventually prove helpful in describing the findings. Main literature review was done as a literature control to explain the various themes and categories that emerged from the data as articulated in chapter six.

8.4.5 Trustworthiness

The study's trustworthiness was assessed and ascertained in terms of its credibility, transferability, dependability and confirmability as explained in chapter four. In order to further demonstrate the extend of transferability of the findings, the all encompassing concept of wholeness was discussed in detail in chapter seven and found to be generalizable and meaningful to adolescents in various situations. The concept was further discussed in relation to existing theories to not only enhance the study's trustworthiness but also to demonstrate how these theories support in a practical way possible interventions that can be employed to enhance adolescents' ART adherence. Further various processes through which the participants strived to

become 'whole' were integrated with existing theories and recommendations that can be used to improve drug adherence for adolescents were then proposed.

8.5 Findings, Conclusions and Recommendations

In this sectionthemes and categories are summarised with reference to the all encompassing concept of wholeness. Informed by these findings, conclusions are drawn and recommendations formulated.

8.5.1 Theme 1: Treatment fatigue

The participants expressed both implicitly and explicitly that they experienced treatment fatigue at some stage because of the fact that the treatment was lifelong and that their condition was not curable. They indicated that their hospital appointment schedules were too close hence because of economic reasons and not wanting to indirectly disclose their HIV status, they missed some of the hospital appointments (data display 6.4.1). Though the participants indicated that they were aware of the need to take their pills every day, they found it rather monotonous to take them every day hence they skipped some days (data display 6.4.2). Adolescents also indicated that it was within their rights to determine what to take or not, hence they were not supposed to be forced to take their own treatment but should determine on their own (data display 6.4.3). They also indicated that they had treatment holidays when feeling well and when away from home (data display 6.4.5).

Conclusion:

Living with HIV and being an adolescent at the same time knowing that it is not curable is a harrowing experience. The evidence shows that though they want to remain as their peers who are not infected, they at times become tired of taking their daily medications. These findings imply that while HIV infection is not curable, the resilience of the adolescents to want to remain whole is overwhelming.

Recommendations

In order to reduce the fear and treatment fatigue experienced by HIV infected adolescents, management of HIV should be tailored to meet their developmental

needs and not be a "one size fit all". Health care services should come up with more innovative ways of managing adolescents on ART in order to retain them in care hence minimizing non-adherence. Scientist should intensify research in long acting antiretroviral drugs such as the long acting penicillin so that monotony of having to take drugs everyday is done away with.

8.5.2 Theme2: Delay in getting to know own HIV status

The defining features of late disclosure of HIV status by care givers were described by almost all the participants as shocking, very painful, traumatic and led to non adherence of treatment. The participants reported that learning of their HIV status resulted in feelings of despair, hopelessness and a sense of total loss of control of one's life. These feelings were best summarised using the Stages of Grief by Elisabeth Kubler Ross. The stages are denial, anger, bargaining, depression and acceptance (data display 6.5.2). In addition to the stages of grief, the participants avoided taking responsibility of their health condition including not taking their medication but blamed someone for it (data display 6.5.3).

Conclusion

Getting to know their HIV status was one of the most difficult stages in the participants' lives especially when most of them had to ask from their guardians why they continued taking continued taking drugs for conditions they had been told they had and yet they were not sick. They had not been well prepared for this stage in their lives.

Recommendations

For better management of the HIV epidemic, it is recommended that informing children and adolescents about their HIV positive status should be a process and guardians and parents should not lie about their children about their medical conditions. This will prepare them to accept their conditions and also manage their health accordingly.

8.5.3 Theme 3: Stigma

According to Mac Henry *et al* (2017:2), stigma acts as a barrier to prevention, treatment and care because of the feelings of shame, blame, guilt and social isolation. Stigmatising attitudes whether experienced or perceived or internalized are important issues of concern to people who have chronic incurable diseases such as HIV. In this current study, participants indicated that stigma and stigmatising acts and attitudes played a major role in their lives and resulting in poor drug adherence experiences (data display 6.6). The participants described different stigmatising situations such as self stigma (data display 6.6.1), health care stigma (data display 6.6.2), stigma at boarding schools (data display 6.6.3) and stigma at home (data display 6.6.4). The stigma according to the participants had long term effects on their socio-psychological functioning including denial of their diagnosis resulting in poor to non-drug adherence.

Conclusion

Stigma is an impediment to the management of HIV; therefore, all forms of stigma should be eliminated if the fight against HIV is to be a reality. Stigma stifles progress it is debilitating.

Recommendations

In order to fight stigma, a lot of health education should be given to the community at large. The Alma Ata declaration of 1978 focused on primary health care, a supermarket approach to disease management. Therefore in order to reduce and manage stigma, healthcare policy should once again refocus on primary health care approach, do away with the specialist HIV clinics and use a one size fit all health booklet for all health care problems except in obstetric and paediatric management.

8.5.4 *Theme 4: Disability (visual impairment)*

Literature has reported that disabled people with disabilities are mostly unable to receive HIV information on an equal basis like their counterparts. Visually impaired adolescents in this current study reported that they faced a lot of problems regarding their drug management because they could not read instructions of medicine bottles (data display 6.7.1) and it was difficult for them to determine the

correct dosage to take because there is no provision mad for them. As a result it meant that they had had to rely on someone to read instructions for them or stop taking the drugs al together. Most of them settled for the later.

Conclusion

From the research findings it is evident that despite that not much has been done to embrace people living with disabilities and at the same time HIV infected. It was evident in this study that despite that HIV infection has been there for over three decades, visually impaired and other people living with different forms of disabilities are still sidelined.

Recommendations

It is about time that issues of disability should be included in HIV information dissemination and management.

8.5.5 Theme 5: Lack of support

Family support has been reported to have a positive effect on HIV and AIDS management. However, in this study the participants indicated that they had poor support. Most of the respondents were orphans being looked after by relatives and as a result, most of them did not get much support but were being blamed for being infected (data display 6.8.1, 6.8.4). The participants also indicated that there was poor support from the health care institutions and workers. Instead they were discriminated and labelled, put into different categories which they viewed as stigma (data display 6.8.2, 6.8.4).

Conclusion

It was clear from the findings that the participants were not getting enough support from their families and health care providers in order for them to try and manage their health.

Recommendations

Support in HIV management is very important and more so when one is an adolescent and HIV infected at the same time. The terms used to describe people

living with HIV should be critically analysed so that should they be a discriminating tool, should be done away with.

8.5.6 Theme 6: Religious beliefs (church)

Higher levels of religion have been associated with less psychological distress, less pain, greater energy and better social functioning especially after a terminal condition diagnosis such as HIV. However, religion can also worsen outcomes because of potential reliance on God and rejection of antiretroviral therapy and also of the view that HIV is a punishment from God for sinful lifestyles. In this study, religion did worsen the therapeutic outcomes (data display 6.91) whereby the religious leaders encouraged their infected congregates to stop taking their drugs because God would heal them since the pastors had prayed for them.

Conclusion

In this study participants who turned to their religion for support had poor ART adherence.

Recommendations

It is recommended that religious leaders should be educated on how antiretroviral drugs work especially on viral suppression. This would help them in better supporting and educating their congregants.

8.6 LIMITATIONS OF THE STUDY

While the study produced some credible information about the lived experiences of adolescents regarding drug adherence, there are however some limitations and among them:

- The qualitative research design used means that the study documented the experience of a relatively limited number of participants and this has a negative bearing on the generalisability of the study findings to other settings and this could have been different if the study had used a quantitative approach.

- The exclusion of some age groups (13-17) is a limitation on its own because these adolescents have challenges as well but they were not considered I n this study.

- Another study limitation is that the context specific nature of the study means analysis and description of the research data depended heavily on the researcher's choices and yet the same data could have been described differently by another and could have potentially led to different findings.

The limitations notwithstanding, the findings are reliable, valid and trustworthy especially given that the data collection and analysis methods used were thorough and independently verified by a qualitative research expect. Importantly despite these limitations, the results present some compelling evidence suggesting that the majority of adolescents while admitting suffering were able to overcome negative and stigmatising effects of being associated with HIV infection. The knowledge gained is thus enlightening since it has contributed to a deeper understanding of HIV infected adolescents' lived experiences regarding drug adherence.

8.7 RECOMMENDATIONS FOR FURTHER STUDY

The findings of the current study suggest for further research notably:

- All the aspects of lived experiences of adolescents living with HIV should be explored and this will present a total picture of the lived experiences of the chosen population.

- Further research on the experiences of care givers of adolescents living with HIV.

- Longitudinal studies to explore the experiences of adolescents in the long run including how the concept of resilience evolves over time.

- Further research to cover a larger sample of participants from various sentinel sites to help widen and gain broader understanding garnered from the current study.

- Research on mental health needs of adolescents living with HIV.

8.8 RECOMMENDATIONS FOR THEORY DEVELOPMENT

In keeping with the general aim of qualitative research regarding theory development, the researcher recommends that the concept of wholeness among HIV infected adolescents be further explicated as a multidimensional and multifaceted concept with the possibility of developing a conceptual framework that can be used to enhance zeal to remain whole in all those living with HIV infection.

8.9 GUIDELINES TO IMPROVE HIV INFECTED ADOLESCENTS DRUG ADHERENCE

The following guidelines are recommended to be used by guardians, health care teams and policy makers in order to improve the resilience of adolescents as they strive to remain whole as a strategy to assist them in resisting and coping with the new realities including maintaining wellbeing and sometimes excelling in the face of their incurable condition. The principle is meant to increase the adolescents' coping resources while at the same time availing support from their environment so that they are not alone in this stressful journey. The guidelines if implemented in a holistic manner would help adolescents to:

- Resist and withstand the challenges they faced.

- Be able to cope with the challenges by enhancing their preparedness.

- Recover from and rebound back to optimal level of functionality.

- Transcend beyond current challenges by accepting the new realities.

- Be able to function to their maximum capacity.

8.9.1 Increasing Adolescents' mental resistance

In order to help the adolescents to withstand the challenges of traumatic shock of having an untreatable condition and that they have to be on treatment everyday of their lives, health care teams should:

- Provide adolescent friendly services that is; effective clinical, mental health and psychosocial services which should be responsive to the needs of

adolescents. Adolescents-friendly services improve access and encourage constructive engagement between the health service and the adolescent and hence improve drug adherence (Fick, Fairlie, Moultrie, Woollet, and Pahad&Thornson 2015:23).

- Specific clinical and psychosocial needs of adolescents living with HIV in addition to the medical management of HIV are important so that specific considerations such as developmental phases and psychosocial aspects as each adolescent is an individual and has specific needs (Fick *et al* 2015:148).

- All services need to be framed by quality of healthcare. These priorities include waiting times, safety, drugs and supplies, infection control and staff attitude and cleanliness.

In addition to the above, they are also some policy related issues which need to be followed and these are:

- "Nothing for us without us", adolescents living with HIV should be involved in policy formulations in those policies which affect their management. In a study on students' responses to ABC and VCT messages at three universities in KwaZulu-Natal the results were that the students said that the messages to them were meaningless and they went on to design messages which they said would catch the attention of their peers and would prompt them to act (Mulwo& Tomaselli 2008:56).

- HIV does also affect people with disabilities; hence they should be embraced in the management modalities. HIV related materials and medicine containers should be produced in the language which these people will also understand especially the visually impaired.

- Discriminating and stigmatising material such as hospital booklets that can be used to identify people with HIV should be done away with and instead a "one size fit all" type of booklet should be designed.

8.10 CONCLUSIONS

In this chapter, an overview of the research process was given. The findings are summarised and conclusions drawn and key recommendations were made. Recommendations pertaining to each of the themes that emerged from the study were made. The chapter ends with proposed guidelines that may be used to improve the life of adolescents living with HIV.

XX THE RESEARCHER'S REFLECTIONS ON THE RESEARCH JOURNEY

This study was indeed a journey… a journey of a thousand miles right from the beginning. I knew I wanted to conduct a qualitative study to get to understand the experiences of HIV positive adolescents. This idea came to mind after I had observed a neighbour's nephew whom I knew was on ART but would always be admitted to hospital every now and then. As the journey started, it was a difficult very difficult journey for me. The initial struggle was to get my research proposal for ethical clearance. I remember I submitted about four to five times to my supervisors who at one time indicated that they were going to give up on me. I almost gave up but the resilience in me pushed me to do better. Then oh yes!!! The proposal was accepted with no corrections at all.

As I embarked on the tortuous road of scholarship, I realised that the qualitative method I had chosen needed me to do a lot of intense reading. Then I wrote a section on phenomenology which I thought was well written. When the paper came back from my supervisors, I was devastated by the comments from my supervisors. I gave myself a month's break. I picked up myself, read extensively about phenomenology and in my readings; I kept on coming across the name "WERTZ". I just said to myself let me look for the contact details of this guru in phenomenology and write to him. True he did respond and not only respond; he sent me a copy of one of his books and indicated that I could always consult if I had challenges in phenomenology. I was excited, my journey continued. The journey was truly in motion. I began focusing pertinently on all the comments from my supervisors. I was now enjoying my studies. AS I wrote the chapters I had to articulate my ideas very soundly and at best they should be well researched. I came to appreciate that phenomenological research goes nowhere without thoughtful writing. I became aware that only by writing can one construct knowledge and in constructing knowledge, we come to write in a more profound manner. This made me realise that the more I wanted to understand my topic, the more I had to read and write!!

Soon I found myself interviewing research participants. The major learning experience in this phase was how emotional an interview could get. I had in no way anticipated how emotionally involving some of the interviews could become, it was

more like a reality shock. On a number of occasions, I experienced severe emotional reaction, often torn between being a researcher and being a counselor, let alone being carried away by their stories of pain and suffering. This was a true test of scholarship; in no way intended for the fainthearted!! I had to learn to deal with severe emotional reaction, especially when an interviewee broke down and cried loudly and sobbed endlessly. On three occasions, I caught myself almost being carried away; I nearly cried...my eyes were teary. After the interviews, it became apparent to me that phenomenological research can truly be an emotion draining event. While I had a gut feeling that this might happen, the extent of the reactions of some participant especially the emotion weight this levied on me was unimaginable. Indeed a journey of a thousand miles had begun.

As I inched forward with the research journey, I experienced yet another surprise during data analysis phase. Despite having all the data with me transcribed, I was surprised by the fact that I spent nearly four (4) months dwelling with the data of thirteen adolescents almost on a daily basis. This level of immersement was totally new to me. The immersion appeared to never end. Occasionally the feeling that the analysis was moving nowhere would envelope me. Sometimes I wondered am I doing the right thing really. Alas, despite the apparent stagnation my supervisors were very encouraging. I began to wonder, is there something wrong with me? I recollected that my frustration was in part because I had imagined that once I had gathered the data, data analysis would be a walk in the park! I later proved this was a terrible assumption to say the least, because this stage proved to be the most time consuming. How wrong could a young researcher like me be! As days went to weeks and weeks into months, every day, I would sit behind my laptop typing away, constantly reading and re-reading, copying, cutting, pasting, accepting changes, let alone deleting, almost incessantly. I would ask…why am I not making progress? Then, suddenly, the cloud of despair vanished and everything seemed to flow without much hassle after the themes and categories and subcategories became clear. I started to enjoy myself especially as I wrote the results chapter. I soon discovered that I had more data to support my themes as well as categories than I actually needed. This apparent plenty abundance of information overwhelmed me on how much information was suddenly available to tell adolescents' story. This

was completely surprising! The ending became even more enjoyable, because with my supervisors' suggestion each turn was easier. Finally, the thesis was completed!

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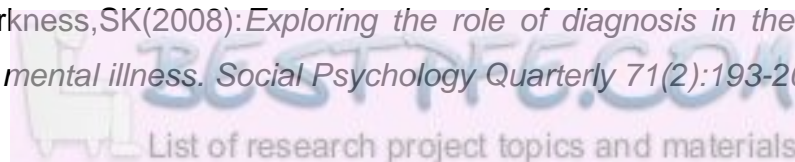
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ANNEXURES

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MINISTRY OF HEALTH
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MPILOCENTRAL HOSPITAL
P O BOX 2096
Vera Road
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BULAWAYO

ZIMBABWE

04 April 2017

University of Science and Technology
Faculty of Medicine
Mpilo Complex
Vera Road
BULAWAYO

Attention: *Ngundu Grace*

RE: REQUEST FOR PERMISSION TO CARRYOUT A STUDY ON EXPERIENCES OF HIV INFECTED ADOLESCENTS REGARDING DRUG ADHERENCE IN ZIMBABWE A CASE STUDY OF MPILO CENTRAL HOSPITAL

Reference is made to your minute in connection with the above matter.

The Institution has no objection in you undertaking your study.

May you give us the results of your study.

Thank you

Mr S Ngwenya
MBChB (UZ), DFSRH (UK) FRCOG (UK)
Consultant Obstetrician & Gynaecologist
Head of Department Obstetrics & Gynaecology
Clinical Director
MPILO CENTRAL HOSPITAL

Adolescent Information Sheet

Good morning/afternoon. My name isGrace Ngundu and I am undertaking a course with the University of South Africa. In order for me toqualify for the course I have to undertake a research exercise. This exercise willbe done at this hospital. I am asking you to participate in this study. I am doing study to understand the experiences of HIV positive adolescents.

You are one of the adolescents who have been selected at random from the adolescent community. Participation in this interview is voluntary.

The interview will be conducted by me here at Mpilo Hospital opportunistic clinic. The interview should take approximately one hour. Things you tell me in the interview will be confidential. Your name will not be mentioned in any report.

During the interview, if you allow me, I will use an audio recorder, which means that what we discuss during the interview will be recorded. This is so that I can remember what we talked about. The audio tape will be kept locked in a cabinet in my office and only me will listen to the tape. It will be destroyed thereafter.

 Some questions may make you feel uncomfortable. You are free torefuse to answer any questions. You can also stop the interview at any time. There are no direct benefits to you for choosing to participate in this interview. However, you will be helping me to add on knowledge that will help developbetter programs to help Zimbabweans in the future. To help in the addition ofknowledge, the results from this research will be published in form of a reportwhich other people may access and read. Your name or home will not bementioned in the report and all your answers will be kept strictly confidential.

At this time, do you want to ask me anything about the interview? If you have anyquestions at any time, you can also speak me on Telephone Number +263773714873.

If you wish to participate in my research study , you can sign the consent form below.

------------------------------------   Date--------------------------------

Ms Ngundu Grace (researcher)

Adolescent consent

YES, I want to take part in this study

- I was invited to participate in the above study which is being undertaken by Grace Ngundu a doctoral student at UNISA.

- This research aims at exploring the experiences of HIV infected adolescents. The results of the study will be presented in a thesis.

- My identity will not be revealed in any discussion and description by the researcher.

- My participation is voluntary. My decision regarding participation or non-participation in the study will in no way affect my lifestyle.

- No pressure was exerted on me to consent to my participation and I understand that I may withdraw from the study at any stage with no penalty.

- Participation in this study will not result in any cost or financial gain for me.

--   ---

Name of participant   Signature of participant

Date

Indepth interview guide

I thought we could begin the interview with you telling me about your background. It would be great if you could each spend a few minutes talking about your age, your family, friends, household and levels of current education. It
would also be nice to hear about your interests and what you like to do in your spare time.Now let us proceed and explore in detail a few questions relating to HIV and AIDS

- When did you first find out that you were infected with HIV?
- How did you find out?
- What have been your experiences since finding out about your status
- Have you ever had about medication adherence and what do you understand about it in your given situation?
- What have been your experiences regarding drug adherence?
- What would say are your most difficult issues which make drug adherence difficult?
- For how long have you been on this treatment?
- Have you had support from anyone regarding drug adherence?
- How often do you come to the clinic?
- What would you like done in order to improve issues around drug adherence?

RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES

REC-012714-039 (NHERC)

1 February 2017

HSHDC/596/2017
MS G Ngundu
Student: 4727-113-2
Supervisor: Prof TR Mavundla
Qualification: D Cur
Joint Supervisor: -

Dear MS G Ngundu

Decision: Ethics Approval

Name: MS G Ngundu

Proposal: Experiences of Drug Adherence by HIV infected adolescents in Zimbabwe.

Qualification: DPCHS04

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted for the duration of the research period as indicated in your application.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 1 February 2017.

The proposed research may now commence with the proviso that:

1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.

2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL

Ref: MRCZ/B/1151   23 February 2017

Grace Ngundu
Faculty of Medicine
National University of Science and Technology
Bulawayo

RE: - EXPERIENCES OF DRUG ADHERENCE BY HIV INFECTED ADOLESCENTS IN ZIMBABWE

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents (among others) that were submitted to the MRCZ for review:

a) Research Protocol
b) Consent forms
c) Study Questionnaires

- **APPROVAL NUMBER**   : MRCZ/B/1151

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF REVIEW**   : **EXPEDITED**
- **EFFECTIVE APPROVAL DATE**   : 23 February, 2017
- **EXPIRATION DATE**   : 22 Fenruary, 2018

- After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Website should be submitted three months before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Website.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Website is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Website.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

[signature]
....

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

MEDICAL RESEARCH COUNCIL OF ZIMBABWE

2017 - 02 - 23

APPROVED

P.O. BOX CY 573 CAUSEWAY, HARARE

PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH