

**THE LIVED EXPERIENCES OF YOUTHS WHO HAVE LOST A PARENT TO AIDS IN
WANNUNE, NIGERIA: A DESCRIPTIVE PHENOMENOLOGICAL STUDY**

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BY

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Declaration

I declare that this dissertation titled “The lived experiences of youths who have lost a parent to AIDS in Wannune, Nigeria: A descriptive phenomenological study” is my original work. It has not been submitted for any other degree. A complete list of references is provided with all source of information utilized in this study.

Tosin Popoola

Signature

Date

Professor Gugu Mchunu

Signature

Date

Dedication

In a special way, I dedicate this study to my beloved mother; Elizabeth Aderiike Popoola whose sacrifices and love has undergirded my academic progress. May God's inexhaustible blessings grant her good health and long life to enjoy the fruits of your sacrifice.

I also wish to express my gratitude to my younger brother, Dr. Tobiloba Popoola for his loving support of our mother and taking full responsibilities for all the challenges and the decisions during my absence of study at the University of KwaZulu Natal.

To the Almighty God who made all things possible and beautiful in His own time.

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Abstract

Although the advent of the antiretroviral therapy is changing the morbidity and mortality of HIV and AIDS epidemic into a chronic manageable disease; it is still the leading cause of death among age group 15-59 years who are in their productive and reproductive years. The HIV and AIDS epidemic has therefore orphaned over 17 million young people worldwide but 90 percent of these orphans are residents of Sub Saharan Africa. This study explores and describes the lived experiences of youths who have lost a parent to AIDS in Wannune, Nigeria. Only AIDS orphans below the age of 18 years are eligible for support from governmental and non-governmental organizations in Nigeria. This study is focused on the unsupported AIDS orphaned youths between the ages of 18-24 years.

Descriptive phenomenology informed the study design, data collection and analysis of data. Purposive and snowballing sampling was used to obtain a sample of six youths who have lost parents to AIDS related illnesses and who were unaffiliated to any support organizations in Wannune. Each participant was interviewed twice using a pre-prepared interview guide that comprised of open ended questions. The second interview served as a closure and debriefing interviews. The data was analysed using Colaizzi's (1978) method of phenomenological data analysis and this methodology facilitated the emergence of themes from the data. Six themes and 13 subthemes emerged from the study and these were grouped under the two objectives of the study. An exploration of the lived experience of youths who have lost parents to AIDS in Wannune demonstrated that participants encounter with AIDS virus started before the actual loss of the parents. The experience of the participants progressed in the following chronological order of experience:

- disruptive life changes before and after parental AIDS loss;
- secondary losses such as loss of educational opportunities;
- premature assumption of parenting roles;
- exposure to vulnerability and continued grief.

The study identified that the participants demonstrated many needs for parenting skills, empowerment, coping skills and need for psychosocial support. This study builds on the existing body of knowledge and demonstrates that the negative adverse effect of AIDS-orphanhood does

not abate after orphans become young adults at 18 years. The study concludes with a number of recommendations in relation to policy making and future research.

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List of abbreviations and acronyms used

| | |
|---------|--|
| ART | Antiretroviral therapy |
| AVERT | Antivirus Emergency Response Team |
| CIHP | Centre for Integrative Health Program |
| FMWA&SD | Federal Ministry of Women Affairs and Social Development |
| NACA | National Agency for the Control of HIV/AIDS |
| NPC | National Population Commission |
| OVC | Orphans and Vulnerable Children |
| PEPFAR | President's Emergency Plan for AIDS Relief |
| UNAIDS | Joint United Nations Programme on HIV and AIDS |
| UNICEF | United Nations International Children's Emergency Funds |
| SSA | Sub-Saharan Africa |
| WHO | World Health Organization |

CHAPTER ONE: INTRODUCTION

1.1 INTRODUCTION

“Every fourteen seconds a child will become an orphan. Together with the effects of poverty, an estimated 500 children a day become orphans. Imagine: parentless, helpless, hungry and cold. This is the plight of the children made vulnerable or orphaned by the twin peril of AIDS and poverty in Africa today” (World Vision, 2008, pg. 1).

The history of Human Immunodeficiency Virus (HIV), the virus that causes the incurable Acquired Immuno-Deficiency Syndrome (AIDS) and its origins are disputed (Antivirus Emergency Response Team [AVERT], 2012). However, since it was first reported just over 30 years ago, it had become one of the world’s most serious threats to human health and development (Ferreira, Pessoa & Dos Santos, 2011). New cases of HIV have been reported in all regions of the world, but approximately 68 percent is in Sub-Saharan Africa (Joint United Nations Programme on HIV and AIDS [UNAIDS], 2013).

With an estimated population of 174 million, Nigeria is the most populous country in Sub-Saharan Africa, a region which carries the globe’s heaviest burden of HIV and AIDS (UNAIDS, 2013). The most recent HIV sero-prevalence figure represents about 3.5 million people infected with Nigeria ranking second among the countries with the highest HIV and AIDS cases in the world, and is surpassed only by South Africa (National Agency for the Control of HIV/AIDS [NACA], 2012). Being a federal constitutional republic located in West Africa, Nigeria comprises 36 states with its Federal Capital Territory being Abuja. A wide variation of HIV prevalence ranging from 0 percent to 21.3 percent exists across many sites within the country. The states with the highest HIV prevalence are Benue (12. percent), Akwa Ibom (10.9 percent) and Bayelsa (9.1 percent) (NACA, 2012). However the highest site prevalence of 21.3% was reported from Wannune, a town in Benue State (NACA, 2012).

The most-at-risk population group that contributes to the spread of HIV are those that practice heterosexual sex (NACA, 2012). Although it is claimed to be the low-risk type it constitutes 80

percent of the HIV infections in Nigeria (NACA, 2012). This can explain the staggering number of young people who have lost parents to AIDS in Nigeria. About 2.4 million young people are AIDS orphans in Nigeria (US Agency for International Development [USAID 2009]). Benue state, and specifically Wannune, contributes 25 percent of the total number of AIDS orphans and 49% of young people in Benue state are vulnerable due to parent's HIV illness or death from AIDS (USAID, 2009).

1.2 BACKGROUND

Globally, the HIV and AIDS pandemic continue to sweep across the continents. HIV is the world's leading infectious killer and the fourth leading cause of death overall (World Health Organization [WHO], 2013). Since the beginning of the epidemic, 70 million people have been infected and 35 million have died from the epidemic (WHO, 2013). The UNAIDS (2013) estimated that in 2012 globally, 35 million people were living with HIV/AIDS, 1.6 million died of AIDS-related illnesses while 2.5 million new HIV infections were recorded.

Although every region in the world has in some way been affected by the epidemic, it is in the continent of Africa that the grip of HIV and AIDS has had the deadliest impact (AVERT, 2012). Sub-Saharan Africa (hereafter SSA) remains the most severely affected with nearly 1 in 20 adults living with HIV, accounting for 69 percent of the people living with HIV worldwide (WHO, 2013). In 2012, approximately 23.5 million people were living with HIV in Africa, with Southern Africa having the highest prevalence rates of HIV in the world; some countries such as Swaziland, Botswana and Lesotho have HIV prevalence of more than 20 percent (AVERT, 2012). South Africa continues to have the most severe HIV epidemic in the world, with 5.6 million of its 2013 population of 52.98 million infected with HIV (UNAIDS, 2013).

The HIV prevalence in West and Central Africa, however, remains comparatively low, with the adult HIV prevalence estimated at 2 percent or under in some countries such as Benin, Burkina Faso and Sierra Leone (UNAIDS 2013). The prevalence of HIV is highest in Cameroon at 5.3 percent (UNAIDS, 2013). Nasidi and Harry (2007) attributed the higher infection rates and prevalence in the Southern Africa countries to an earlier start of the epidemic in the countries,

different behaviour patterns and risk factors, more pathogenic and or transmissible strains of HIV, variation in susceptibility to HIV, or a combination of those factors.

Although the HIV prevalence in Nigeria is relatively low (4.1 percent) when compared with HIV prevalence in other African countries such as (17.3 percent in South Africa, 23.4 percent in Botswana); its large population size of 174 million in 2013 means that about 3.5 million people are living with HIV in the country (NACA, 2012). The HIV epidemic has had a negative impact on life expectancy in Nigeria reduced to about 45 years in 2002, down from 53 years in 1990 (Nasidi & Harry, 2007). Without the HIV epidemic life expectancy was projected to reach nearly 62 years in 2015 (NACA, 2012). Research data suggest that unprotected sex is a significant factor to the spread of HIV epidemics in SSA region (UNAIDS, 2009); and it accounts for 80% of new infections in Nigeria in 2011 (NACA, 2012).

Casualties of the HIV and AIDS epidemic include not only the infected, but the affected. In SSA, AIDS is the leading cause of death among ages 15-59 years and it primarily affects young people and those in their productive working years (Ferreira et al., 2011). Similarly, this age group comprises those who are in their reproductive years. 2011 statistics confirmed that approximately 17.3 million children under the age of 18 lost one or both parents to AIDS (United Nations International Children's Emergency Funds [UNICEF], 2012). Furthermore, UNICEF (2012) reported that while other regions in the world such as Asia, Latin America and the Caribbean have been witnessing a decline in the number of children orphaned from all causes since 1990, the number of orphans increased in SSA by 50 percent within the same period due to the HIV epidemic. This means that 90 percent of the world's total orphans are living in SSA. Also, about 80% of those who were orphaned due to AIDS live within the African continent (Emanuel, 2012).

In countries such as Zimbabwe, Zambia, Botswana, Lesotho and Swaziland, approximately 15 percent of the children population are AIDS orphans (UNICEF, 2010). Other countries in the SSA such as Uganda, estimated their AIDS orphans to be 2 million (Harms, Kizza, Sebunnya & Jack, 2010), while the AIDS orphans in South Africa was 830, 000 in 2005 (Cluver & Gardner,

2007). The condition of AIDS orphans is similar in Nigeria based on the data provided from the situation analysis conducted to determine the magnitude of orphans and vulnerable children (Federal Ministry of Women Affairs and Social Development [FMWA&SD], 2008). The study revealed that of the 17.5 million children who are living in vulnerable conditions; 9.7 million of them were orphans with 2.4 million of them orphaned through AIDS (FMWA&SD, 2008). Twenty-five percent of the total orphans are found in Benue State and this also accounts for about 49 percent of children who are vulnerable from HIV and AIDS epidemic country wide (FMWA&SD, 2008).

The catastrophic long-term outcome of parental death from AIDS has given rise to a large population of young people who have lost one or both parents is not showing signs of abating. Tragically, the number of orphans in SSA will continue to rise in the years ahead, due to the high proportion of SSA adults already living with HIV and AIDS and the continuing difficulties in expanding access to life-prolonging antiretrovirals (The International Labour Organisation [ILO], 2006; UNICEF, 2010; Woodring, Cancelli, Ponterotto & Keitel, 2005). The phenomenon of AIDS-orphanhood is therefore a pressing challenge for social structures and healthcare systems throughout SSA.

Parental death regardless of its cause places survivors under heightened risk for problems such as depression, anxiety, loss of opportunities, hardships and loss of parental guidance. This is even more complicated when the parental death is attributed to AIDS because of the pervasive influence of stigma and discrimination that is often passed on to survivors (Van der Heijden & Swart, 2010). But yet, considerable amount of effort is still being devoted to the counting of HIV and AIDS affected children with limited action taken to identifying the broader developmental and age-specific risks to their health (Doku, 2009).

Addressing the needs of Orphans and Vulnerable Children (OVC) and mitigating negative outcomes of the growing OVC population worldwide is a high priority for national and international stakeholders across the globe. In the past decade, the body of research (such as Cluver et al., 2013; Skovdal, 2010) into the phenomenon of AIDS-orphanhood has been steadily

growing (Harms et al., 2010). Contemporary research covers a wide range of topics ranging from strictly medical studies to the social, academic, physical, psychosocial, mental and demographic implication of AIDS-orphanhood, as well as research into interventions and best practices that will improve the wellbeing of orphans. International policies recognize that programming for AIDS orphans contributes to the achievement of an AIDS-free generation (Emanuel, 2012). Interventions for AIDS orphans have, therefore, targeted poverty reduction programmes such as cash transfers (Adato & Bassett, 2009), educational support (Lewin & Bates, 2012), home visiting/mentoring support (Mikton & Butchart, 2009) and various forms of counselling and psychotherapy (Rotheram-borus, Weiss, Alber & Lester, 2005; Thupayagale-Tshweneagae, Wright & Hoffman, 2010).

In response to the potential catastrophic proportions of AIDS orphans that Nigeria is facing, the federal government initiated a national response which is coordinated by the Federal Ministry of Women Affairs and Social Development (USAID, 2009). The strategic planning, programme priorities and implementation arrangements were facilitated by the Rapid Assessment, Analysis and Action Planning Process (RAAAPP) and the national OVC conference that was held in 2004. Since then, Nigeria has put in place the following policies, strategies, structures and systems to respond to the challenges posed by the large numbers of OVC:

- National Plan of Action (NPA, 2006-2010 for OVC);
- Guidelines and Standards of Practice for OVC;
- defining a minimum package of services for OVC;
- National OVC Monitoring and Evaluation (M & E) Framework;
- OVC eligibility criteria; OVC advocacy package;
- Psychosocial training manual; OVC unit in FMWA&SD and
- National steering committee on OVC.

However, it was observed that most of the current interventions in Nigeria only cover OVC aged zero to 17 years and have failed to include young people over 18 years old. Since the age group for OVC is from zero to 17 years (FMWA&SD, 2008), USAID (2009) argued that AIDS orphans are not always children and the problems that they face extend well beyond 18 years.

Gana et al. (2014) added that there is a definite need for programs to cover vulnerable youths because their transition into adulthood (18 years) necessitates increased assistance in higher education and skills training which are more expensive and therefore less affordable and accessible.

Young people between the ages of 18-24 years have often been referred to as youths (Kurz, 2012) and they represent a unique category of OVC since their needs are distinct and separate from those of children below the ages of 18 years and adults above 25 years (Gana et al., 2014). International development discourses and interventions for AIDS orphans and vulnerable children, however, does not regard young people over 18 years as dependent „orphans“ in need of support and therefore excludes them from assistance when they reach the threshold of 18 years (Evans, 2012). Research exploring AIDS-orphanhood has, therefore, concentrated on children below 18 years and the voices of orphans above 18 years have been suppressed and neglected. However, emerging evidence from South Africa, Uganda and Tanzania has revealed that AIDS-orphanhood interacts with increased age to magnify harmful psychological, psychosocial and physical outcomes among youths over 18 years who have lost parents to AIDS (Cluver, Orkin, Gardner & Boyes, 2012; Evans, 2010). This suggests that the impacts of AIDS-orphanhood are sustained over time, even for those children who have transitioned into the category of young people between ages 18-24 years old.

Youth within the SSA are growing up in a context marked by pervasive poverty, limited educational opportunities, high HIV and AIDS prevalence and weak social controls (Kabiru, Izugbara & Beguy, 2013). In a life stage that is characterized as a period where there is heightened threat of chronic illnesses, drug and alcohol use/abuse, poor scholastic performance, and risk-taking behaviors (Barnes, Hoffman & Welte, 2006); parental loss as a youth is likely to be damning. Most of the tasks (completing high school, making career choices, securing first part-time job, dating and assuming more personal and social responsibilities) of this life stage renders them more in need of assistance (USAID, 2009). Youth orphans require different kinds of assistance than children and adults. In some ways their needs are more complex than the needs of younger orphans because of physical and psychological development during puberty and the steps needed to move towards inter-dependence and adulthood (Ruland, et al., 2005). However

the tendency of many organizations is focused on the protection and care of children orphans because it seems to be politically and economically more rewarding.

In the Wannune community that has the highest prevalence of HIV; health workers have acknowledged the need to understand the impact of AIDS parental loss on young people aged 18-24 (Hilhorst, van Liere, Ode & de Koning, 2006). The data from studies carried out with children below the age of 18 years could be irrelevant to the context of those over 18 years old. Some studies have criticized the rigorous application of age to determine support eligibility of AIDS orphans but they were carried out outside of the Nigerian context (Woods, 2010, Cluver et al., 2013). It could be argued that variations in local realities, societal context, family processes and communities' responses to HIV and AIDS epidemic; means findings cannot be directly extrapolated to the situation in Wannune, Nigeria.

The experiences and needs of unsupported AIDS orphaned youths have not been adequately dealt with in scholarly literature within the SSA context. Therefore this study constitutes an attempt to describe the lived experience of orphaned youths within the context of Wannune, Nigeria. Exploration of lived experience of any phenomenon provides insights and it is central to the design of effective interventions because it takes into account both the universal aspects of individual's development and local cultural practices (Van der Heijden & Swart, 2010).

1.3 STATEMENT OF THE PROBLEM

Previous research has found that AIDS-orphanhood interacts with increased age to magnify harmful psychological, psychosocial and physical outcomes and that the impact of AIDS-orphanhood gets worse, with time and with the developmental process of growing up (Cluver, Orkin, Gardner & Boyes, 2012; Evans, 2010). Parental loss to AIDS carries unique ramification that complicates adjustment and coping (Sikkema, et al., 2000). This is because it is complicated by a set of material and psychosocial stressors that accompany parental death (Wild, 2001) and challenges historical models of bereavement (Kain, 1996). Parental failing health and eventual loss to AIDS means young people face a unique crisis of losing parental love, guidance, stability and support, as well as risk of losing the link with past experiences and the possibility of a shared

future (Wild, 2001). The experience of losing a parent to AIDS can be fundamentally detrimental for youths who are not supported by policies and programs in Nigeria.

Family Health International (2009) estimates that the prevalence of AIDS orphans increases with age; making older AIDS orphans constitute 55 percent of the total number of orphans worldwide. The reason for the large proportion of older orphans is due largely to the time lag that exists between parent's infection and eventual loss to AIDS. In Nigeria, 2.4 million young people are orphaned due to AIDS (FMWA&SD, 2008). New infections have stabilized, but owing to a time lag between parents' infections and death, adults death will continue to add to the number of AIDS orphans in the next decade (AVERT, 2012). Even with improved effectiveness, ease of administration and access to treatment, the number of AIDS orphans will remain exceedingly high (UNICEF, 2012). Ongoing prevention strategies must be joined by efforts to improve the quality of life for all who are and will continue to live with and be affected by HIV and AIDS in Nigeria.

Despite increasing research interest in the phenomenon of AIDS-orphanhood which has exposed the needs of AIDS orphans worldwide and Nigeria in particular, there has not been sufficient research focus on young people ages 18-24. Their voices, experiences and needs have been suppressed under those of AIDS orphaned children below the ages of 18 years. It is therefore necessary to explore the lived experience of youths in order to identify their challenges and needs so that appropriate strategies can be designed in response to their life threatening circumstances. This study was therefore conducted to explore and describe the lived experiences of the AIDS-orphaned young people in Wannune by providing a safe space for them to describe and discuss their personal experiences of parental AIDS loss.

1.4 PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the lived experiences of youths who have lost a parent to AIDS in order to identify what are their core needs and how they can be met.

1.4.1 OBJECTIVES OF THE STUDY

The objectives of this study are to:

1. Describe the lived experiences of youths who have lost a parent to AIDS.
2. Identify and describe the needs of the youths who have lost a parent to AIDS.
3. Offer recommendations based on the lived experiences of the study participants.

1.4.2 RESEARCH QUESTIONS

1. What is the youths' description of their experiences of the loss of a parent to AIDS?
2. What are the needs of the youths who have lost a parent to AIDS?

1.5 SIGNIFICANCE OF THE STUDY

Youths as research participants: The stage of youth constitutes a developmental phase of transition between childhood and adulthood and involves journeying into the world of work. It catapults the youth to embrace greater autonomy and to take responsibility for his/her sexual maturity (Kurz, 2012). This stage is also characterized by diverse physical, psychological, social and health risks (Germann 2006). While these challenges have far-reaching implications for the health and wellbeing of youths, it can be argued that HIV and AIDS constitute one of the biggest challenges towards the development of healthy youths. According to Kabiru et al. (2013), investment in youths generates the greatest returns when started early and continued throughout their transitions, because the consequences of risks suffered at this stage tends to be a life-long encumbrance. This study seeks to provide youth participants with the opportunity of safe space to discuss some of the issues that affect their healthy development that urgently need attention. This study can provide participants with the chance to connect with professional services that can improve their wellbeing and welfare while also giving them the chance to come to terms with their loss.

Practice environment: The findings of the study can be used by practitioners from various fields to design programmes that can benefit youths that have lost their parents to AIDS.

Policy making: The findings of the study have the potential to offer insights for development of policies about interventions that might include youth AIDS orphans above the age of 18 years in Nigeria.

Public health research: It is hoped the findings from this study can be used to further the area of research focusing on the OVC. More appropriate and evidence based interventions can be developed to provide support and care to those older children that have lost parents to AIDS related illnesses.

1.6 OPERATIONAL DEFINITION OF CONCEPTS

Youth: In this study, youth is defined as any person between the ages 18 and 24 years. The definition will include a young person who has lost a parent to AIDS.

Lived experiences: In this study, the first-hand account of having an encounter with AIDS parental loss refers to the lived experience of the participants.

Loss of a parent to AIDS: This refers to parental death that is attributable to HIV and AIDS related illnesses which participants confirmed knowledge of through either direct disclosure by the HIV infected parents or through other reliable sources.

1.7 CONCLUSION

In summary, this chapter introduced the reader to the background of the study and attempts to provide the justification for the study. The chapter outlines the factors that gave rise to this phenomenological study. The issues raised provided rationale on the need for more research into the lives of AIDS-orphaned young people between the ages of 18-24 years because they are at a life stage which renders them at need for complex interventions due to transitions from childhood to adulthood and the antecedent risks that comes with. In the absence of parental love, guidance and support, AIDS orphans within this age bracket are at risk of deleterious physical, social and mental health outcomes considering that their parental loss is attributed to a highly stigmatized condition. This chapter also covered the problem statement, research purpose, research questions, objectives and significance of the study.

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

The overarching aim of this research was to explore and describe the lived experiences of youths who have lost a parent to AIDS in order to identify their psycho-social needs. This chapter presents a review of literature that covers the key concepts covered in the topic that are explored critically by scholars that have done research on the experience and needs of AIDS orphans. In addition, although limited literature is available on the experiences of youth 18-24 years old, the narrative that is derived from the children orphans (below 18 years) sharing their experiences will cover the identifiable literature gap. It is important to highlight that part of the literature review for the study was conducted after data collection and analysis were completed. This strategy was in line with the strategy of „bracketing“ which is the hallmark of descriptive phenomenology and this assisted the researcher to set aside preconceived ideas. The findings of the study were therefore not influenced by what has been previously reported in the literature.

2.2 METHOD

Both conceptual and empirical electronic articles were accessed for this study. The literature reviewed is categorized under two broad themes which correspond to the objectives of the study which are: the lived experiences of youths who have lost a parent to AIDS and their psycho-social needs. The search was carried out through EBSCOHOST which consists of Cumulative Index to Nursing and Allied Health (CINAHL), Academic Search Complete, Medline, PsychINFO and Health source databases for the year between 1991 and 2014. Corporate publications and policy statements were accessed from Google search engine and these were used to set the background for the review discussion and argument on HIV, AIDS and youths. The key words used were AIDS, HIV, youths, orphans, young people, lived experience, experience, needs, Nigeria and Africa.

2.3 SNAPSHOT OF THE GLOBAL STATE OF HIV AND AIDS PANDEMIC

The year 2015 marks the juncture when an evaluation will be made of the Millennium Development Goals (MDGs) that include goal six that calls for working towards halting and reversing the spread of HIV. It could be argued that efforts toward improving the quality of lives of those affected by HIV and AIDS require greater urgency. The latest update on the status of the pandemic revealed substantial gains in the fight against the epidemic; for instance, UNAIDS (2013) reported that globally: 8 million people are now receiving the life-saving antiretroviral therapy; new infections from HIV also declined by 33 percent (from 3.4 million in 2005 to 2.3 million in 2011) and mortality from AIDS also decreased by more than 50 percent.

Despite the encouraging news and the striking gains against HIV and AIDS, UNAIDS (2013) reported that national epidemics in many parts of the world continue to expand. For instance, treatment has not yet reached 7 million people, 50 percent of people living with HIV do not know their status and the most affected people still face marginalization and exclusion (UNAIDS, 2013). The HIV epidemic not only affects the health of individuals, it impacts households, communities, development and economic growth of nations (Emanuel, 2012). For people infected and affected by the epidemic, HIV is not only a medical experience; it is also a psycho-social and emotional experience that profoundly affects their lives (Emanuel, 2012). Continued and strengthened international solidarity and determination to address the contemporary health challenges of HIV have been strongly advocated for.

There are different routes that an individual can acquire HIV infection such as sexual, parenteral and mother-to-child. However, sexual transmission is by far the most common mode of transmission globally (Morison, 2001; NACA, 2012). In some countries, especially in SSA, heterosexual sex, particularly of the low risk type makes up the bulk of HIV infections. Most people living with HIV and AIDS are in the economically productive age-group supporting children and elderly relatives and most will receive minimal care when they finally develop AIDS-related illness (Morison, 2001). The global HIV and AIDS epidemic is thus an enormous tragedy for humankind from many aspects (Morison, 2001).

In 2013, WHO, UNICEF and UNAIDS jointly released the 2013 WHO antiretroviral guidelines. Over the years, improved access to Antiretroviral Therapy (ART) has been identified as the key strategy for prevention of new HIV infections, increases in life expectancy, declines in AIDS related mortality and the ongoing drop in annual new HIV infections around the world, including among children (WHO, 2013). As an illustration: WHO (2013) estimates that ART increased adult life expectancy to about 80% of normal life expectancy, provided it is started early; over 800 000 new infections among children was averted through PMTCT program and about 4.2 million deaths was also averted between 2002 and 2012 through the use of ART. Massive scale up of ART has thus been advocated for. However, the changing economic landscape has hampered the availability of ART services to eligible HIV positives especially in the low resource countries which are the hardest hit by the epidemic (WHO, 2013). The current strategy against the tragedy of HIV epidemic is ensuring that all infected individuals have access to ART.

2.4 AFRICA: THE EPICENTRE OF HIV AND AIDS PANDEMIC

The burden of the epidemic continues to vary considerably between countries and regions, but SSA remains the most severely affected region in the world (WHO, 2013). Although SSA region contains just a little more than 12% of the world's population, nearly 1 in 20 adults in SSA are living with HIV and this accounts for 71 percent (23.5 million) of the people living with HIV worldwide (WHO, 2013; AVERT, 2012). In 2011 alone, 75 percent (1.2 million) of AIDS-related deaths occurred in SSA and the region's new HIV infections accounted for about 72 percent (1.8 million) of the global new infections (UNAIDS, 2013).

Sub-Saharan Africa is the only region in the world where women are disproportionately affected by the HIV epidemic in comparison with men, with the proportion hovering around 60 percent over the last five years (UNAIDS, 2010). In 2011, 92 percent of pregnant women living with HIV resided in SSA and more than 90 percent of children who acquired HIV in 2011 live in SSA (UNAIDS, 2012). Since the beginning of the epidemic, UNAIDS (2010) estimates that 14.8 million children in SSA have lost one or both parents to HIV and AIDS. The HIV/AIDS epidemic in Africa is occurring in a context of increased poverty, food insecurity, indebtedness,

poor economic performance, gender inequality, gender-based violence, conflicts, natural disasters, ignorance, fear, stigma and discrimination (WHO, 2013).

The magnitude of HIV and AIDS epidemic in Sub-Saharan Africa becomes clearer when one considers that Swaziland with the world's highest prevalence of HIV (26.5 percent), one out of every three adults is infected, and the figures for Lesotho, Botswana, and Zimbabwe are not much different (Ferreira et al., 2011). AVERT (2012) noted that the HIV epidemic in SSA continues to devastate communities and it is significantly rolling back decades of development progress. For instance in Botswana, life expectancy went from 60 years in 1985 to less than 40 in 1999, while in countries such as Swaziland, Zimbabwe, Zambia and South Africa, life expectancies decreased in the same period by more than 10 years (Ferreira et al., 2011).

Both HIV prevalence and the number of people dying from AIDS vary greatly between African countries. For instance in Somalia and Senegal the HIV prevalence is under 1%, whereas in Namibia, Zambia and Zimbabwe around 10-15 percent of adults are infected with HIV (AVERT, 2012). South Africa is the worst AIDS impacted region in Africa: In South Africa the HIV prevalence is 17.8% and in three other Southern Africa countries, the national adult HIV prevalence rate now exceeds 20 percent (UNAIDS, 2013). These countries are Botswana (23 percent), Lesotho (23.1 percent) and Swaziland (26.5 percent). According to the UNAIDS 2010 Global Report, out of the total number of people living with HIV worldwide in 2009, thirty four percent resided in ten Southern African countries namely; Botswana, South Africa, Swaziland, Lesotho, Zimbabwe, Zambia, Namibia, Malawi, Mozambique and Angola (UNAIDS, 2010). The South African Development Community (SADC, 2012) lamented that as many countries in its region grapples with the severe impact of the mature HIV and AIDS epidemics, the hard won gains of the past are being reversed.

In contrast to the reported high prevalence of HIV in the Southern African countries, the HIV prevalence in West and Central Africa remains comparatively low, with the adult HIV prevalence estimated at 2 percent or under in 12 countries in 2009 namely Benin, Burkina Faso, Democratic Republic of the Congo, Gambia, Ghana, Guinea, Liberia, Mali, Mauritania, Niger,

Senegal, and Sierra Leone (UNAIDS, 2013). The prevalence of HIV is highest in Cameroon at 5.3%, Central African Republic 4.7%, Côte d'Ivoire 3.4%, Gabon 5.2%, and Nigeria 4.1% (UNAIDS, 2013). Adult HIV prevalence in East Africa exceeds 5% in Uganda (7.2), Kenya (6.1) and Tanzania (5.1%), as reported by UNAIDS (2013).

2.4.1 HIV AND AIDS IN NIGERIA

Worldwide, Nigeria has the second highest number of new HIV infections estimated at 310 000, second only to South Africa whose new HIV infections were estimated at 610 000 (UNAIDS, 2013). Approximately 210 000 people died from AIDS in Nigeria in 2011 and in 2012, the national life expectancy went down to 52 years (United Nations Development Programme [UNDP], 2013). The national life expectancy which was around 45.5 in 2002 has been rising since access to ART became available in the mid-2000s (Nasidi & Harry, 2007; AVERT, 2013). If the HIV epidemic did not exist, life expectancy in Nigeria have been projected to reach nearly 62 years in 2015 (NACA, 2012), but the significant mortality rate from AIDS have diminished any positive effects that might have occurred as a result of other improvements in life standards and health care (Nasidi & Harry, 2007).

Nigeria, despite having the largest economy in Africa and the 26th biggest economy in the world (Ogunlesi, 2014), has some of the worst healthcare outcomes and indicators in the world, with over 70 percent of its population living in poverty (Onwudiegwu and Awolowo, 2012). For instance, Nigeria with a maternal mortality ratio of 1 100 per 100 000 is one of the fourteen countries worldwide with a maternal mortality ratio of at least 1000 per 100 000 and despite being just 2 percent of the world's population, the country contributes as much as 8% of the world's annual mortality in neonates (UNICEF, 2009). Nigeria is home to 10 percent of the global population of people living with HIV, and still has a long way to go in tackling its devastating HIV and AIDS epidemic (AVERT, 2013).

Key drivers of the epidemic in Nigeria was listed by NACA (2012) and this are low personal perception, multiple concurrent partnership, intense transactional and inter-generational sex, ineffective and inefficient services for sexual transmitted infections (STIs) and inadequate access

to and poor quality of healthcare services. Entrenched gender inequalities and inequities, chronic and debilitating poverty, and stubborn persistence of HIV and AIDS related stigma and discrimination are also contributing significantly to the continuing spread of the infection in the country (AVERT, 2012). In Nigeria, heterosexual sex particularly of the low risk type between men and women in long term and committed relationships contributed a whopping 80% of new HIV infections in the country (NACA, 2012). This suggests that HIV epidemic in Nigeria is a family disease and might explain the high prevalence of children that have lost one or both parents to the epidemic.

2.5 THE IMPACTS OF HIV AND AIDS ON YOUNG PEOPLE

Young people are an ever-growing part of the HIV and AIDS epidemic. The HIV and AIDS epidemic has exacted a terrible toll on young people and their families. During the 30 years of the global HIV epidemic, an estimated 17 million children have lost one or both parents to AIDS, 90 percent of these young people live in SSA (Emanuel, 2012). In addition, 3.4 million children under age 15 are living with HIV. UNICEF (2012) further noted that, despite some decline in HIV adult prevalence worldwide and increasing access to treatment, the number of young people affected by or vulnerable to HIV remains alarmingly high. Using formative models of predictions, Voluntary Service Overseas (VSO, 2006) estimated that an additional 10 million children will be orphaned by AIDS before the end of 2015.

In Nigeria, 2.4 million young people are orphaned due to AIDS (FMWA&SD, 2008). New infections have stabilized, but owing to a time lag between parents' infections and death, adults death will continue to add to the number of AIDS orphans in the next decade (AVERT, 2012). Even with improved effectiveness, ease of administration and access to treatment, the number of AIDS orphans will thus remain exceedingly high (UNICEF, 2012). Ongoing prevention strategies must thus be joined by efforts to improve the quality of life for all who are and will continue to live with and be affected by HIV and AIDS in Nigeria. According to PEPFAR (2012), programming for children and youths affected by HIV/AIDS contributes to achievement of an AIDS free generation and calls for appropriate responses to the social and emotional consequences of the disease on them. Furthermore UNICEF (2010) and FMWA&SD (2008) also

recommended that interventions for these youths should reflect local realities and should incorporate the unique experience of individual affected youths so that HIV-sensitive care can be rendered.

2.5.1 TOWARDS CONCEPTUAL CLARITY: WHO ARE THE YOUTHS WHO HAVE LOST PARENTS TO AIDS

Youth, as a concept varies from culture to culture and from society to society. This variation in the conceptualization of youth has important implications for research, planning and interventions. Researchers exploring the complex, evolving and multi-dimensional phenomenon of AIDS orphanhood have therefore used terms such as “youths”, “adolescents”, and “children” to describe AIDS orphan. It is apparent that there are important conceptual differences between terms, which make it difficult to understand who an AIDS orphan is. Binikos (2008) argued that the shrewdness in conceptual clarity and definitions may be attributed to schisms between legal, academic and cultural constructions of the phenomenon of „youth“. Regardless of the age of orphans, researchers have often treated them as a homogenous group.

Considering that every youth who have lost a parent to AIDS is part of a family, research exploring the impact of AIDS on youths can be conceptualized as a family-related research and there are important methodological and theoretical implications. Woodgate and McClement (1998) stated that conceptual or theoretical framework underpinning family research should drive: definition of the family; conceptualization of the family, that is; were the families conceptualized as systems or were they conceptualized as the environment for individual family members?; sampling of the participants; and analysis of data. Demi and Warren (1995) and Woodgate and McClement (1998) added that inability of researchers to control variables such as age, living conditions and bond between family members can undermine the result of a family-related study. Wide age variation between participants might undermine successful design of intervention.

In Sub Saharan Africa, persons aged 10-24 comprise about 33% of the total population (Kabiru et al., 2013). Nigeria’s population is made up of one-third of young person’s between the ages of 10-24 (National Youth Policy, 2009). The progression from childhood to youth involves some

systematic rites of passage. These rites have symbolic significance in that, simply by participating in them, an individual achieves a new status and position (National Youth Policy, 2009). It is therefore necessary to separate the experience of a youth from a child, this study conceptualize a youth as a Nigerian citizen between the ages of 18-24 years.

2.6 SEARCH STRATEGY FOR SCHOLARLY STUDIES

The search strategy aimed to find published peer reviewed studies that explored the phenomenon of AIDS-orphanhood. There was no date restriction set because the researcher wanted as many studies as possible. Only studies published in English were retrieved. The search was carried out through EBSCOHOST which consists of Cumulative Index to Nursing and Allied Health (CINAHL), Academic Search Complete, Medline, PsychINFO and Health source databases were used.

The key words „orphans“ and „AIDS“ produced 1 253 articles; when combined with „experience“ and „needs“, the articles were reduced to 880 articles. Following the removal of 87 duplicate titles, the titles and abstracts of the remaining 793 articles were reviewed against the review inclusion criteria.

2.6.1 Inclusion criteria

Studies that met the following inclusion criteria were included in the review:

- Participants of interests: AIDS orphans were the interest of this review with a special focus on those who are over the age of 18 years.
- Phenomena of interest: The researcher was interested in exploring the experience and needs of AIDS orphans with a special search light on orphans who are above the age of 18 years.
- Types of studies: The review included primary empirical research that collected data from AIDS orphans and whose focus is on their experience, needs or a combination of both.

During this process, 714 studies were excluded; leaving 79 articles which were retrieved for full text examination. After review of the full text, 19 studies were included that met the inclusion

criteria for the review. The reference list of the 19 studies that met inclusion was also examined for additional studies that might meet the review inclusion criteria but none met the criteria.

Table 2.1: Search strategy used to identify scholarly relevant studies

| Database | Key words | No. of hits | No. of articles deemed relevant following abstract reading |
|---|-------------------------------------|-------------|--|
| Academic Search Complete | Orphans, AIDS, experience and needs | 289 | 33 |
| CINAHL | Orphans, AIDS, experience and needs | 239 | 22 |
| Medline | Orphans, AIDS, experience and needs | 161 | 09 |
| Psychinfo | Orphans, AIDS, experience and needs | 101 | 10 |
| Health Source: Nursing and Consumer Edition | Orphans, AIDS, experience and needs | 90 | 10 |

2.6.2 THE LIVED EXPERIENCE OF YOUTHS WHO HAVE LOST A PARENT TO AIDS

Parentification, the early and premature assumption of parental roles and adult responsibilities by young persons before they are emotionally or developmentally prepared for such roles was reported by several of the reviewed articles. In the ethnographic study conducted in Zambia, Yamba (2005) found that orphans started living in child-headed households immediately after the loss of parents and the eldest child who was a 10 year old girl became the head of the household. Yamba (2005) who followed three AIDS orphans for nine years documented that the age of orphans predict headship of a child headed household with the older orphans more likely to sacrifice personal gratifications such as leisure, education and healthy choices in order to ensure the survival of the family. Within the span of just nine months, the participants in the ethnographic study by Yamba (2005) in Zambia went through three phases of bereavement that involved not only the loss of their dearest caregivers (parents, grandparents and uncle) who gave them emotional support and love but the loss of physical homes and environments that they had come to love and feel secure in. While Yamba (2005) can be commended for following three AIDS orphaned siblings for nine years, the study by Yamba (2005) raised moral and ethical questions about the ancillary-care responsibilities of researchers. Yamba (2005) witnessed how the oldest orphaned child became pregnant at the age of 13 years, got infected by HIV, lost her

child to Meningitis and was in a critical health condition at the time the study was concluded but the researcher did not do anything to intervene in the plight of the participants.

In Uganda, Harms et al. (2010) conducted semi-structured in-depth interviews with 13 AIDS orphans who were conveniently sampled. The youths in the study described how their childhood ended after the loss of parents to AIDS and how they had to take up adult responsibilities such as caregiving and economic roles in order to survive. However, the authors seem not to distinguish clearly the experience of the youths before and after the loss of their parents to AIDS. As such, it seems the authors reported feelings and emotions instead of experience and this might be attributed to the short duration of orphanhood which was two months among some of the participants. The disparity between HIV statuses of the orphaned youths might mean that participants might not be experiencing the same phenomenon in the study conducted by Harms et al. (2010). Literature has revealed that the experiences of HIV positive orphans are different from the experience of orphans who are HIV negative (Wild, 2001).

Being the eldest emerged as the most important feature that defined parentification among AIDS orphans from the result of the ethnographic study conducted among orphans in Zimbabwe (Francis-Chizororo, 2010). Francis-Chizororo (2010) used a variety of data collection tools such as participatory diagramming, in-depth interviews, focus group discussions over a period of two months to study the experiences of AIDS orphans in relation to their socialization and gender relations, and found that cultural expectations creates a sense of obligations in children over siblings. Considering that the study by Francis-Chizororo (2010) was conducted within two months, some of the claims by the author such as the instability, socializations and dynamics of child-headed households might not be sufficiently explored to make ambiguous conclusions of conflicts, discipline, income generations and patterns of care raised by the study.

Similarly, Evans (2010) reported multiple losses of childhood, identity and inheritance as some of the experiences of AIDS orphans in Uganda and Tanzania. The study whose main objectives was to gain insight into the experiences and support needs of youths who are orphaned by AIDS by piloting qualitative and participatory research methods in two different countries criticized the

strict age-based definition of „orphanhood“. Evans (2010) argued that the strict age-based „orphanhood“ definitions specified in international development interventions which excludes youths aged 18 and over from support means they faced untold hardships that might impact negatively on their transition into healthy adults. Evans (2010) utilized focus group discussions to gather data from fourteen young people between the ages of 12-23 and triangulated their opinions with 39 community members and NGO staffs. The study revealed that most young adults started experiencing care giving roles between the ages 12-15 before parental loss to AIDS and this continued till when they transitioned into youths. As expected, majority of their AIDS orphans“ experience centred on caregiving activities such as engagement in income generating activities, experience and management of relationships conflicts between themselves and siblings, experience of poverty, loss of educational opportunities because of caregiving roles and the likes. There was no significant difference between youths who were household heads in Uganda and Tanzania except that: young men in Uganda spent longer hours in activities related to income generation for their family. Again, the disparity between participants age range is a cause for concern because even though all participating young persons were all household heads, they were at different developmental stages. While those between the ages of 12 and 18 might be struggling to resolve issues about identity and roles; those in the older age group are likely to be more concerned about intimacy. Evans (2010) even reported that older orphans are sometimes torn between getting married and leaving their siblings to survive on their own or rejected marriage chances in order to continue supporting siblings.

In-depth semi-structured interviews conducted among orphans aged 17-22 years in Zimbabwe also reported that AIDS orphaned youths felt „grown-up“ or „like adults“ because of previous emotional challenges of parental HIV illness and present caregiving responsibilities (Wood, Chase & Aggleton, 2006). Most of the findings of Wood et al. (2006) suggest that significant proportion of the participants were still grieving and have not accepted the death of parents at the time of data collection (pg. 6); hence, the findings of their study is more of feelings rather than experience of AIDS-orphanhood. The insufficient description of participants“ variables such as duration of orphanhood makes the reader question if participants were allowed to resolve their grief before study enrolment.

The hardship that AIDS orphans endure on a daily basis is indescribable as elicited by the literature reviewed. Almost all the participants in the study by Ogina (2010) in South Africa reported being plagued by hunger despite being supported by a local NGO. Ogina (2010) reported that some of the study participants revealed during the interview sessions that they had health conditions that require constant medical care but lack of funds and parental support meant that these participants are in constant agony. The data collection strategy (drawing) employed by Ogina (2012) seems to place several eligible orphans at a disadvantage considering that their initial sample size reduced from 57 to 12 because 45 out of the 57 orphans were unable to depict their experiences in form of drawing. Using drawings might not be sensitive enough for children who have been previously disadvantaged due to parental illness and poverty; and this strategy is likely to be developmentally, socially or academically inappropriate. The authors also did not sufficiently describe the criteria that informed arrival at a sample size of 12 such as data saturation or practical reasons.

At a critical time of their childhood development AIDS orphans in South Africa experience abandonment by those who were supposed to be their primary care givers (Van Rooyen, Froot & Ricks, 2012). Similar to the findings by Yamba (2005), Van Rooyen et al. (2012) reports that most AIDS participants in their study have witnessed multiple phases of bereavement and some of the participants had no one to be their foster parents, thereby leaving them bewildered, confused and hurt. The study by van Rooyen et al. (2012) however lacks detailed description of the participants' status such as their recruitment strategies and data collection period which calls into question the validity and transferability of their findings. Given that there were no official interventions from government or NGOs in supporting the participants' recruited by Rooyen et al. (2012); there is insufficient research data to substantiate the discovery of resilience which was reported. The participants build their resiliency and hope from relationships with the opposite sex in their own network. This strategy carries some psycho-social risks of exposing them to unhealthy lifestyles such as early sexual intercourse considering that they were even below 18 years.

In a bid to engage in income generation endeavours, Daniel and Mathias (2012) states that AIDS orphans constantly experience physical abuse such as beatings; psychological abuse such as insults and false accusations; and sexual abuse such as sexual harassment and rape. The poignant issue identified in the study of Daniel and Mathias (2012, page) was the helplessness of AIDS orphans when faced with abuse. The study used phenomenological in-depth interviews to explore the experiences of AIDS orphaned youths in Tanzania and identified that orphans sometimes faced the risk of losing their home, income and being killed if they refuse to submit to forced sex (reference). Some of the participants got infected with HIV infections as a result of being raped and some of them were force to become prostitutes. The experience of psychological abuse and mistreatment by foster families was the primary reason for child headed households in the study conducted by Evans (2010). Child headed households are particularly vulnerable to negative outcomes such as unplanned pregnancies, sexually transmitted infections, and exploitation because of lack of a supportive adult figure.

Thupayagale-Tshweneagae et al. (2009) utilized a qualitative phenomenological approach to explore the lived experience of eight young persons between the ages of 14 to 18 who have lost parents to AIDS in South Africa. Reflective journals were used to collect data about participants' feelings, thoughts and experiences about AIDS orphanhood with the aim of extracting information about participants' mental health challenges. The findings of the study by Thupayagale-Tshweneagae et al. (2009) established that a thin line existed between caring for AIDS orphans and what could be perceived as discriminatory care. As an illustration, participants described that they felt that adoptive families tried to take the place of their dead parents when they refer to them as „sons“ or „daughters“ rather than cousins or niece (page 11). This calls for sensitivity when designing caring approaches to meet the needs of AIDS orphans. A comprehensive health education services should be made available to those rendering any form of support for AIDS orphans.

Ogina (2012) also noted that interview sessions with AIDS orphans in South Africa yielded experiences of alienation by peers, caregivers and community members which consequently made orphans to feel frustrated, angry and helpless. Harms et al. (2010) complemented the study

of Ogina (2012) and reports that orphans in Uganda are subjected to derogatory stigma remarks and often reminded of their inferior societal position because of their parental AIDS illness and death. Harms et al. (2010) argued that stigmatizing terms are used in the community to invoke gratitude from the orphans, especially from the caregivers and that regardless of the orphans' HIV status. Stigma makes integration of orphans into their environment difficult and they often experience social difficulties (Ogina, 2012).

All the reviewed articles offered important opening into understanding the experience of AIDS orphans. They assisted to build a picture of what AIDS orphans experience on a daily basis. These studies that met the inclusion criteria for this review were all conducted in SSA and therefore confirm that SSA researchers are pretty much aware of the need to explore the experiences of AIDS orphans. All of the articles reviewed were qualitative studies. However, the researchers used various approaches such as ethnography, case study and phenomenology to explore the phenomenon of AIDS-orphanhood to arrive at the findings described above. None of the twelve reviewed articles was specifically carried out among the age group (18-24 years old). Three studies conducted in Zimbabwe, Tanzania and Uganda (Francis-Chiroro, 2010; Wood, 2006 and Evans, 2010) combined children and youths in their samples (10-19, 17-22 and 12-23 years old respectively). This study is interested in carving out the experience of those youths aged 18-24 from those of children. This meant that the three studies that combined children and youths and those that were entirely on children offered limited help in answering the research question of this study. More worrying is the fact that no study was identified from Nigeria, despite the reality of having one of the highest numbers of AIDS orphans in the SSA.

2.6.3 THE NEEDS OF YOUTHS WHO HAVE LOST A PARENT TO AIDS

Thupayagale-Tshweneagae and Mokomane (2012) purposively recruited 15 adolescents who are AIDS orphans and regular attendants of a Hospice centre in South Africa for the purpose of understanding their needs. The study which was a phenomenological study revealed that adolescents in the study needed strong social support system through family, friends and other significant persons. The need for love, acceptance and security was profusely expressed by the participants. It is important to note that the study by Thupayagale-Tshweneagae and Mokomane

(2012) only recruited regular attendants of a support facility, suggesting that the irregular attendants and other eligible adolescents that might need greater psycho-social assistance were not included in the study. The over-reliance on photography and photo-elicitation as a means of data collection suggests that some of the needs of the participants might not be properly accounted for in situations where the participants were unable to capture needs that relates to emotional, psychological and abuse; mal-functionality of the camera and poor expertise in its use can also rob the reportage of important needs of the participants”.

Chitiyo, Changara and Chitiyo (2008) admitted that AIDS orphans have special needs which qualify them for special curriculum with in-built psychosocial support. Chitiyo et al. (2008) therefore instructed school teachers in some designated schools in Zimbabwe to observe the behavioural manifestations of AIDS orphans in their classes and designed psychosocial training program (hereafter PSS) for the orphans based on the observations of their teachers. The teachers reported that AIDS orphans demonstrated signs of withdrawal, short temperament, crying and bullying (Chitiyo et al., 2008). The researchers designed a PSS training program that included counselling for grief and bereavement, games, buddy system, provision of physical needs and administration of biblical scripture union lessons (Chitiyo et al., 2008). The PSS program was then evaluated for effects on the orphans after eighth months of exposure and the findings were that the orphans self-esteem, trust in others, rate of work completion and motivation had increased significantly due to the PSS program. While not undermining the influence that the PSS had on the wellbeing of the AIDS orphans, Chitiyo et al. (2010) relied exclusively on the reports of teachers before the intervention and after the intervention. This study might not be a complete and sound reflection of the needs of the orphans considering that the teachers who observed them were their classroom teachers. It is likely that the teachers are reporting their expectations from the participants rather than their felt needs or expectations.

Cluver, et al. (2012) followed 1021 children under the age of 18 for four years to determine persisting mental health challenges and found that the impact of AIDS-orphanhood got worse not better, with time and with the developmental process of growing up. Cluver et al., (2012) interviewed AIDS orphans, orphans from other causes of parental death and non-orphans with

standardized and validated instruments to assess anxiety, depression and post-traumatic stress disorder in 2005 and 2009. Analysis of variance and backward stepping regression were used to analyse the collected data. The findings from the 2005 study revealed that after controlling for co-factors such as age, gender and type of bereavement, AIDS orphaned children had higher anxiety, depression and post-traumatic stress disorder (PTSD) scores when compared with other orphans and non-orphans. Cluver et al., (2012) reported that age interacted with AIDS-orphanhood status to magnify the rise in levels of depression, anxiety and PTSD. This suggests that negative mental health outcomes were maintained or worsened after four years since the orphans children have move on into a different status of being classified as youths.

However, despite most of the participants being youths at the time of the follow-up study, participants' age still varied greatly (12-23) and there were variations in settings where participants were recruited for follow-up interviews. For instance, some of the participants became inmates in prisons, some migrated outside of Cape Town where the initial study participants were recruited and other became drug addicts using illicit substances. This raises a hypothetical question whether similar psychological outcomes would be achieved for youths 18-24 to that of orphan children under 18 if the same assessment scales used? This concern calls into question how researchers conceptualize youth. Furthermore, AIDS orphans appeared not to be closely matched with other children that became orphans from other causes of parental death.

Addressing the emotional needs of orphans was identified as a potential to mitigate future deviant behaviours such as prostitution, hooliganism in Nigeria (Adejuwon & Oki, 2009). Adejuwon and Oki (2009) purposively recruited 100 AIDS orphans who were permanent residents of orphanages and administered checklists to elicit information about the emotional needs of orphans. The study revealed that AIDS orphans are emotionally unstable and the study recommended de-institutionalization of orphan care to the community because the orphanages were not meeting their emotional needs. The study utilized two checklists (social stigmatization and emotional wellbeing) to gather the information. However, none of the scales have been previously tested among children population in Nigeria. The reliability and validity of the checklists was reported from other countries (Zambia) with different peculiarities (page 5). This made the reader to question how understandable were some of the questions such as, "how often

would you say you have scary dreams” (Adejuwon & Oki, 2009, pg. 8) to draw inferences about the unhappiness, anger and food refusal of the participants and considering that a handful of the participants were seven years olds.

Kumar, Dandona, Kumar, Ramgopal and Dandona (2014) reported that AIDS orphans suffer more depressive symptoms than orphans from other causes in India. Kumar et al. (2014) purposively recruited 397 orphans who were residents of several orphanages in India and used standardized scales to measure depression. The authors listed discrimination, bullying and stigma as some of the factors that predicts increased vulnerability of AIDS orphans to depression and documented that higher mean score for depression was rife among female AIDS orphans. The study also provided evidence on the psychological needs of AIDS orphans which can be provided through counselling. However, the authors mentioned that they were unable to confirm parental cause of death in several occasions and it is likely that the findings might be misreporting depression among AIDS orphans.

Mnubi-Mchombu, Mostert and Ocholla (2009) recognized that access to information underpins AIDS orphans ability to empower themselves for survival and therefore used both qualitative and quantitative methods to examine the information needs of AIDS orphans in Namibia. As expected, AIDS orphans needed a wide array of information that centred around financial assistance and school fees (91%), childcare (82%), psychological support, health services and farming skills (78%), feeding schemes and will writing (74%) and information on identity documents (69%) (Mnubi-Mchombu et al., 2009). A striking finding of the study is that despite the participants“ getting most information through the media sources (radio, television, and newspaper); almost all of them preferred and wanted one to one oral communication about their needs and concerns. Mnubi-Mchombu et al. (2009) even discussed that the information needs preferences of participants that were engaged in individual interviews were different from those in the focus group discussions. This seems to suggest that one size fits all approach might not be appropriate when planning for the care of AIDS orphans. However, the criteria for allocating 19 orphans into focus groups and another 23 for in-depth interviews were not discussed by the authors. Considering that the world is now a global village connected though the internet,

exploring the use of internet among the participants to acquire information would have added more depth to the study.

Satzinger, Kipp and Rubaale (2012) conducted semi-structured interviews with 20 AIDS orphans who were house-hold heads in Uganda for the purpose of exploring their health related worries and needs. The study revealed that most of the orphans interviewed are more concerned about the wellbeing of their younger siblings than their own personal needs. Some of the participants expressed fears about younger siblings' risks of contracting HIV, fears of abuse and discussed that watching siblings crumble to the effect of hunger and illness is probably as agonizing as the loss of their parents (Satzinger et al., 2012). Satzinger et al. (2012) commented that some of the orphans who were households head were not interviewed because they were older than 18 years and did not meet the UNICEF definition of orphans. However the authors were unable to interview the house-hold head and they interviewed the second oldest child instead. While this strategy could have increased the depth of the study and the shared experience of participants, it can also distort the reality of the needs of those orphans.

Okawa, Yusuoka, Ishikawa and Krishna (2011) added that AIDS orphans cohabitation with biological siblings increased perceived social support (PSS) scores which consequently increased their psychological wellbeing. Okawa et al. (2011) used a number of scales (multidimensional scale of perceived social support and depression scale for children) to establish what constitutes perceived social support for 327 AIDS orphans in Kenya. While establishing that PSS is positively associated with the psychological wellbeing of orphans, lower depressive scores and higher self-esteem; cohabitation with siblings was the most important source of social support. However, a distressing finding of the study is that PSS was low among non-HIV infected orphans; suggesting that infected orphans are shown more support by organizations despite that the non-infected orphans are at a risk of becoming infected without prompt interventions. It is important to note that the scales used in the study were not validated in Kenya as at the time when the study was conducted and the researchers relied on the reliability and validity of the scales based on the report of a study conducted in China; this have implications for the study findings.

Germann (2006) challenged the conventional view that conceptualized AIDS orphans as the object of charity and therefore advocated for strategies such as resilience that can sustain them for life. Germann (2006) adapted the WHO quality of life psychometric assessment tool and the social support scale to explore the quality of life of AIDSs orphans who are head of their households in South Africa. One of the reassuring findings of the study by Germann (2006) is the remarkable resilience and extraordinary resourcefulness displayed by the AIDS orphans. The study advocated for capacity building that is related to resilience development and argued that direct approach interventions for individual orphans can undermine the orphans coping abilities, stigmatize them and lower community support for them. However, all the findings of this study were not grounded in the data and the credibility cannot be ascertained. Important information such as the age of participants, recruitment strategies, research settings and data analysis were missing in the paper and most of the claims of the authors where not supported by any data or quotations from the participants. This meant that one cannot have complete confidence in the author's data that 105 orphans were followed over a 12 month period but later claimed again that 142 participants were engaged in various form of data gathering. While not undermining the findings of the study by German (2006), it is important to state that the lack of clarity on how results were arrived at, did little to assist in the understanding of the needs of orphans and throws the search for their needs into more confusion.

In Zimbabwe, Gregson et al. (2005) reports that among AIDS orphans who are women, 3.2 percent were HIV positive whilst no cases of infection were found among non-orphans. This suggests that AIDS orphans are more at risk for adverse reproductive health outcomes than non-orphans. Gregson et al. (2005) used multivariate logistic regression models to explore the effects of being an AIDS orphans on adverse reproductive outcomes among 1,253 AIDS orphans in Zimbabwe and found that having an HIV infected parent and the loss of a mother constitute the greatest and most consistent sources of vulnerability to adverse reproductive health outcomes. The findings of the study by Gregson et al. (2005) suggests that among the AIDS orphans, the female orphans are more vulnerable to adverse reproductive outcomes because they are more likely to have commenced sexual activity at a very young age and to have been married than

their non-orphan counterpart despite their tender age. As they grow older, female orphans face lower status, limited personal autonomy, and reduced life and ultimately survival chances due to curtailed education, poor health, early child-rearing and marital responsibilities (Gregson et al. 2005).

2.7 CHAPTER CONCLUSION

This chapter reviewed relevant conceptual and empirical articles about HIV and AIDS and the impact of the epidemic in Africa and among young people. The focus of this chapter was to engage with the literature review of what researchers are reporting on the experiences of youths above age 18 years who have lost parents to AIDS. However, the usage of the concept „youth“ seems to vary between researchers, making it a near impossible task to delineate research findings to the contemporary context of AIDS orphaned youths in Wannune, Nigeria. Furthermore, majority of research studies were conducted among children below the age of 18 years who are AIDS orphans. This validates that the experiences and voices of AIDS-orphaned youths who are over 18 years are missing in the literature. This might explain the reasons provision was not made for them in AIDS policy frameworks for orphans. Attempts were made to critically analyse researchers“ approaches to data collection, sampling strategies, characteristics of participants and other materials in order to identify what can be improved on. Some of the concerns found in the reviewed empirical studies that can hamper extrapolation of data among children and other context to the present research settings were discussed.

Table 2.2: Description of the reviewed articles related to the ‘experience’ of AIDS orphans

| | Author(s) and Country | Study aim | Participants“ detail |
|----|---|---|----------------------|
| 1. | Harms et al. (2010) Uganda | To explore youth narratives related to orphaning experience | Age: 12-18 years |
| 2. | Ogina (2012) South Africa | To explore life experiences of orphaned children | Age: 10-17 |
| 3. | Thupayagale-Tshweneagae et al. (2009) South Africa | To explore the mental health challenges of the lived experiences of adolescents | Age: 14-18 |
| 4. | Yamba (2009) Zambia | To explore the lives of children who suffer from the parental AIDS loss | Age: 14-18 |

| | | | |
|----|--|---|------------|
| 5. | Wood et al. (2006) Zimbabwe | To explore the narratives of older children who have been affected by parental AIDS related illness and death | Age: 17-22 |
| 6. | Daniel & Mathais (2012) Tanzania | To examine the challenges and coping strategies accompanying the experiences of orphaned children without adequate adult care | Age: 12-18 |
| 7. | Francis-Chizoro (2010) Zimbabwe | To explore the experience of orphaned children in terms of domestic and paid work roles and their socialization | Age: 10-19 |
| 8. | Van Rooyen et al. (2012) South Africa | To explore and describe the lived experiences of AIDS orphans in a township | Age: 12-18 |
| 9. | Evans (2010) Tanzania and Uganda | To explore the experiences and priorities of young people caring for their siblings in sibling headed households affected by AIDS | Age: 12-23 |

Table 2.3: Description of the reviewed articles related to the needs of AIDS orphans

| | Author (s) and Country | Study aim | Participants' details |
|-----|---|---|-----------------------|
| 1. | Thupayagale-Tshweneagae & Mokomane (2012) South Africa | To understand the needs of adolescents orphaned by AIDS | Age: 14-18 years |
| 2. | Mnubi-Mchombu et al. (2009) Namibia | To examine the information needs of OVC | Age: 8-18 years |
| 3. | Gregson et al. (2005) Zimbabwe | To explore the effects of OVC status on adverse reproductive health outcomes | Age: 15-18 |
| 4. | Cluver et al. (2012) South Africa | To assess changes in psychological needs of AIDS orphans | Age: 12-23 |
| 5. | Germann (2006) Zimbabwe | To explore the quality of life and the coping strategies of child headed households | Age: Not mentioned |
| 6. | Chitiyo et al. (2008) Zimbabwe | To examine the emotional psychosocial support needs of OVC | Age: 10-14 years |
| 7. | Satinger et al. (2012) Uganda | To explore the health related worries and needs of orphans in charge of their households. | Age: 13-17 |
| 8. | Okawa et al. (2011) Kenya | To explore associations between perceived psychosocial support (PSS) and psychological well-being among AIDS orphans and to identify social demographic determinants of PSS | Age: 10-18 |
| 9. | Adejuwon & Oki (2011) Nigeria | To provide a better understanding on the emotional wellbeing of OVC | Age: 7-18 |
| 10. | Kumar et al. (2014) India | To conduct a comparative study of the mental health needs among children orphaned by AIDS and orphans of other diseases | Age: 12-16 (sampling) |

CHAPTER THREE: METHODOLOGY

3.1 INTRODUCTION

This chapter discussed the research methodology approach, including the study setting, sampling strategy of participants, data collection process and instrument, data analysis, trustworthiness and ethical considerations. Justification was also given for particular strategies and decisions made. Again, the questions that this study aims to answer are:

1. What is the youths' description of their experiences of the loss of a parent to AIDS related illness in Wannune, Nigeria?
2. What are the psycho-social needs of the youths who have lost a parent to AIDS related illnesses in Wannune, Nigeria?

3.2 RESEARCH PARADIGM

Individual researchers have a matrix of beliefs and perception that guides their action and Creswell (2009) referred to these beliefs as worldview or paradigms. Paradigms are patterns of beliefs and practices that regulate inquiry within a discipline by providing lenses, frames and processes through which investigation is accomplished (Weaver & Olson, 2006). Creswell (2009) identified four paradigms that are mostly utilized in research studies, namely: post positivism; constructivism, advocacy/participatory and pragmatism. The paradigm chosen for this study is the qualitative constructivist paradigm. The choice of a qualitative methodology was theoretically and practically driven because there was a commitment to seek in-depth knowledge of the experiences of the participants being studied (Bryman, 1988). Also there were only small numbers of respondents available to take part in the research, making the collection of quantitative data impossible.

The choice of qualitative paradigm affords the researcher to understand the significance and meaning that different individuals attach to social or human problems (Yilmaz, 2013) and it tends to be more suitable in situations where little is known (Patton, 2005). The nature of this research study requires an exploration of the lived experience of the participants and as Converse (2012) noted, studies of human experiences are not approachable through quantitative methods. Furthermore, the researcher is unaware of any previous study in Nigeria conducted to explore the

lived-experience of unsupported AIDS orphaned youths. There is little information available about how they are making sense of their orphanhood experience.

Paradigms for human inquiry are characterized in terms of the ways in which they respond to philosophical assumptions, namely: Ontologic; Epistemologic and Axiologic (Yilmaz, 2013). The ontological nature of constructivist enquirer with regards to these assumptions is that constructed reality is subjective, multiple and influenced by the context of the situation (Ponterotto, 2005). Epistemologically, constructivists maintained that reality is socially constructed and therefore the dynamic interaction between the researcher and the participants is central to capturing and describing the lived experience of the participants (Ponterotto, 2005). Axiologically, constructivist further noted that researcher's values and lived experiences cannot be stripped from the research process (Ponterotto, 2005). The researcher should therefore acknowledge, describe and bracket his/her values (Wojnar & Swanson, 2007).

In this study, the ontologic assumption was that youths have unique individual experiences whose meaning are constructed from the complex process of interaction between themselves and the social context, epistemologically, these meanings can be understood by interacting with the youths directly without holding prior understanding, thoughts or feelings (axiology). Although qualitative research is not unconcerned with outcomes, a major strength of qualitative studies is their ability to expose the processes that lead to these outcomes something that experimental and survey research are often weak at identifying (Maxwell, 2004).

3.3 APPROACH TO RESEARCH INQUIRY

There are many possible approaches that can be applied to data gathering, management and analysis in order to develop a literary presentation of human experience. Some of these approaches tend to lean towards quantitative or qualitative research methods while others use a combination of both. Research studies, whether qualitative or quantitative usually involve explicit, disciplined and systematic approach to finding things out using the strategy most appropriate to the question being asked (Hancock, Ockleford & Windridge, 2009). According to Starks and Trinidad (2007), qualitative research methods enable health researchers to delve into

questions of meaning, examine social practices and processes, identify barriers and facilitators to change, and discover the reasons for the success or failures of interventions. Qualitative research describes research models that focus on the meaning of the phenomena investigated (Garza, 2007). Thus, in the broad context of research strategies, qualitative research is identified with a commitment to the natural logic of language as the preferred medium for understanding human affairs (Creswell, 2012).

Several approaches provide specific directions for procedures in qualitative constructivist paradigms. These are often subsets of the more general qualitative research term. Among the qualitative research strategies are:

- Phenomenology, whose goal is to identify the essence of human experience about a phenomenon as described by the participants and focuses on the “lived meaning” of the phenomenon it investigates (Moustakas, 1994; Mapp, 2008);
- Grounded theory, which utilizes an inductive process to develop abstract concepts and propositions about the relationships between various categories of the data that reflect the phenomena (Creswell, 2009; Charmaz, 2006);
- Ethnography, which attempts to study an intact cultural group in a natural setting over a prolonged period of time (Creswell, 2012);
- Case studies whose goal is to explore in-depth a program, event, activity, process or one or more individual within its context (Baxter & Jack, 2008) and
- Narrative research, whose focus is on the organization of human knowledge by studying exclusively the lives of individuals (Spector-Mersel, 2010).

Regardless of the strategy employed to answer a qualitative research question, its application is rigorous. As Bogdan and Biklen (1982) noted:

“Qualitative studies are not impressionistic essays made after a quick visit to a setting or after some conversations with a few subjects. The researcher spends considerable time in the empirical world laboriously collecting and reviewing piles of data. The data must bear the weight of any interpretation, so the researcher constantly confronts his or her own opinions and prejudices with the data” (p. 42).

Yilmaz (2013) suggests that the tradition of qualitative inquiry selected by a researcher can shape the design of the study. A judicious choice of method guides the research toward the intended aims and helps ensure that its findings are useful (Starks & Trinidad, 2007). For this study, phenomenology appeared to be the most appropriate strategy considering its emphasis on the understanding of meaning from human phenomena and from the perspectives of those who have experienced it. It also contributes to a deeper understanding of lived experiences by exposing the „taken-for granted“ assumptions about ways of knowing (Sokolowski, 2000). The locus of phenomenological research is human experience and it offers nurse scholars and clinicians an approach to inquiry that has a good fit with nursing philosophy and nursing art that facilitates understanding unique individuals, their meanings and interactions with others and their environment (Lopez & Willis, 2004). Meleis (1996) emphasized that it is important for nurse scholars to develop knowledge that is culturally relevant and respectful of the social realities of those living within the situation.

3.4 PHENOMENOLOGY

Phenomenology is fundamentally concerned with understanding the meaning of human phenomena and provides an excellent methodology for studying the lived experience of human beings (Polit & Beck, 2008; Halldorsdottir, 2000). Kumar (2012) believes that giving a particular phenomenon of interest, a fuller and fairer hearing is the core of phenomenology. The nursing profession constitutes a unique combination of art and science that concerns itself with human responses to actual and potential health problems. Therefore specialized knowledge for the practice of nursing must reflect the lived, contextual realities and concerns of the clients for whom nurses provide care (Lopez & Willis, 2004)

Phenomenology is derived from philosophy and provides a framework for a method of research (Marshall & Rossman, 2010). Phenomenology can therefore refer to a research method or a philosophy (Creswell, 2009). Phenomenology is a philosophical perspective that helps researchers to explore and to understand everyday experiences without pre-supposing knowledge of those experiences (Converse, 2012). That is, the researcher is open to what presents itself

during a phenomenon. The phenomenological method, which examines subjective human experience, is commonly used in answering questions that are foundational to sound nursing science (Lopez & Willis, 2004). Sokolowski (2000) mused about the power of a phenomenological inquiry as follows:

“Phenomenological statements, like philosophical statements, state the obvious and the necessary. They tell us what we already know. They are not new information, but even if not new, they can still be important and illuminating, because we often are very confused about just such trivialities and necessities” (p. 57)

Through close examination of individual experiences, phenomenological analysts seek to capture the meaning and common features, or essences of an experience or event; phenomenologists are therefore interested in common features of the lived experiences (Starks and Trinidad, 2007). The purpose of phenomenology as a method of enquiry is to discover patterns or structures of phenomena as lived within the fabric of everyday life (Edward & Welch, 2011). Phenomenology is acknowledged as a suitable methodology for gaining insight into the essence or structure of the lived experience (Walker, 2011). The nature of the inquiry is to search for truth and understanding from the perspectives of those being studied and is especially useful when a phenomenon of interest has been poorly defined or lacks conceptualisation (Thibodeau, 2015).

However, there is more than one philosophical school of phenomenology, and the research findings generated will depend on which philosophical approach that is used (Lopez & Willis, 2004). In relation to phenomenology, Kupers (2009) argued that it is not a rigid school or uniform philosophic discipline. There is great diversity in the points of views of thinkers who could be classified under the general rubric phenomenology (Kupers, 2009). The diversity in opinions and ideas of various phenomenological scholars has modified the phenomenological approach to doing research and this has been termed phenomenological movement (Kupers, 2009; Lopez & Willis, 2004).

Phenomenology as a philosophical movement and as a method of qualitative enquiry has many different strands, interpretations and followers (Tuohy, Cooney, Dowling, Murphy & Sixmith,

2013). Because assumptions drive methodological decisions, Lopez and Willis (2004) advised phenomenological researchers to be cognizant of the values and claims associated with each phenomenological approach before making a commitment to a choice. Several authors (Polit & Beck, 2008; Lopez & Willis, 2004; Kumar, 2012; Hamill & Sinclair, 2010) identify two types of phenomenology. These are descriptive and interpretive phenomenology. Although both types shares some similarities, Balls (2009) stressed that lack of clarity and muddling of the types can significantly reduce the value of the research.

While different philosophical commitments have taken research practice in diverse directions, all phenomenological research has at its core the description of the things as they appear and a focus on experience as lived (Kumar, 2012). The special strength of phenomenological research is the way it can capture some of the ambiguity, poignancy, complexity and richness of lived experience, allowing readers to see the worlds of others in possibly new and deeper ways (Finlay, 2009). This study leans towards descriptive phenomenology because the study is aimed at description of experience and not primarily interpretation which is the focus of interpretive phenomenology.

3.4.1 Descriptive Phenomenology

Husserl's (1970) philosophical ideas about how science should be conducted gave rise to the descriptive phenomenological approach to inquiry (Kumar, 2012, pp. 792). An assumption specific to Husserl's philosophy was that experience as perceived by human consciousness has value and should be an object of scientific study (Lopez & Willis, 2004). Husserl believed that subjective information should be important to scientists seeking to understand human motivation because human actions are influenced by what people perceive to be real (Kumar, 2012). Although, phenomenological research has overlaps with other essentially qualitative approaches including ethnography, hermeneutics and symbolic interactionism (Hays & Singh, 2012), pure phenomenological research seeks essentially to describe rather than explain, and to start from a perspective free from hypotheses or preconceptions (Kumar, 2012).

Descriptive phenomenology proposes that a phenomenon be described instead of being explained or having its causal relations searched for, and it focuses on the very things as they manifest themselves to those who lived it (Sadala & Adorno, 2001). A core element of descriptive phenomenology is that extraneous factors, such as religious, cultural thoughts and beliefs that can influence how phenomena are understood, should be put aside before they can be understood in their purest sense (Tuohy, et al., 2013). Husserl's approach to phenomenology conceived human beings as free agents that are responsible for influencing their environment and it calls for exploration of phenomena through direct interaction between the researcher and the objects of the study (Kumar, 2012). Several authors (Converse, 2012; Tuohy et al., 2013) identified bracketing, intentionality and essences as the distinguishing elements of a descriptive phenomenological study and these elements will be discussed below in relation to this study.

3.4.2 Bracketing

The term bracketing, derived from mathematics is a fundamental methodological principle of descriptive phenomenology (Finlay, 2009). The researcher's pre-conception are held in abeyance to ensure that researchers do not allow their assumptions to shape the data collection or impose their understanding and constructions on the data (Polit & Beck, 2008). In mathematics, brackets are used to separate one part of an equation from another, allowing focus on that part placed in isolation from the others (Hamill & Sinclair, 2010). In phenomenological research, brackets are used to temporarily hold in abeyance the fore-knowledge of the researcher (Priest, Roberts & Woods, 2002). By bracketing, the researcher does not influence the participants understanding of the phenomenon and it therefore becomes their reality.

What made descriptive phenomenology distinct from naturalistic science and other qualitative approach to research, is the idea of philosophical reduction, also known as bracketing or epoche (Converse, 2012). The hallmark of descriptive phenomenology is the assumption that researchers put aside their culturally induced interpretation of a phenomenon in order to discover the essential meaning of the phenomenon (Garza, 2007). Husserl's greatest contribution was to articulate the reduction (or epoche) as a radical self-meditative process where the researcher suspends the natural world and world of interpretation to see the phenomenon in its essence

(Finlay, 2009). This entails the process of intuition, in which phenomenologist researchers“ attempts to be open and to meet the phenomenon in a fresh way and bracketing out habitual ways of perceiving the world (Finlay, 2009). In the context of phenomenological research, bracketing is the suspension of the researcher“s prejudices, preconceptions and beliefs (Dowling, 2007), so that they do not influence participants“ descriptions of their experience (Converse, 2012, Hamill & Sinclair, 2010; Chan, Fung & Chien, 2013; Finlay, 2009). Therefore the bracketing implies that no judgement is made (Koch, 1995) because descriptive phenomenology has as its focus the description rather than explanation of individual“s lived experiences (Wojnar & Swanson, 2007).

Essentially, each participant can present the researcher with new knowledge and new understanding in the search for the essence of things through the identification of essential themes (Beech, 1999; Parahoo, 2006). By bracketing, one can temporarily suspend what one thinks and already knows by actively listening to individual participant“s reality. LaVasseur (2003) suggests we regard bracketing as our natural attitude: that is, as the ordinary lack of curiosity with which most of life is lived.

Bracketing assist the researchers to focus on the uniqueness of the phenomenon being studied (Van Manen & Adams, 2010) and occurs when researchers go beyond their natural attitude by suspending or bracketing their pre-suppositions. The process of bracketing has been described by authors (Kumar, 2012; Giorgi, 2009; LeVasseur, 2003) as:

- separating the phenomenon from the world and inspecting it;
- dissecting the phenomenon to unravel the structure, define it, and analyse; and
- suspending all preconceptions regarding the phenomenon and confronting the subject matter on its own terms, to ensure that the researcher holds in abeyance any preconceived ideas while he or she is listening to, interacting with, and analysing the stories of the participants.

Bracketing Applied

To achieve bracketing in this study, the researcher only relied on the prompt of the report of a situation analysis conducted on OVC (USAID, 2009) in Nigeria that clearly identified AIDS

orphaned youths who are over 18 years as an unexplored category of OVC. To this end, the researcher did not review any material relating to experiences and needs of AIDS orphaned youths in the literature before data collection and analysis were completed. This meant that all the themes presented in the findings of this study were gleaned from the life stories of the study participants and were not influenced by what has been reported previously in the literature. Furthermore, the researcher has never lost a parent as a youth to AIDS; and therefore did not know the reality and experiences attached to AIDS-orphanhood. This assisted in the non-interference of the researcher with participants' description of orphanhood phenomenon during interviews, data analysis and reportage of findings. Bearing in mind that the participants of this study were diverse and the way they experienced the orphanhood were somewhat different due to family composition, support factors available, age position in the family and economic factors; all participants presented a fresh and unique account of the orphanhood experience.

All the factors and strategies presented above meant that during interviews, the researcher was just „like an empty vessel“ waiting to be filled up with the participants' stories. I was presented with stories that I could describe as new, strange, incisive, emotional and powerful; that made me unable to judge, but rather to receive and accept. It was like if I was faced with a pyramid with several sides and angles because all participants presented something new. Although some of the experiences and needs had converged, the road to the convergence of their experiences was not the same. It was like an adventure and I had to concentrate on the side of the pyramid facing me at a particular time. The researcher further used reflective journals to document feelings, thoughts and perceptions during the interviews and analysis. This was used to examine my position on the issues raised and the emerging themes.

3.4.3 Intentionality

The term intentionality refers to the fact that any act of mind is directed to an object: that is, whenever someone wants, they must want something, whenever someone thinks, they must think something; and so on for all mental phenomena (Hamill & Sinclair, 2010). Husserl (1970) argued that intentionality is the distinguishing characteristic of consciousness as consciousness is always consciousness of something (Crane, 1998). Conversely, Johnson (2000) assumed that

there is a phenomenon only when there is a subject who experiences the phenomenon; meaning is projected onto the object by the perceiving subject.

In descriptive phenomenology, one's experience is directed towards something through particular concepts, thoughts, ideas, images and so on (Kupers, 2009). In order to study the structure of consciousness, Kupers (2009) argued that a phenomenological researcher should distinguish between the act of consciousness and those phenomena at which it is directed. Descriptive phenomenology therefore makes a distinction between the perceiving act of consciousness (noesis) and the phenomena at which it is directed (noemata). Moustakas (1994) describes „noema“ as that which is experienced while „noesis“ is the way in which it is experienced. From a phenomenological point of view, the „noesis“ is not the colour of the tree which changes according to the intensity of the light, but the colour itself as we perceive it (Moustakas, 1994). On the other hand, the „noema“ of a colour corresponds to the sensed colour (Moustakas, 1994). Both „noema“ and „noesis“ makes up the concept of intentionality in descriptive phenomenology.

In the context of this study, the „intentionality“ of the youths is their relation to the phenomenon of parental loss to AIDS and their orientation towards the phenomenon. Although the youths in the study were affected by the same phenomenon which is the loss of their parent to AIDS related illness, they possessed experience of the phenomenon in different ways. Parental loss from AIDS related illness is the „noema“ and it is the phenomenon that is being experienced by the youths. The way they experienced the phenomenon of parental loss from AIDS related illnesses is the „noesis“. Among children under 18 years who are orphaned by parental AIDS related illness, UNICEF (2010) reiterated that the experiences of orphaned and vulnerable children vary across families, communities and countries. It is therefore expected that factors such as the youth relationship with his or her caregivers, wealth of households, age of the youth when parental loss occurred, type of orphanhood (double or single), support networks, HIV prevalence in the community can determine how the phenomenon is perceived by the youths. Moustakas (1994) hinted that the „noema“ (external perception and the subjective side of an act)

and the „noësis“ (internal perception and the objective side of an act) must be unified in order to arrive at the essences of a phenomena.

3.4.4 Essences

Another assumption underlying Husserl's approach to the study of human consciousness is that there are features to any lived experience that are common to all persons who have the experience (Converse, 2012). These are referred to as universal essences (Kupers, 2009). The essences are considered to represent the true nature of the phenomenon being studied. Phenomenological inquiry holds the assumption that there is an essence or essences to shared experience (Patton, 2002). The assumption that essences generated through phenomenological research result in one correct interpretation of experiences of the participants represents a foundationalist approach in inquiry (Kumar, 2012). For the description of the lived experience to be considered a science, commonalities in the experience of the participants must be identified, so that a generalized description is possible (Lopez & Willis, 2004). By working with the description of the phenomenon, the researcher focuses on searching for its essence, the most invariable parts of that experience as it is located within a context; the essence, therefore is the very nature of what is being questioned (Sadala & Adorno, 2001).

The end product of descriptive phenomenological investigation is to present a theoretical model representing the essential structures of phenomenon under study (Lopez & Willis, 2004). Swanson-Kauffman and Schonwald (1988) referred to such model as a “*universal skeleton that can be filled in with the rich story of each informant*” (p.104). If the true structure of the phenomenon is identified, then anyone who has experienced the phenomenon should be able to identify their own experiences in the proposed description (Kumar, 2012). In order to determine the essence or meaning of a phenomenon, descriptive phenomenology aims to describe the phenomenon's general characteristics rather than the individual's experiences (Giorgi, 2009). Thus, a phenomenon can be said to exist only when there is a subject who experiences the phenomenon and the focus is to identify the commonalities in the participant's experiences. However, while phenomenology can be seen as aiming to describe general meaning structure, it can also be a search for meanings in an attempt to understand the individual (Finlay, 2009).

In this study, all participants that were interviewed shared the common characteristics of being a youth between the ages of 18-24 and have all experienced the death of a parent to AIDS. Despite variations that existed in individual participant such as living arrangement, support factors, life orientation and how the parental loss to AIDS was encountered, there were commonalities in what they narrated as their experience of loss to AIDS. The commonalities identified in the participants' stories will be presented in the next chapter on data presentation.

3.5 STUDY SETTING

The study was conducted in Nigerian town of Wannune. Wannune was chosen because of its high HIV prevalence, the highest in the country. Wannune is the administrative headquarters of Tarka Local Government Authority (LGA), which is one of the 23 LGA in Benue state, Nigeria (National Population Commission [NPC], 2007). Wannune is a small town with an area of 371 km² and a population of 79 494, based on the census of 2006 (NPC, 2007). Wannune is situated in a rural setting and the major occupation of the people is farming, with only a few employed in white collar jobs (Goon, Toriola, Uever, Wuam & Toriola, 2010). Benue state is located in the mid-eastern region of Nigeria (NPC, 2007). The predominant ethnic group in the town is the Tivs and they speak Tiv language; Christianity is also the predominant religion of the residents (Goon et al., 2010). The only secondary health facility in the town is the General Hospital Wannune (GHW) and it provides antiretroviral therapy (ART) services for 4,000 HIV infected adults and 200 infected children (Goon et al., 2010). The hospital is supported by Centre for Integrative Health Program (CIHP), which is a non-governmental organization funded by the United States of America (USA) government and provides OVC care for under-18 children and adolescents orphaned by HIV and AIDS (Goon et al., 2010).

3.6 SAMPLING STRATEGY OF THE PARTICIPANTS

Wannue General Hospital is the only secondary health facility in Wannune town (Goon et al., 2010). The facility (GHW) coordinates and support AIDS orphans below the ages of 18 years and those children who are vulnerable from the epidemic. Permission was sought and given from the Medical Director of GHW to contact the social workers and the psychologists that were

responsible for coordinating the care for children orphaned by AIDS. This General Hospital only coordinates care for AIDS orphans and vulnerable children between the ages of 0-17, so the researcher was aware that youths between the ages of 18-24 were not under their care. However, the assistance of the social workers was sought because they have the knowledge of youths who have lost a parent to AIDS in Wannune through their care coordination for the AIDS orphans below the age of 18 years.

Youth orphaned through the loss of parents to AIDS are not officially counted and therefore hidden within the general population and are not formally recognised as a focus group because they do not access formal organizations for any support such as psycho-social, financial or educational supports. The sensitivity surrounding issues with HIV and AIDS meant that the study participants were not approached directly, but rather through the Social workers running the OVC support care at GHW. The social workers conducted community household visits to identify participants who met the definition of „youths“ in this study and referred them for interview. For this study, a purposive sampling technique was initially used to obtain an initial sample of limited participants (Creswell, 2009). Purposive sampling permits the selection of participants whose qualities or experiences permit an understanding of the phenomena in question that would enable the researcher to answer the research question (Cohen & Crabtree, 2006).

Multiple purposive sampling technique was used in this study in order to ensure that the required participants are sampled. According to Teddlie and Yu (2007) this is a mixed methods (MM) technique that involves the use of multiple qualitative sampling techniques in the same study. Poorman (2002) cited in Teddlie and Yu (2007) presented an example of multiple purposive sampling techniques where four different types of purposive sampling techniques were used (namely theory based, maximum variation, snowball, and homogeneous) in combination with one another in selecting the participants for a series of four focus groups. In the current study purposive sampling was used in combination with snowball sampling. Purposive sampling was the most suitable approach to start the recruitment of participants in this study because it permitted the social workers to choose a participant because he/she illustrates some traits which

were of interest to the researcher. Purposive sampling approach facilitated identification of this hidden category of OVC because they were difficult to identify. However, as anticipated, despite the immense expertise of the social workers in the recruitment, organization and coordination of programs for AIDS affected young people; recruitment of participants for this study was a challenging task for the social workers. Snowballing sampling approach was also utilized to gain access to the young AIDS orphans who are difficult to identify. Snowball sampling is especially useful when the researcher is trying to reach populations that are inaccessible or hard to find (Polit & Beck, 2008) , such as the young people orphaned by AIDS. Some of the challenges identified by the social workers while recruiting participants for this study were:

- the youths were not affiliated to any form of support from either the government or Non-Governmental Organizations (NGOs);
- the stigma and discrimination attached to HIV and AIDS made the participants almost invisible;
- lack of adequate record keeping of HIV infected adults and significant loss to follow up of patients on ART.

3.6.1 SAMPLE SIZE

After several household visits by the social workers, only three participants were identified as meeting the inclusion criteria and all the three participants agreed to participate in the study. In order to increase the depth of the experience sought for in this study, sample size was expanded using snowballing sampling approach. All of the three interviewed participants were asked if they knew other youths that might share similar experiences like them (Cohen & Crabtree, 2006). Participants suggested six additional names which the social workers traced again through household visits but only two of the suggested persons met the inclusion criteria and both of them agreed to participate in the study. The two participants recruited through snowballing method were asked to suggest names of other young persons that might have lost parents to AIDS but both of them declined any knowledge of such.

During the closing phase of the data collection and preparing to leave the field, the researcher received a telephone call from one of the social workers that assisted in the initial recruitment of the participants to confirm that another participant was identified who met the inclusion criteria of the research project. He had returned home after being away for educational purposes. He agreed to participate in the research project and arrangements were made for the meeting between the researcher and the participants and interviews were conducted. In the end, a total of six participants were interviewed.

The researcher therefore engaged all participants with in-depth interviews to ensure that data saturation was reached with all the six participants who participated in the study. For all the participants, this research study was the first opportunity they had to discuss issues that affect them and they never thought someone would be interested in their experiences.

3.6.2 Inclusion criteria

Participants were selected based on the following criteria

- They were all youths between the ages of 18-24
- All the participants have lost the parents for a minimum of one year and maximum of three years
- Ability to give verbal autopsy of their parents loss to AIDS
- Willingness to be interviewed and tape recorded

3.7 DATA COLLECTION PROCESS AND INSTRUMENT

Understanding, getting close to the experience of the participants of the study and not controlling their narrative was at the heart of the researcher's interest. Interviews were an appropriate method of data collection because the research objectives required the examination of personal narratives. The following statement by Glaser and Strauss (1967, pg. 75) was directed at development of grounded theory but it seem applicable to the approach used in this study:

At the beginning of research, interviews usually consist of open-ended conversation during which respondents are allowed to talk with no imposed limitations of time. Often the researcher sits back and listens while the respondents tell their stories (Page 75).

While acknowledging that interview has been the main data collection procedure in qualitative research, it is important to note that different types of qualitative interview approaches exist such as structured, semi-structured and unstructured. However, it is more important to select the type that will align well with the philosophy of descriptive phenomenology.

Phenomenological interviews provide a situation where the participants' descriptions can be explored, illuminated and gently probed (Kvale & Brinkmann, 2009). Semi-structured interviews were used to ensure that some areas were covered in every interview. For example, it took into account whether the participants' experiences would have been different if they were younger when their parents died. Apart from providing the basis for a loose structural form of data generation (Boyce & Neale 2006), the semi-structured interviews allowed both the researcher and the participants to diverge, in several instances, in order that the recollections of participants' experiences were vividly captured in detail.

The diversity of the participants and how they have experienced AIDS orphanhood meant that the researcher needed a kind of interview approach that allowed the participants to set the agenda concerning how they answer the research questions. Therefore semi-structured interviews were chosen because of this advantage over other interview approaches and it also facilitated easier coding of participants' responses, since similar wording was used during interview sessions.

The interviews were conducted in one of the GHW's library discussion rooms, which was set aside for the purpose of this research through the approval of the hospital management. The library is located within the hospital premises but it is a stand-alone building which is equipped with facilities such as sound-proof discussion rooms for meetings, rooms for medical presentations, general library rooms for staff readings and consultation with library workers. The library is only accessible to the hospital staff upon presenting a valid identity card and it operates for 12 hours (08:00 till 20:00). The library's discussion room provided a comfortable and non-

threatening environment for the interviews to be conducted and because all interviews were conducted in the evenings (between 5:00-7:30 pm); there was no distraction throughout the duration of the interviews.

In order to generate a fully informed description of a participant's prior experience of losing a parent to AIDS the researcher had to establish good rapport and trust among the participants. The researcher was aware that issues about HIV and death are very private and sensitive issues in people's life and are often enmeshed in secrecy. The researcher therefore requested for a preliminary meeting with the participants before the actual interviews because they were recruited by the social workers and was unknown to the researcher. The social workers set up the meeting one week before the actual interviews were conducted and this gave the researcher an opportunity to get acquainted with the participants and to establish rapport with them. The participants were telephoned individually and different appointment times were allotted for each person. The preliminary meeting was eventful and was an eye-opener to know the participants better and psychologically prepared the researcher better on what to expect during the actual interviews.

The participants asked some interesting questions during the preliminary meeting, such as:

- So you came all the way from South Africa to interview us?
- Why are you so interested in us?
- Have you ever lost your parent or any of your siblings?
- Have you ever cried?
- Have you experienced suffering before?

While the participants questions allowed somewhat lengthy discussions in some cases, it was a very thought provoking meeting. The participants signed the consent forms and the research questions were reviewed with them. This was done to ensure that the participants spent some time to reflect on their experience before the actual interview.

The researcher was the main data collection instrument in this study and played the role of a facilitator throughout the interview sessions with the participants. The researcher conducted all interviews without the help of research assistants and all interview questions sought for clarification, illustration and further exploration where necessary. Some of the participants tried to validate their experiences, opinions and expressions of AIDS loss by asking the researcher what his own experience of any loss was. The researcher however made the participants understand that he does not know anything about the phenomenon but he believed they have stories to tell and constituted the reason for conducting the study. The researcher's attempts to be open and to meet the phenomenon in as fresh a way as possible was also aided by not reviewing the literature before conducting interviews with the participants. This meant that the researcher's prejudices, preconceptions, judgement and beliefs did not influence the participants' description of the phenomenon being researched. This procedure of maintaining a neutral stance in a descriptive phenomenological research is termed „bracketing“ and the essence of bracketing is to obtain an objective description of the phenomenon being researched (Finlay, 2009).

The study involved two interview sessions with each participant. The first interview sessions aimed at collection of participants' responses to interview questions about their experiences and were audio-taped. The duration of the first interviews ranged from 40 minutes to 60 minutes and no interview was terminated in the interest of time. The second interviews were aimed at participants' verification and validation of how their responses were transcribed, analysed and described by the researcher. The purpose of this was to allow participants to confirm or reject the how their responses was represented. All participants' agreed with the representation of their experiences and the follow up interviews was less than 15 minutes in all cases.

It is important to note that all participants have lost a parent to AIDS for a minimum of one year and the recollection of their experiences depends on how good was their memory. Van Manen (1990, 10) states that the phenomenological reflection, *“is not introspection but rather retrospective. Reflection on lived experience is always recollective; it is a reflection on experience that is already passed or lived through”*. Parental loss through any circumstance cannot be regarded as a once-off event because it continually provokes meanings and

experiences from daily encounters with life circumstances. Therefore, the descriptions of the youth experiences in this study can be regarded as objective accounts of their experience because they are living through this phenomenon.

3.7.1 Description of the data collection instrument

The semi-structured interview guide focussed on three main questions. The first set of questions focused on the context of orphanhood. Key questions asked were directed at demography of the participants and their situations before parental deaths. The second set of questions focused on the lived experience of the participants just before the death of the parent/s and immediately after. Key question asked was „how have you experienced the loss of your parent to AIDS“. The third set of questions was on the identified needs necessary to support these young people who have lost parents to AIDS related illness. Majority of the questions asked were open ended questions which were followed by a lot of probing using clarifying questions such as „Can you explain further...“, „Like what...“, „Are you saying that...“. The interviews were conducted in English language and tape-recorded with participants' consent and permission. The semi-structured interview guide used in the study is attached as appendix 1.

3.8 DATA ANALYSIS

The strength of a qualitative data has been advocated to be judged on the competence with which the analysis is carried out (Miles & Huberman, 1994). This suggests that data analysis is a critical step in qualitative research, the handling of which can make or mar the entire research study. The variety and diversity of approaches in qualitative research design mean there are different ways of analysing social life, and therefore multiple perspectives and practices in the analysis of qualitative data (Punch, 2009). The decision to decide on the best analytic approach to analyse any qualitative data was advocated to be based on the purpose of the study (Punch, 2009). However, whatever the method of data analysis used in qualitative studies, it should be systematic, disciplined and able to be seen and described. In descriptive phenomenological studies, commonalities in participants experiences must be identified before the findings can be

considered a science (Lopez & Willis, 2004). Considering that descriptive phenomenological studies involves in-depth exploration of experience which results into large amount of generated data, analytic approach that captures commonalities in participants' experiences was selected for this study.

Carcary (2009) describes data analysis in qualitative research as an interactive process and requires an ongoing examination of how the theoretical, cultural and political context of individual and intellectual involvement affects interaction with what is being researched. The need for constant reflection on the emerging themes during interviews meant that data analysis was concurrently done with data collection. Data analysis was guided by the phenomenological method of data analysis proposed by Colaizzi (1978) cited in Sanders (2003). Experienced researchers such as (Thupayagale-Tshweneagae, et al, 2010; Chan et al., 2013) have successfully used the Colaizzi (1978) method of data analysis in their descriptive phenomenological studies. Furthermore, data were displayed using table matrices as suggested by Milers and Huberman (1994) to justify how conclusions were made.

The following steps represent Colaizzi process for phenomenological data analysis (cited in Sanders, 2003; Speziale & Carpenter, 2007; Thupayagale-Tshweneagae et al., 2010).

1. Each transcript should be read and re-read in order to obtain a general sense about the whole content.
2. For each transcript, significant statements that pertain to the phenomenon under study should be extracted. These statements must be recorded on separate sheet noting their pages and lines numbers.
3. Meanings should be formulated from these significant statements.
4. The formulated meanings should be sorted into categories, clusters of themes and themes. Within and across case analysis occurs at this stage.
5. The findings of the study should be integrated into an exhaustive description of the phenomenon under study.
6. The fundamental structure of the phenomenon should be described.

7. Finally, validation of the findings should be sought from the research participants to compare the researcher's descriptive results with their experiences.

The data analysis followed the above outlined steps to analyze the transcribed interviews and the process of arriving at the structure of the phenomenon will be explained further in the next chapter.

3.9 DATA QUALITY

3.9.1 Rigour in Phenomenological research

Morse (2003) noted that without rigour, research is worthless, becomes fiction and loses its utility. As the debate on rigour in qualitative inquiries continues to evolve, De Witt and Ploeg (2006) argued that the great theoretical and methodological diversity of qualitative approaches might mean that a sole set of criteria may not be appropriate for all types of research. Rigour in qualitative inquiry involves trying to understand phenomena that cannot be studied quantitatively because they have personal dimensions which can be more properly researched by means of a qualitative approach (Lincoln & Guba, 1985).

3.9.2 Trustworthiness

In order to ensure rigor in qualitative research, the concept of trustworthiness has been adopted by researchers. Trustworthiness in qualitative research entails the production of findings that reflect as close as possible to the meanings described by the participants (Lincoln & Guba, 1985). Issues such as reactivity and biases from either the researcher or participants can threaten the trustworthiness of the study and varieties of strategies have been proposed to manage these threats (Padgett, 2008; Lietz, Langer & Furman 2006). In qualitative research, the concepts credibility, dependability and transferability (Lincoln & Guba, 1985) have been used to describe various aspect of trustworthiness and this will be discussed in relation to this study.

3.9.3 Credibility

Effort was made to ensure that all participants were selected because they possess the lived experience of AIDS-orphanhood and their experience was adequately captured through prolonged in-depth interviews. The experience of the research participants is the priority of the study. Therefore, all the researcher's personal observations, knowledge and beliefs about the phenomenon were recorded in a reflexive journal. This assisted the researcher to apply the principle of „bracketing“ and to be open to the new insights that the participants brought to the research. The researcher was engaged in extensive dialogue with the research supervisor through email, Skype and physical meetings and deliberations were made over the unfolding of the data collection, data analysis and its reportage. Also, all the participants were given copies of their personal transcripts in a process called member checking (Kisely & Kendall, 2011); to allow them review their own personal transcribed interviews and how it was analysed; in order for them to confirm or challenge the accuracy of the work. All the participants“ agreed and confirmed that the transcripts were a true representation of their experience.

3.9.4 Dependability

The study utilized a semi-structured interviewing strategy and this assisted in using almost the same wording of open questions from interviewee to interviewee. The tape recorded interviews were also transcribed immediately to prevent inconsistencies in the data collection. An audit trail (Lincoln & Guba, 1985) of all the research process, including data analysis and decisions taken were described, justified and recorded. The above listed strategies assisted the research supervisor to peer debrief the analysed data and to ensure identification of commonalities and differences that warranted further analysis.

3.9.5 Transferability

In order for readers and other researchers to consider applying the findings of the study to their setting (Polit & Beck, 2014), the context and culture of the research settings, participants

selection and characteristics, data collection and process of data analysis was exhaustively described. The research findings were also backed up with appropriate quotations from the participants' statements. The data analysis documents used to generate answers to the research questions is attached as (appendix 1) for public viewing and comments.

3.10 ETHICAL CONSIDERATIONS

Ethical considerations were an important part of this research study because the research participants have experienced traumatic life circumstances through the loss of their parents to AIDS and they can be described as living in particularly vulnerable situation. The study was reviewed and granted ethical approval by two Independent Ethics Committees namely, the Biomedical Research Ethics Committee (BREC) at the University of Kwazulu-Natal (UKZN) and Benue State University Teaching Hospital (BSUTH Ethics Review Board. In addition, written informed consent was obtained from all participants, which indicated that participants voluntarily participated in this research study. The Belmont Report (1979) established the foundational ethical principles of respect for persons, beneficence and justice for research involving human volunteers (Ryan et al., 1979). The application of the universal ethical principles to the present study is discussed below.

3.10.1 Ensuring respect for persons

The application for ensuring the respects for persons (participants) in research is found in the informed consent (Ryan, et al., 1979). Informed consent (hereafter IC) is the ethical requirement that stipulates that before participating in any research, research participants should freely agree to participate, on the basis of sound understanding of what the research is about. It is important to respect participants' autonomy and right to self-determination before enrolling participants in research studies. Although informed consent is a process, it normally terminates into participants decision in some formal record. All information to enable participants' make good personal decision about the study participation were discussed with participants' individually. Participants' were provided with opportunities to ask questions and clarification about their fears

and misconceptions. In order to ensure comprehension of the IC process, the researcher asked the participants to respond to the following questions about the study:

- What is the purpose of the study?
- What are the risks?
- What are the benefits?

All the participants responded satisfactorily to the questions and consented to the study participation by signing the IC form. The participants were given a copy of their signed IC form and were told that participation is voluntary, and that they were free to withdraw their consent and participation at any time without them suffering any form of disadvantage. This study also recruited youths who are over the age of 18 years and they have the legal capacity to consent on their own to the study without the interference of guardians or surviving parents.

3.10.2 Ensuring beneficence of the study

The application for ensuring beneficence in research involving human volunteers is in the careful assessment of risks and benefits (Ryan et al., 1979). Richardson (2008) conceded that the IC process means that researchers and participants are in a kind of entrustment-styled partnership and this involves the researchers to act appropriately to the information gleaned from the participants. As earlier noted, entrustment relationship that develops after the completion of the informed consent impose special duties of care, incumbent on those in whom trust is reposed (Belsky & Richardson, 2004). Richardson and Belsky (2004) continued that any entrustment obligation possesses two main elements (discretion and vulnerability); inherent in the two elements however are the moral obligations of compassion, engagement and gratitude. The researcher thought that one of the duties owed to the study participants was that of confidentiality of their identity and their interview responses. The researcher therefore did not use the participants' real names in the reportage of data, analysis and in the tape recordings. The interview transcripts, tape recordings and signed IC forms are being kept securely for the prescribed time of three years and will be destroyed soon after at the appropriate time has passed.

It is commonly argued that benefits and risks of a study must be balanced and shown to be in a favorable ratio (Ryan, et al., 1979). Most ethicist advocates that the benefits of any research participation must outweigh its risks (Pratt et al., 2013; Leung, 2012). There are different types of risks in research such as physical, psychological, social and economic. The anticipated risks in this study were psychological and social, and appropriate measures were instituted to minimize these risks to the barest minimum. Protection of the research participants was paramount to the researcher and appropriate decisions about participants' exposure to psychological risks were planned against right from the design of the study. In order to be eligible for study participation, the participating youth parental loss must have occurred for over one year before data collection. This decision was taken in order to preserve the grief resolution of the participants. Although all the participants broke down in tears during the recollection and narration of the AIDS parental loss, none of them was distressed to the point of requiring psychological care or counselling. Participants were given time to cry and express their feelings and pain of loss. Also, all the participants were assessed for psychological distress by the GHW psychologist before and after interviews were conducted.

Courtesy stigma, stigma attached to people because of their association with HIV-positive people have been reported to be rife among AIDS orphans because of their inability to often control their circumstances (Doku, 2009; Deacon & Stephney, 2007; Campbell, Skovdal, Mupambirey & Gregson, 2010). The researcher was aware of the possibility of courtesy stigma in Wannune, therefore participants were recruited through the assistance of the social workers because of their working knowledge with the OVC children.

Although, the participants were in some ways disadvantaged when compared with non-orphans especially economically, no compensation in form of gifts, money or coupons was offered to the participants. This measure was taken to avoid undue inducement and to prevent narration of experience that might over-magnify their disadvantage. However, the participants acknowledged that this research study was their first opportunity for discussing the events of their parents' HIV illness and loss. Participants also had the opportunity to connect with professional services such as psychologist and social workers. The researcher, in collaboration with the GHW management

made post-study counselling and psychological care freely available for all the participants for six months after the end of data collection.

3.10.3 Justice

The application for ensuring justice in research is found in the fair selection of research participant (Ryan, et al., 1979). Before recommendations can be suggested and before appropriate interventions can be planned, it is ethically and morally right to involve participants that are affected by a particular phenomenon (Emanuel, Wendler, Killen & Grady, 2004). The choice of Wannune as the research setting was because it has the highest recorded prevalence of HIV in Nigeria and unsurprisingly, the town also contributes significantly to the large amount of AIDS orphans recorded from the state. In order to generate scientific valid results and findings with social value, participants were carefully selected. Only AIDS orphaned youths who met the study inclusion criteria were recruited and interviewed.

3.11 DATA MANAGEMENT AND DISSEMINATION

All recordings with documented data both written and electronically captured from interviews were stored securely on the researcher's password protected personal computer and in a secure locked cupboard at the researcher's residence. All files were also backed up on Icloud and on a hard drive. The real names of participant's did not appear on the interview transcripts as participants were labelled using their pseudo details. No persons will be permitted to access this data other than the researcher and the supervisor. All data will be destroyed five years after completion of the study by shredding of written documentation and deletion of electronic documentation and audio files from the external hard drive, Icloud and the recycle bin. Throughout the process of simultaneous data collection and analysis, the researcher submitted articles for publication in national and international journals. The articles focussed on the research objectives and systematic literature review (attached as appendix 7).

Further dissemination of findings will be through presentation of findings at conferences or workshops held nationally and internationally. Findings will also be shared with relevant institutions in Nigeria.

3.12 Conclusion

This chapter discussed the research methodology that was employed in this qualitative study, which is that of a descriptive phenomenological approach. The researcher used literature evidence and practical reasons to provide rationale for the appropriateness of the research design, the data collection process, data quality, data analysis approach and ethical assurances. The following chapter presents the results for this study, where they will be examined and assessed.

CHAPTER FOUR: PRESENTATION OF FINDINGS

4.1 INTRODUCTION

The purpose of this descriptive phenomenological study was to explore and describe the lived experience of youths who have lost a parent to AIDS in order to identify their needs. This chapter presents the findings of this inquiry and will include: (a) description of the pertinent characteristics of the participants (b) description of the Colaizzi's (1978) phenomenological data analysis method and how it guided the analysis of data obtained in this study, (c) presentation of the essential themes and how they were derived and (d) an exhaustive description of the fundamental structure of the experience of losing a parent to AIDS as a youth.

4.2 DATA REALIZATION

The researcher's aim was to recruit as many participants as possible who have the experience of the phenomenon under study but due to pragmatic reasons, the sample size for the study was six youths. Factors that limited the availability of participants were inadequate record keeping, high mobility of AIDS orphans, and the conservative stance of the community on death and HIV issues. Some of the participants were also not eligible because their parental AIDS loss was less than one year and some have lost their parents for more than 3 years which prevented them from participating.

Table 4.1: Participants' demography

| Participant code | Pseudonym | Age | Gender | Type of orphan | Occupation | Age at parental loss |
|------------------|------------|-----|--------|----------------|--------------------|----------------------|
| 1 | Dreamer | 22 | Female | Maternal | Student/piece jobs | 19 |
| 2 | Reality | 19 | Female | Maternal | Student | 17 |
| 3 | Dependable | 20 | Male | Paternal | Student | 17 |
| 4 | Change | 21 | Male | Paternal | Student/farming | 19 |
| 5 | Reluctant | 20 | Male | Paternal | Student | 19 |
| 6 | Flower | 24 | Female | Paternal | Student/piece jobs | 21 |

4.2.1 Description of participants

The rigor of a qualitative study has been advocated to be judged on the basis of its thick description (Ponterotto, 2005). Morrow (2005) defined „thick description“ as involving a detailed and rich descriptions of not only participants experience of phenomenon but also of the context in which those experiences occur. The researcher gave the participants pseudonyms based on their personality and the way they responded to the researcher during rapport building and the actual interview sessions. The use of pseudonyms is one of the strategies of ensuring anonymity and confidentiality of the participants and this was also explained to them.

Participant 1: Dreamer

Dreamer is a soft-spoken young lady. She is currently studying Chemistry at a University, but her dream is to become a medical doctor. Her pseudonym is derived from her resolve to pursue a career in Medicine.

Dreamer is a 22 year old lady who initially grew up in a family of six. She is the second child of her parents and the first daughter. She is a double orphan as she first lost her father at the age of eight years and lost her mother at the age of 19 years. The loss of her father was not connected to AIDS but rather complications from a motor vehicle accident. Although she is studying to become a Chemist, her ambition is to become a medical doctor. Although the interview started with all smiles, Dreamer’s countenance fell apart mid-way into the interview. Her reason for crying was that apart from the actual loss of her mother to AIDS her siblings were under-performing.

Dreamer has reached some milestone in her life, some of which are graduation from high school and gaining admission to tertiary institution. However, her joy is not complete because she felt that she has no one with whom to celebrate her achievement. Despite that, she works part-time designing computer programs and organizing public functions. Her siblings’ welfare was the priority on her mind because she felt that their lack of schooling is slowing her progress and will continue to do so for some time. Dreamer and her siblings live in the home inherited from their mother; she is the head of the household because her older brother left the town. She has been

the head of the household for 12 months before her uncle brought his family to live with them. Dreamer narrated how she started living a false life because her uncle did not give her the chance to be herself anymore due to his constant rebuke and lack of understanding. Dreamer resides in Wannune but leaves the town frequently for educational purposes.

Participant 2: Reality

Reality is still battling with the realization of how life changed after the loss of her mother.

Reality is a 19 year old lady whose life ambition is to become a Lawyer. She is the first child of her mother, although she has older step brothers with whom she is not well acquainted. Her father is a foreigner who came to work in Wannune several years ago and fathered two children (all girls) with Reality's mother. Her mother had other relationships about five years prior to her death which produced a set of twins and they all lived together. She does not seem to have a good memory of her father and her father does not seem to affect her life in anyway, before and after the death of her mother that occurred when she was 17 years old. Reality had a relatively stable life when her mother was alive. She participated in what any other happy kids of her age would do. Her mother was described as a family person and because of that, many of their extended family members were always in their house and she enjoyed their company, the fellowship of witnessing marriages, Christmas parties, child christening and many other family rituals.

It seems like the absence of her father during her formative years led to the transfer of affection to her mother and other male figures in her extended family. However, when the loss of her mother occurred through AIDS related illness, she began to realize that people accepted her and her siblings because of their mother. Once she had died no one cared about them. She recounted how her siblings were unable to understand that their mother had passed away and never to return. She watched them being confused about the loss of their mother and it continues to worry her. Reality spoke about the interruption of AIDS in her life, her education and how she became a caregiver by becoming the head of the house left by her late mother. She is resident in

Wannune and she is the head of her new household which comprised of her three younger siblings.

Participant 3: Dependable

Dependable was like his father's right hand man after his mother relocated to live abroad after irreconcilable differences bordering around the HIV illness of the father. His father even relied on him to prepare his favorite food. Tragedy came one day when he found him dead on entering his bedroom with the food in his hands.

Dependable is a 20 year old boy whose parental AIDS loss occurred when he was 17 years old. His experience of AIDS related parental illness started with the experience of family conflicts between his mother and father. Dependable's mother constantly accused his father of infidelity and she relocated to live abroad with her sister after the family members were unable to broker peace between the parents. Being the eldest child and without the mother in the home again, he significantly took up the caregiving and upkeep of the home. He narrated that his experience was filled with hope, victories, defeats, conflicts, responsibilities and solidarity. Even before the eventual loss of his father to AIDS, he had significantly taken up caregiving roles and was elevated into the position of parenting because during his father's illness crisis, he had to make several decisions on behalf of his ailing father.

Most of the story of Dependable centered on his weighty caregiving roles which resulted in self-neglect and self-sacrifice. He is just trying to write his matric examination because he lost many months of school attendance caring for his ill father. Feelings of regret and anger directed towards relatives because of their lack of support were also evident in his narrative. Although his uncle took control of his late father's business, he lived alone with his younger siblings in the home of his late father at Wannune.

Participant 4: Change

Change is also the eldest child of his parents but he wants to become an accountant because no one has ever achieved that feat in his lineage and he has the plans to accomplish that dream.

Change is a 21 year old male whose parental loss occurred when he was aged 19. He is a self-motivated young man who seems not to pay close attention to his current situation. Perhaps, Change is the only participant that changed household before the loss of his father due to financial constraints which lead to the break-up of his family. The support of Change's mother was not enough to save him from sacrificing his childhood for the survival of his family and he narrated how he was constantly under pressure to make things work for his siblings and mother. Due to the significant loss of finances that preceded the death of his father, two of his siblings had to be sent to relatives because they lost their rented apartment to soaring rent debts which lead to forceful ejection by the owner of the house. Change focused more on farming than schooling because his mother's business is seasonal and the school fees of his siblings and himself had to be paid without interruption.

The various adversities and life disruptions that he has experienced do not deter him from his ambition to become an accountant. Change took the researcher on a journey of his experience with AIDS and the specific vulnerabilities that he suffers due to his loss of his father and the sequel that followed. Change currently live with his mother in a dilapidated house that was given to them by a rich man in the community who had no family.

Participant 5: Reluctant

Reluctant seem not to have gotten over the loss of his father despite that the loss occurred more than one year. Reluctant was the best friend to his father, they seem like buddies and he was just beginning to enjoy his newly formed attachment with his father when AIDS struck.

Reluctant lost his father at the age of 19 years. He is the third child out of four children. Compared to other participants he was the only one that was not involved in any income

generating job. Reluctant seems to have a model family despite the absence of his father from home due to his job. His experience was filled with the new found love for his father after he turned 15 years. He started appreciating the role of a father and he felt like he became detached from his mother and moved towards bonding with his father. His new found love for the father transformed him into his role model and therefore losing him was more than tragic. Despite that, his parent's relationship introduced him to an ideal family that demonstrated the importance of love and solidarity that ought to exist in a functioning family. However, this did not prevent him from becoming a significant caregiver during his father's illness. The participant discussed how life changed after his father's death. Reluctant attends a tertiary institution in another town and only visits his mother who lived in Wannune during the holidays.

Participant 6: Flower

Flower was the oldest of the participants and the only participant with a child. In the three years that followed her father's death, she managed to build a house for her mother but her joy was not complete because she felt that she neglected herself while she was trying to forge a better life for her mother.

Flower is a 24 year old young lady who was 21 years at the time of her father's loss to AIDS. She is the third child among the five children of her parents and she seems to experience a troubled childhood due to the separation of her parents and constant conflicts even before the father passed away. Flower narrated how she was unable to enjoy an ideal family and how her hope of witnessing the re-union of her parents never materialized. Flower narrated how she initially hated her father because of the neglect and lack of love towards her and her mother. However, her story was filled with regret over the need for her father at a later stage of her life. She described how the loss of a male figure opened her and her sisters to vulnerability and abuse by the men of the community.

Flower is now focused on trying to discover herself because she had lost herself in the process of making her mother happy. Her mother currently lives with HIV and has lost her job because of some disability due to the reaction of ART. She discussed with the researcher what she has

experienced after the loss of her father, including the significant sacrifices that she has made despite the crippling effects of AIDS in her life. She currently combines schooling with part-time piece jobs.

4.3 STRATEGY OF DATA ANALYSIS AND PRESENTATION

4.3.1 Colaizzi's (1978) method of phenomenological data analysis

Before delving into the description of the analytical procedure of the dataset, it is important to provide a brief description and reminder of the data collection which was earlier described in the previous chapter. Semi-structured, face-to-face interviews were conducted using a prepared interview guide which was developed by the researcher and the supervisor. Participants were encouraged to talk freely and to tell their stories of AIDS-orphanhood using their own words. The semi-structured interviewing strategy afforded the researcher to ask almost the same questions; the difference being in the sequencing of questions which was due to the variation in the response and peculiarities of each participant. Each interviews lasted from 40 minutes to 60 minutes, and all of the interviews were conducted by the researcher. On completion of each interviews, the researcher reminded the study participants about the need to contact them for the second time in order to discuss the study findings and to make sure that the study findings reflect their own experiences.

The following steps representing Colaizzi process for phenomenological data analysis (cited in Sanders, 2003; Speziale & Carpenter, 2007) was used for the analysis of the study data.

1. Each transcript should be read and re-read in order to obtain a general sense about the whole content.
2. For each transcript, significant statements that pertain to the phenomenon under study should be extracted. These statements must be recorded on separate sheet noting their pages and lines numbers.
3. Meanings should be formulated from these significant statements.

4. The formulated meanings should be sorted into categories, clusters of themes and themes. Within and across case analysis occurs at this stage.
5. The findings of the study should be integrated into an exhaustive description of the phenomenon under study.
6. The fundamental structure of the phenomenon should be described.
7. Finally, validation of the findings should be sought from the research participants to compare the researcher's descriptive results with their experiences.

Step one: Transcription and data immersion

The researcher transcribed all audio-taped interviews and each transcript was read several times to gain a sense of the whole document. During this stage, all the researcher's personal observations, knowledge and beliefs about the phenomenon under study were recorded in a reflexive journal. This assisted the researcher to apply the principle of „bracketing“ and to be open to the new insights that the participants brought to the research.

Step two: Extraction of significant statements

In this stage of analysis, significant statements and phrases pertaining to the experience of youths who have lost a parent to AIDS and their needs were extracted from each transcript. These statements were written in separate sheets and coded based on their „transcript, page and line numbers“. After extracting the significant statements from the transcripts, the researcher submitted the draft to the supervisor for review. Two hundred and forty two significant statements were extracted from the 42 paged transcripts of the 6 interviews conducted. The table below provides examples of significant statements which were identified and extracted from participants' data.

Table 4.2: Significant statements

| Significant Statements | Participants' Number | Page No | Lines No |
|--|-----------------------------|----------------|-----------------|
| “It was when I reached the age of 15 that I started to experience something to my father, to know what a father is, what father do in the family. I just started to appreciate what a father is in the family” | 5 | 29 | 758-760 |
| “I was unable to experience what an ideal family was. I transitioned from someone living in a relaxed and enabling environment to someone now living in fear and | 1 | 3 | 52-53 |

| | | | |
|---|---|--------|--------------------|
| anxiety” | | | |
| “I know taking care of my mother is something that I have to do but somehow I neglected myself. I deprived myself of so many things and now I am looking forward to my own life” | 6 | 36-37 | 954-956 |
| “The most painful thing was my younger siblings. I felt sorry for them because they were so confused about what was happening.....Up till when I separated with my siblings, they never understood why we are going to bed without mother. I felt so powerless because I could not provide what they need for them, I could not explain what death and dying was to them” | 2 | 7 9 | 173-175 236-239 |
| “Being the eldest child made my responsibilities weighty, I hardly had time for myself, equilibrium was never reached” | 3 | 15 | 389-390 |
| “I am constantly under pressure to work hard in order to meet our needs. I feel like I am not a child anymore when I think of the things that my father’s death has caused” | 4 | 25 | 652-653 |

Step three: Formulation of meanings

Meanings were formulated from the significant statements. Each underlying meaning was coded in one category as they reflected an exhaustive description. The researcher submitted the formulated meanings to the supervisor to compare with the original meanings in order to validate that the formulated meaning reflected the originality of the participants’ data and to check consistency. Two hundred and forty two formulated meanings were derived from the 242 significant statements. The formulated meanings did not distort the original data collected from the participants. The table below provides examples of how significant statements were converted into formulated meanings.

Table 4.3: Formulated meanings from significant statements

| Significant Statements | Formulated meanings |
|---|---|
| “Actually, the greatest of my worries are those of my siblings who I feel I have to make sure they are not as affected as I have been. Now, I am trying to re-take my matric and go to tertiary. I am worried how life will be like for them if I make that decision” (Participant 3, page 17, lines 451-453). | Participant is worried about the welfare of the younger siblings and sacrificing personal gratification for their survival. |
| “Hmm! I think I would be more confused because I would not have known much about him. At least at the age I was when he died, I knew the kind of person that he was. If he died when I was like 10 years old, I would have been relying on other people’s information to know what kind of a father I had” (Participant 6, page 40, lines 1093-1096). | Participant discussed the advantage that older age afforded her, which is having a better knowledge of the dead parent and better understanding of death. |
| “There should be a kind of modeling programme, especially for us who are taking up responsibilities of the home because we have lost our childhood and in order to get the best out of our adulthood, we need counseling and support so that the missed childhood would not hunt us later in life” (Participant 3, page 18, lines 468-471). | Participant expressed the need for a kind of grooming for them to reach their potentials despite the loss of the parent. |
| “I saw her strength vanish in front of me. She became someone that I have to feed; she lost her balance and was so dependent on me and my siblings | Participant described the process that lead to her caregiving roles and the |

| | |
|--|---|
| for most activities” (Participant 1, page 2, lines 28-30). | pain of watching her mother lose her ability to perform her usual activities. |
|--|---|

Step four: Grouping of formulated meanings into categories

After constructing the formulated meanings, the researcher grouped all the formulated meanings into categories that reflect a unique structure of clusters of themes. Each cluster of theme was coded to include all formulated meanings related to that group of meanings. After that, group of clusters of themes that reflected a particular experience of orphanhood experience were incorporated together to form a distinctive construct. Thirteen theme clusters emerged which were grouped later into six emergent themes. The following tables show the process of constructing the emergent theme through the integration of various formulated meanings and clusters of themes:

How themes were constructed from different clusters of themes and formulated meanings.

Table 4.4: Theme one (Disruptive life changes)

| Formulated meanings | Theme clusters | Emergent theme |
|--|----------------|-------------------------|
| <ul style="list-style-type: none"> • Participants experienced dwindling state of health of parents and death, and this left them with deep pain. • Participant started having nightmare after the loss of the parent | Adversity | Disruptive life changes |
| <ul style="list-style-type: none"> • Participant started living in fear after the loss of her father and she is always scared that she might also lose her HIV positive mother • The participant does not have a stable accommodation after the father passed on and this is always a source of concern and fear | Uncertainty | |

Table 4.5: Theme two (Multiple losses)

| Formulated meanings | Theme clusters | Emergent theme |
|--|-----------------------------------|-----------------|
| <ul style="list-style-type: none"> • Participant’s family fell apart after parental loss • Participant no longer had the chance to observe and partake in family rituals after parent’s death • Participant transitioned from someone living in a relaxed home environment to a home filled with fear | Loss of the ideal family | Multiple losses |
| <ul style="list-style-type: none"> • Participant was just starting to bond with the father when the loss occurred • Participant shared so much cordiality with the father and they often eat together. | Loss of attachment | |
| <ul style="list-style-type: none"> • Participants experienced significant absenteeism from school due to parents’ illness • Participant experienced loss of concentration at school | Loss of educational opportunities | |

| | | |
|---|--|--|
| <ul style="list-style-type: none"> • Participants had poor results due to parents AIDS illness | | |
|---|--|--|

Table 4.6: Theme three (Parenting)

| Formulated meanings | Theme clusters | Emergent theme |
|--|---|----------------|
| <ul style="list-style-type: none"> • Participant's ailing mother was dependent on her for activities of daily livings (ADLs) • Participant missed several nights of sleep because the HIV sick parent only wanted him around • Participant had to contend with siblings demands and needs | Caregiving | Parenting |
| <ul style="list-style-type: none"> • Better appreciation of dying and less confusion for participants because of their older age • Realization of agentic abilities and abilities to devise strategies to cope with their circumstances | Positive experiences of parentification | |
| <ul style="list-style-type: none"> • Participant sacrificed future ambitions such as pursuit of tertiary education for the safety and wellbeing of siblings • Participant expressed that she did not pay attention to herself while she was struggling for the survival of the family | Negative experiences of parentification | |

Table 4.7: Theme four (Vulnerability)

| Formulated meanings | Theme clusters | Emergent theme |
|--|----------------|----------------|
| <ul style="list-style-type: none"> • Participant and her siblings were open to abuse and harassment by boys in the community because they had no male figure. • Older men come around the participant because they knew she was in need. | | Vulnerability |

Table 4.8: Theme five (Continuous grief)

| Formulated meanings | Theme clusters | Emergent theme |
|--|-----------------------|--------------------|
| <ul style="list-style-type: none"> • Participant is only experiencing the loss of her father now because she has been concentrating on other issues such as the care of the family • Participants would have preferred having their s father as the old man chasing after woman than dying from AIDS | Delayed gratification | Continued grieving |

Table 4.9: Theme six (Multiple needs)

| Formulated meanings | Theme clusters | Emergent theme |
|--|-------------------------------|----------------|
| <ul style="list-style-type: none"> • Participant described that he prays to God and believed that he will overcome | Need for coping | Multiple needs |
| <ul style="list-style-type: none"> • Participants could not meet the expectation of siblings on many occasion | Need for parenting skills | |
| <ul style="list-style-type: none"> • Participant expressed need for counselling and psychological care • Participant expressed being worried over almost everything in | Need for psychosocial support | |

| | | |
|--|----------------------|--|
| her life because life is just not easy for her | | |
| <ul style="list-style-type: none"> • Participants expressed need for food, habitable housing and education • Participant seek survival needs and resources that can make her less vulnerable | Need for empowerment | |

Step five: Exhaustive description of the categories

At this stage of analysis, all emergent themes was defined into an exhaustive description. It is important to highlight that the lived experience of the participants of this study is a process that started before the loss of their parents. After merging all the themes derived from the formulated meanings, the essential structure of the „lived experience of youths who have a lost a parent to AIDS in Wannune, Nigeria“ was derived. Finally, a validation to this exhaustive description was submitted to the research supervisor for validation.

4.4 PRESENTATION OF THE ESSENTIAL THEMES

The central research question of this study was: what is the youths“ description of their experience of the loss of a parent to AIDS? The study also explored their needs in order to meet the third objective of this study which was to offer recommendations based on the lived experiences of the participants. The themes constitute a mixture of both the experiences of the participants and their needs.

4.5 PARTICIPANTS LIVED EXPERIENCES OF PARENTAL LOSS TO AIDS

4.5.1 DISRUPTIVE LIFE CHANGES

The participants of this study were just like any other kids before the deterioration of their parents“ health and eventual death due to AIDS. The participants ate, slept, played and all went to school just like any youth of their age group. Participants were living a contented and relatively stable life but HIV and AIDS interrupted every facet of their lives. The participants“ lived experience of AIDS actually started before parental loss and their experiences started with

adversity (watching parental health deteriorate), and continued with frequent experiences of „uncertainty“ in the presence of pain that might not heal without appropriate interventions.

Adversity

All the participants lost parents to AIDS related circumstances and this meant that they were challenged by an unusual situation that ultimately set them on an adverse journey of life. The dwindling state of health of the AIDS sick parents and their inability to perform routine tasks made the situation of the participants tangible and portend present and future trauma experience. In the life time of the participants, the illness of their parents was not their first encounter with illness. However, something was different about the particular type of illness that their late parents had and the challenge that it posed. Parental AIDS illness and death was a significant source of uncertainty for the participants.

The older age of the participants afforded them to take part in the trajectory of the AIDS illness and participants described their experiences in the following quotes:

“I can describe the illness of my father in three distinct phases. The first was the period before he started medication. That was hell, I saw a strong and independent father become a weakling. It was a nightmare. Is it the cough that was not showing signs of cure or the lack of appetite or loss of strength that I will think about?” (Dependable)

“About a week before his death, he was not talking, not eating. He only wants me at home and by his side always....He does not sleep at night and I watched helplessly. Sometimes he will tell me to go and sleep, that he is okay but I never left his side” (Reluctant)

Uncertainty

Since the participants“ realized that the health of the parents was declining very fast, they experienced living in fear, anxiety and uncertainty.

After the death of **Flower’s** father, her mother was diagnosed with HIV and she started presenting with some of the signs that her father experienced and she expressed that:

“I just thought she is going to die. Every time I received a call, I always thought now they are gonna tell me she is dead because her condition was worse than that of my dad. She was losing her mind, they always tell us in the hospital that she could not sleep at night....I have never seen anyone so sick in my life”.

Other participants narrated how fearful they were during parental illness.

“You know I was always praying and hoping that he will get better because the way his sickness shook our family, I was expecting the worse if he could die. I started crying when I thought of my school fees, food, clothing and the possibility that we could be thrown out of the room that was given to us by his friend when he is no more” (Change)

Indeed, the experience of fear, anxiety and uncertainty did not abate after parental death but grew worse. Although the most feared reality (parental death) has occurred, the participants lived in constant fear of the unknown. For the AIDS orphaned youths in Wannune, there is no plan for the future, they live for the moment. **Flower** had this to say about her expectations after the death of her father.

“...it was about thinking of the next day, what you will eat for supper and the next day. No thoughts of the future. It was as simple as that. No thoughts of steps that you can take that will change your life completely. If your bed gets broken, you sleep on the floor or if the chair gets broken, you throw it away. No hope of replacing it. It is as simple as that” (Flower).

Change and his mother were ejected from the accommodation given to them by his father’s friend before his death. He had this to say

“We had to move from my father’s friend’s house due to conflicts and we are now staying in a mud house with thatched roof which is poorly ventilated. If you will find us there tomorrow or next, I don’t know”.

Before the death of the participants’ parents’ concerns over electricity, feeding, shelter, educational and survival needs were the responsibilities of the parents but after their death they had no one to provide for them. **Dreamer** explained that

“When my mother was alive, we don’t have to struggle, she provides everything. We celebrate our birthdays, she gives us everything. But now, you have to think of the electricity, food, clothes and what not what”.

4.5.2 MULTIPLE LOSSES

Apart from the actual loss of parents, all participants described several types of losses during the time of parental illness and death. However, the most poignant losses are the loss of educational opportunities, loss of the ideal family and loss of financial stability.

Loss of the ideal family

All of the participants had their personal conceptualization of an ideal family. The participants, irrespective of their previous family compositions, valued the inter-dependencies that previously existed between family members but this was lost after parental death.

Participants had this to say about the loss of their families.

“The family has just fallen apart, our home was deserted, no one was living there with us anymore, and I and my siblings were deserted. It was like if she was the fabric that held the whole family together and everything just crumbled in my eyes. Before her death, the family comes together for celebration of so many events and festivities, but all was gone in a twinkle of an eye and this makes me feel empty” (Reality)

“I grew up in a broken house; I did not experience what a family structure should be like. I sometimes ask myself, what I am going to do in my own family if I have one. How am I going to treat my husband? I wish I still have her around. I can’t relax, it’s like I have been thrown into a deep end and I have to fight over everything. Imagine not having anyone to promise you a dress after month end. Sometimes I get tired; I have been fighting for too long” (Dreamer)

Some of the participants’ experiences of losing the ideal family were further compounded by internal and external conflicts. They experienced diverse kinds of family conflicts, such as

arguments and discord among parents while others emanated from the extended family after the loss of their parent. As an illustration, Flower described that the parents had “*a lot of misunderstandings and were not on talking terms till his death*”. Further probe into what culminated into the amount of bitterness between the parents, the participant thought that the father constantly left the house to be with other women and cared less about them. Another participant (**Dependable**) discussed that the mother constantly insulted the HIV positive father and called him names in their presence. The rancour between the parents grew worse to the extent that even though some of the extended family members mediated and tried to broker peace; the mother still left to live overseas.

Most of the participants“ experienced some form of family conflicts. Reluctant“s experience was different from the rest of the participants. He described that:

“Sometimes I will observe them without them noticing. My father was very sick, to the extent that sometimes he refused food but my mother bathed him, prepared him food, force him to eat and take his pills. I just got that information on what a good family was supposed to be” (Reluctant)

Loss of attachment

Participants“ loss of attachment illustrates the relationships that participants shared with their late parents. This is so because there will be no sense of loss without a considerable attachment to someone (Parkes, 2002). Attachment that was lost sometimes leads to expression of regret and pain. Loss of attachment was significant for all participants because their deceased parents were a role model whom they relied on for various forms of support and advice. Participants narrated their relationships with their participants in the following quotes:

“It was when I reached the age of 15 that I started to experience something to my father, to know what father is, what father do in the family, I just started to know what a father is in the family” (Reluctant)

“I was very close to him. We eat together. Up till now, I still see him in my dreams and it seems that is the only peaceful time of my life because he is always his usual self in my dreams and always giving me hope” (Change)

Although **Flower** did not value the attachment that existed between herself and her father, at the time of his death because he neglected his family, she described how she is now missing him.

“At that point, I just hated my dad. I was just angry at him, I did not see so much on his part because of his way of life. He leaves the house to be with other woman and cared less for us and I got very angry with him. But as a grow up, when I reached the age of 23/24, that is when I started realizing the need for my dad, You know now I need my father, because I thought probably he would have changed, he would have seen me developing myself and would have contributed to my development”.

The narratives of some of the participants“ suggest that the loss of parents created a gap between their heritage (family values, norms and culture) and future expectations.

“When he died, I had a lot of questions on my mind that were unanswered. There are some things I wanted to ask him about the family and about the culture. I use to hear the old people in the family gossip about some past issues in the family but I don’t know about them. I had a desire to ask him about these issues when I become older, say like 20 years..... he was my favorite person and I wanted to hear all these things about my root from him” (Reluctant).

Loss of educational opportunities

Parental AIDS illness and death interrupted the schooling of all the participants and significantly set them back. Most of the participants“ had to give up attending school because of the need to care for their parents or loss of parents“ financial income and capabilities. Participants“ discussed the following ways by which AIDS parental illness interfered with their educational pursuits.

“I lost concentration in school because situation at home was very bad and the thought of your father seriously sick made me not to be composed most times. My teachers are always complaining about me that I am losing attention, they complain of my sleeping in class and that I am appearing untidy” (Change)

“The part that was most difficult for me was that I just completed my matric exam that time and my results were not so good because it was when I was about starting the exam that her condition started deteriorating (Flower)

4.5.3 PARENTING

Parental AIDS illness and death marked the end of the participants’ childhood and ushered them into the world of caregiving and performance of parental roles despite their immaturity to take up those roles. Participants’ involvement in caregiving started before the parents’ death but this increased exponentially after their death. Before parental death, participants experienced a form of role reversal in which they were directing care to their AIDS sick parent and this seems like a training ground for a journey of caregiving that followed with the care of their siblings. Participants’ role reversals were experienced in the following ways.

Caregiving

According to **Dreamer**, her mother’s failing health meant increased responsibilities and increased involvement in the running of the home affairs.

“She was a healthy person but all of a sudden, she started losing her strength, relying on us for assistance to do those activities that she has been doing before”.

Dreamer highlighted that she became a guardian immediately after the demise of her mother and this came with increased work and responsibilities.

“I have to contend with my siblings asking what they will eat, though you don’t have anything in mind but you have to make a plan. I have too much responsibility; psychologically, physically and sometimes I feel like if I am going to break”.

The gender of the participants’ does not determine their involvement in caregiving as exemplified by the case of **Dependable**. **Dependable** was the eldest child and so he automatically assumed the responsibilities that were previously performed by his mother after she left the home, he explained his caregiving experience.

“You know I took up responsibilities of the home before his death and due to our mother’s departure. So, the responsibilities of home keeping, looking after the home, my

younger ones and myself continued. The little thing that has changed is just the fact that I feel like if the shield of parental presence, control and security has been taken away”

Although **Reluctant** was also involved in caring for his father during his illness, his caregiving roles stopped after his father’s death. The reasons being that his mother was healthy, financially stable and he was the second to the last born which meant that his younger brother does not need to rely on him for any needs.

Change and **Flower** had to significantly take up income generating activities to provide for the needs of the family. **Flower** narrated the following experiences of being parentified:

“I started working. I did not have time to look after myself. I have to make sure that I make my mum happy, built a home for her. I have to forego my studies. I have to work and study so that I could pay the bills and look after my family”

The participants’ experience of parenting responsibilities comprised of mixed experiences and this will be discussed below under positive and negative experiences. These experiences were gleaned out when the researcher requested that the participants’ should compare whether their lived experience of parental loss to AIDS will be different if they were younger at the time of parental loss to AIDS.

4.5.4 Positive experiences

Better appreciation of dying and death

The participants had the opportunity to witness and take significant part during the period of parental AIDS illness, the moment of death and the life after their departure. Indeed, the prolonged duration of illness which is characteristic of HIV and AIDS infection provided a kind of buffer for the participants to be somehow prepared for the eventual death. Participants were asked if their experience would be different if the death of their parents was due to another illness or circumstance such as heart attack or Road Traffic Accident and they had this to say:

“...If it was a sudden death, ahh!!!! it will be different. You know if someone is sick, somehow you get a sudden acceptance that they might die, every time you think about it.

But if it was a sudden death, it will be shocking and traumatic and you won't be prepared" (Reality)

Participants also discussed the role their age had on their general experience of orphanhood. Participants were asked if their experience would likely be different if they were several years younger than they were at the time of parental death.

"Hmmm! I think I would be more confused because I wouldn't have known much about him. At least, at the age I was when he died, I knew the kind of person that he was. But then if he died when I was like 10 years, I would have been relying on other people's information to know what kind of a father I had" (Flower)

"Yes, I think I would not understand what was going on. Because at my age, I understood clearly what death meant. Yeah!!! Being older was advantageous because I was not in confusion over her death unlike my siblings who were confused" (Reality)

Realization and development of agentic abilities

Parental death illuminated the participants to their abilities to contribute to the welfare of their families. Their previous dependence on their parents to provide for their needs radically changed after parental death and this meant early independence as the following quotations illustrate:

"..Even if you were not serious before, now you have to be serious. Seriously, we are talking of you losing someone who has been taking away your worries. Although you are a child, now you have to become a parent" (Dreamer)

"If I was younger, I would have been helpless because when he died I was able to work and assist the family but being younger meant that I won't only be helpless but powerless and I won't be able to contribute to the welfare of my family" (Flower)

4.5.5 Negative experiences

Although being older at the time of parental death was advantageous to the participants in some aspects as described above, the negative experiences of orphanhood dominated the participants' experiences and are discussed below.

Overwhelming responsibilities

Participants reported that matters became worse when their parents died and their responsibilities increased significantly.

“Obviously! Her death immediately places burden and responsibilities on me. The older you are, the more expectations. Even if you were not serious before, now you have to be serious” (Dreamer)

“I am constantly under pressure to work hard in order to meet our needs. I feel like I am not a child anymore when I think of the things that my father’s death has caused” (Change)

“Although the negative circumstances are motivating me, like wanting to be a good model for my siblings, the load I am carrying emotionally, financially and psychologically are too much of a burden and sometimes I feel like dying or needing a psychologist” (Reality)

Overwhelming worry over siblings

Since these young participants took up adult roles, most of them are burdened by the welfare of their siblings.

“What if my younger siblings ask you for this and that and you were not able to offer it, what are you going to do?” (Dreamer)

“I am even more worried about my younger ones; they get intimidated easily and feel so inferior to their peers. It is like if they don’t understand that he is dead and not coming back again. They sometimes give puzzling comments like I will report you to father when he is back at the weekend. I don’t think they know he is dead and we don’t talk about this because I don’t have the right knowledge myself” (Dependable)

Flower even thought that his younger brother might be in a crisis when she commented that, *“Like my brother, that boy has a crisis. He needs his father”* and this constantly worries her.

Participants sometimes feel like failures in situations where they were unable to meet the expectations of siblings:

“Sometimes there is a deadline for payment for exams or they need to attend an excursion at school and they need money which I and my mother can’t make happen. Those times, the heroics I have been performing and been seen as a father disappears and those times you see yourself as a failure” (Change)

“..when I look back, I feel I have left my siblings down. After I left home to pursue tertiary, my sister packed out of the house to start staying with friends, my brother was stabbed and was left to die” (Dreamer)

Self-sacrifice and self-neglect

In order to meet with the expectations of the surviving siblings or parents in some cases, participants had to sacrifice many things such as their childhood, personal gratification and education. The act of self-sacrificing lead to participants’ neglect of themselves and this gave rise to feelings of regret and guilt. Participants discussed the following ways by which they sacrificed for their households:

“...I started working, I did not have time to look after myself.....So, somehow then I started thinking that life is not always about other people. I am here on earth on my own journey, I know taking care of my mother is something that I have to do but somehow I neglected myself. As I was striving to build a house for my mother, I neglected myself” (Flower)

Participants’ self-sacrifice resulted into the verbalization of being delayed in their respective lives:

“After I left home to pursue tertiary, my sister packed out of the house to start staying with friends, my brother was stabbed and was left to die. I was not there when they needed to make choices about the courses to pursue and now I felt the death of my mother has pulled me back several years and delayed my progress because I have to hustle for myself and my siblings” (Dreamer)

“In fact, the time I was supposed to sit for matric, I was denied registration because I did not obtain the minimum attendance that was required. I had to wait till the following

year. The following year, father was still there battling with sickness and I only managed to write the examination after two years” (Dependable)

4.5.6 VULNERABILITY

Participants’ experience of vulnerabilities were diverse and from varied channels. Some of the participants are vulnerable because they lost a „male figure“ that protected them from abuse within the local community, while some of the participants were at risk because of economic hardship. The vulnerability was just a result of parental loss and the sequel that followed the event.

As an illustration, **Flower** only had a brother who was younger and defenseless when their father died, leaving them without respect in the community and at the mercy of the gangsters.

“We were vulnerable in some way, not that because we did not have a father in the real sense of it, because most families were like that. What was happening was that, there was this gangsterism, you know the boys, you know they want to go out with you, they want to abuse you because there is no male figure in your family. Like when you are going to school, this guys can snatch you or take you and say you are gonna be my girlfriend, knowing there is no one going to talk on your behalf. It’s like your family is not respected because there is no male figure in the family. That’s how it was for us” (Flower)

Other participants expressed the avenues by which they were liable to vulnerability

“As a female growing up, you just think of a lot of options to making money. When you see some of your peers afford some things; you become eager to try several means and short-cuts..... Some men have proposed marriage to me and advised me to quit school and be their wife. I was vulnerable but then I knew those means are not the way and can’t help me” (Reality)

4.5.7 CONTINUOUS GRIEF

Despite that parental death has occurred for more than one year, participants’ narratives revealed that some are still grieving the loss of parents; some have not even started the grief resolution

process. Some of the possible reasons gleaned for this continuous grief in the participants could be their increased caregiving roles and self-neglect that prevented them from acknowledging the emotions and feelings attached to their loss. As mentioned earlier, this research was the first chance that the participants had to discuss the loss of their parents. Evidence for continuous grief among the participants“ is illustrated in **Reluctant’s** experience. His father was his favourite person and the death left him with a „sore“ that he expressed will take a long time to repair.

“Father is just a father any time. Whenever I hear someone talking about his or her father; the thoughts of my father comes to me and I close my mind. I tried to forget it but it’s not easy”.

Although **Flower** was angry at the way the father lived and how his wife and directed anger towards him when he died, she however seems to be experiencing a form of delayed grieving as clarified below:

“...it’s not like if he really cared but as I grow older, I am now realizing that I need my father and I need him more and more...I would have preferred having him as that older man chasing after women rather than him dead. But then who can answer that, no one. You just continue asking yourself these questions. Sometimes I just wish I could dream about him”.

Dreamer also expressed how she constantly get consumed in thoughts during the good and the bad times of their orphanhood experiences

“Ah!!!! It’s a crazy world, it’s a crazy situation, and you would not even wish that for your worst enemy. Even now when something goes well for me, I feel sad because my parents don’t have d opportunity to enjoy the fruits of their labour” (Dreamer)

4.6 THE IDENTIFIED NEEDS OF YOUTHS WHO HAVE LOST A PARENT TO AIDS

4.6.1 MULTIPLE NEEDS

Parental loss comes with different kinds of needs that must be met if the participants are going to develop into healthy and socially responsible adults. In order not to recommend needs that will be insensitive to their circumstances, the researcher asked all the participants to suggest their needs. The participants suggested several needs but they seem to prioritize them based on their present pressing challenges, parental values before death and future expectations. While some of

the participants were more poised to discuss survival needs such as feeding, some were more interested in educational assistance.

Need for parenting skills

Due to the participants' involvement in caregiving responsibilities for their siblings, majority of them verbalized the need for parenting skills. The participants wanted unity in their family with siblings living together because they would draw support from each other. However, they faced some challenges due to their parenting roles. This influenced them to suggest training programmes that involves parenting modelling skills and national mentor initiatives. Participants were stressed out by their inability to meet the expectations of siblings and were only able to offer limited support during the sicknesses of siblings. They verbalize the following strategies to combat their parenting challenges:

“There should be a kind of modelling programme especially for us who are taking up responsibilities of the home, because we have lost our childhood” (Dependable)

“...and maybe if there was a national mentor programme where we have individuals who are committed to making sure that we orphans in charge of our homes do not suffer much by providing us with guidance” (Dreamer)

Reality seemed frustrated because she felt that the stakeholders and partners in her family's wellbeing had abandoned her and her siblings and advocated for clear official channels of support to meet her parenting needs.

“Also, the government should provide a clear channel of help for people like us. Like the social workers; although I am not saying they are not doing their work, but we are here suffering, I have never seen any social worker walking through the door. I don't know if we are supposed to go somewhere to ask for help. I don't know these things. Some people need to be at the grass root monitoring youths of our age because the death of our parents have now forced us to become adults and we have never walked in that path before. We are just alone; we don't feel like we belong to this country”.

Need for empowerment

Participants expressed several means by which they could be empowered, ranging from educational assistance, feeding assistance, better accommodation to sexual empowerment. Some of these empowerment needs were gleaned from the question that requested that participants should offer advice to other youths who might be in the same situation as them.

Flower for instance had episodes where she was at the mercy of gangsters after the death of her father that opened her to some vulnerability. She felt that orphans can be empowered in the following way.

“I think at the age of 18, you just need guidance. How to do things, what to expect? It depends on the role the dead parents are taking before their death”.

Although **Reality** recognised that educational assistance could positive transform their predicament, they were more concerned about feeding assistance. They explained

“...education is not paramount when you have not eaten. We need to survive first before thinking of school. Maybe a special welfare care can be set up for people like us. At least there is a community council that knows these things, they know someone has passed away and they supposed to assess and arrange care for us based on our situation. Maybe to get people to watch over us, support us, mmmm; people that will be interested in our stories” (Reality)

Dreamer’s worry would have been less if a financial and educational plan existed for orphans that cover the payment of their tuition until they reached the age of 25 years.

“I would say that financial support can and it would make an orphan's life a bit easier and bearable because one will maybe just worry about other kinds of support, like emotional and many others. I think my life and those of my siblings’ lives would have been so much better if we grew up knowing that our school fees are paid for already from elementary to tertiary level, at least up until age 25”.

Need for psychosocial support

The load that participants are carrying emotionally made them verbalize the need for counselling and psychological care. Participants expressed frustrating experiences attached to the overwhelming need of their homes. Failure to acknowledging their unhealed emotions has placed

them at risk of mental breakdown. Some of the expression of the participants suggests the following need for psychological care:

“Firstly, the emotions need to be assessed so that you can make the right choices and the psychological aspects need to be addressed” (Reality)

“I can’t express my frustrations and emotions in the home because my siblings look up to me for strength. Sometimes I feel like if I am crashing, like if I am going to die or lose my head” (Dependable)

Need for coping skills

Participants exhibited some coping strategies used to adapt to their situations. While some of these coping needs might be erosive over time, it is important for them to embrace practical coping skills such as resilience for better outcomes.

The orphans discussed the following resiliency strategies used in alleviating their situation.

“I farm on our land and cultivate items like vegetables so that I can sell to afford the very basic needs” (Reality)

“I just believe in God and I use to tell myself that I can’t struggle in life” (Reluctant)

“I usually pray and sometimes I cry when no one is watching or around. I am always consumed in wishful thinking, wishful thinking” (Change)

However, the participants were silent on the use of social and support networks to manage their circumstances and the researcher finds this worrying because it meant the participants“ are not pro-active in their help seeking behaviors. Most coping theories go beyond the dispositional personal attributes of the individual to advocate for greater use of social supports before effective coping strategies can be adopted but this was an un-used resource by the participants.

Step six: Reduction of findings

This step is a bit similar to the previous step, but no exhaustive meanings were sought. In this step, a reduction of findings was done in which redundant, misused or overestimated descriptions were eradicated from the overall structure. Such attempts were made to ensure that the

fundamental structure was arrived at. Some amendments were made that includes shuffling of quotes to themes that were more relevant to a particular experience and this assisted in the generation of clear relationships between clusters of theme and the emergent themes. Some ambiguous structures that weaken the whole description were also eliminated.

Step seven: Participants' validation of description

This step was aimed at validation of the study findings using „member checking“ technique. It was undertaken through returning the research findings to the participants and discussing the results with them. Participants were telephoned and the findings of the study were discussed including the description of their experiences. All participants were satisfied with how their narratives were described by the researcher and they hope that something positive can develop from the dissemination of the study findings

4.7 DESCRIPTIVE SUMMARY OF THE ESSENTIAL THEMES

This chapter presented the findings from the participants and described the Colaizzi's process of phenomenological data analysis used in generation of the themes. Colaizzi's data analysis method provided an active strategy to achieve the description of lived and living experience for the participants. Youths in Wannune who have been orphaned by AIDS experienced disruptive life changes and suffered other losses apart from the death of their parents such as:

- Becoming parents prematurely,
- Becoming vulnerable,
- Grieving and having multiple needs which should be filled if better health and social outcomes will be achieved.

All of the essential themes offered a small glimpse into the lived experience of the youths. To comprehend the nuances of these lived experiences, the themes must be interpreted together. The researcher acknowledged that the whole thematic map might be quite different than the sum total of its parts (Omery, 1983). While there is chronological flow in the way the researcher presented the essential themes, they are intertwined and in motion. Each theme can be understood as a

moment in the lived experience of AIDS orphanhood as a youth and then be brought back into the whole as a new development or challenge.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 INTRODUCTION

The findings and conclusions of this study are presented in this chapter. The chapter presents a discussion on what the study contributed to the existing literature regarding the phenomenon of AIDS-orphanhood and the implications for research and policies. Recommendations are offered on relevant interventions based on the presented lived experiences of the participants. The chapter concludes with a critical reflection of the researcher on the approach used in the study, the limitations and the conclusions that can be reasonably drawn.

5.2 OVERVIEW

The phenomenon of interest in this study was the lived experience of youths who had lost a parent to AIDS. The study explored and described the lived experiences of participants" using a descriptive phenomenological approach. In this qualitative study six youths between the ages of 18 to 24 years were recruited using a mixture of purposive and snowball sampling as multiple purposive sampling technique. The duration of orphanhood was carefully selected and it ranged between one and three years for the following reasons. Firstly, to preserve the grief resolution of participants which studies on bereavement has documented that is likely to occur after one year of loss (Gilbert & Charles, 2012; Prazak, 2012). Secondly, to minimize wide variations within participants experience so that the essence of the shared experience would not be distorted by extremes.

Phenomenology was chosen as the methodology of choice for this study because its locus is that of human experience and this afforded the researcher the opportunity to gain in-depth insight about the subjective experience of AIDS-orphanhood from the perspectives of youths. This study utilized a phenomenological methodology underpinned by the philosophy of Edmund Husserl. Although phenomenological methodology has several approaches which have been discussed earlier (see chapter three), the approach that was best suited to answer the research questions of this study was the descriptive phenomenology which was championed by Edmund Husserl. Descriptive phenomenology is unique from other methodologies in that its preference is for a

phenomenon to be described rather than explained or having its causal relationship searched for (Sadala & Adorno, 2001).

The structure for describing the lived experiences of the participants was derived from the application of the Colaizzi (1978) framework of phenomenological data analysis of the transcribed interviews. Each of the participants narrated their experience of AIDS parental loss within the framework of their values, family history and family dynamic, past and present experiences of loss and future expectations. The researcher, who has never experienced AIDS parental loss in the past, met the participants like an „empty vessel“ that was open to the participants“ stories. The credibility of a descriptive phenomenology is in the identification of the true structure of the phenomenon, so that anyone who has experienced the phenomenon should be able to identify their own experience in the proposed description (Kumar, 2012).

The process of phenomenological reflections is that of retrospection rather than introspection (Van Manen, 1990). This suggests that the narration of the participants required reflection in order to be understood. Participants narrated their experiences of AIDS-orphanhood from the period before the loss of the parent and discussed how their lives have been affected and how it continues to be affected. The analytic approach utilized in the study (Colaizzi, 1978) allowed the themes to emerge from the data and assisted the researcher to describe the orphaning experience of the participants which is the youths relation to the phenomenon of parental loss to AIDS and their orientation towards the phenomenon.

5.3 CONTRIBUTION TO KNOWLEDGE

As with the review of literature in chapter two, this section is organized into the two areas of focus: first, the lived experiences of youths who have lost a parent to AIDS and secondly, the needs of youths who have lost a parent to AIDS. This study, despite its small sample size, builds on the existing body of knowledge that explores the lived experience of AIDS orphans. The political and economic factors seems to be charting the course of HIV and AIDS related researches and thus, the priority of OVC policy makers and researchers seems to be directed at the orphans who are children under the ages of 18 years. This study does not seek to weaken the

overwhelming focus on children AIDS orphans because of their peculiar vulnerability, rather it seeks to highlight the great opportunities open to researchers who are interested in the phenomenon of AIDS orphanhood if they extend their interest to youths who are over 18 years.

5.4 THE LIVED EXPERIENCES OF YOUTHS WHO HAVE LOST A PARENT TO AIDS

5.4.1 Disruptive life changes

Participants in this study described how their life changed negatively right from the period of parental HIV illness and how this continued even after the death of the parents to AIDS. The disruptive life changes that befell the participant started with the experience of adversity and this was compounded by uncertainty due to fear of the unknown. The participants are living for the moment and they have no guarantee over their housing, feeding, clothing, health and safety. This finding is in line with that of Yamba (2005) who reported that AIDS orphans experience of orphanhood came with frequent changes in households, migration, instability and uncertainty. Ogina (2010) also added that AIDS orphans are often plagued by hunger. In the presence of reduced income; Ogina (2010) reported that AIDS orphans live in agony because they are sometimes unable to seek healthcare services when the need arises. Similar to the findings of a study by Harms et al. (2010) these young orphans also felt that their lives had been disrupted in that they had lost educational opportunities because of caregiving roles which resulted in them dropping out of schools.

The finding of disruptive life changes found in the current study can be attributed to the dependency style of relationship that existed between parents and children before death, where children depended entirely on parents for all kinds of support. Parental AIDS illness and subsequent death thus have a ripple effect on the present and future stability of the children who are not physically, emotionally and financially matured to be independent members of the society.

5.4.2 Multiple losses

Although the phenomenon of interest in this study was the actual loss of parents to AIDS related illness, the reality is that the participants suffered several losses of ideal family, attachment and educational opportunities. While the loss of educational opportunities due to loss of financial capabilities and the loss of the ideal family can be expected as accompanying parental loss; a striking finding of this study was the loss of attachment. The researcher was expecting to find the reportage of attachment loss if the study was carried out among younger orphans. Participants' loss of attachment can be attributed to advanced age of the study participants which afforded them better knowledge of parents personality and bonding better with their parents before death, caregiving roles directed at parents during illness, closeness with the lost parent and their youth age which comes with the developmental tasks of forming their own identity. Literature has been somewhat silent on the loss of attachment by AIDS orphans, however some of the other poignant losses that come with parental AIDS loss in the literature are:

- loss of educational opportunities, loss of identity and familiar properties (Harms et al., 2010);
- loss of childhood, loss of educational opportunities (Gilbert & Charles, 2012);
- financial and material losses (Ogina, 2012),
- loss of companionship, loss of role model, loss of parental fellowship, and loss of ritualistic practices (Rooyen, et al., 2012, Thupayagale-Tshweneagae, 2012)
- loss of ideal family, loss of stability, loss of hope, loss of childhood, loss of and loss of identity (Francis-Chizororo, 2010, Yamba, 2009).

5.4.3 Parenting

One of the main findings in this study was that the parental illness and death which marked the end of the participants' childhood. The participants felt that they were forced to enter the world of caregiving and performance of parental roles despite their immaturity to take up those roles. This finding was in line with that of Harms et al. (2010), Evans (2010) and Wood et al. (2006). As an illustration, Wood et al. (2006) described that the emotional challenges of parental HIV illness and caregiving roles after parental death made orphans felt „grown-up“. Harms et al.

(2010) and Evans (2010) also found that AIDS orphans take up adult responsibilities such as caregiving and economic roles in order to survive and provide care for dependent siblings. This finding was an unexpected finding of this study because the researcher's premonition was that orphans in Nigeria are traditionally absorbed by the extended family or other significant others regardless of their age group. This finding therefore suggests that the magnitude of HIV and AIDS in Wannune might be eroding the nurturing and protective capabilities of extended families that traditionally provides safe landing for orphans and this needs to be taken into consideration when planning care and support services for AIDS orphans. As explicated by Francis-Chizoro (2010), being the eldest surviving orphan is the most important determining factor for taking up parental roles and this was evident in this study because the participants who were older had to act as parents automatically for their younger siblings.

Some of the participants" became breadwinners of their respective families after the death of parents but this premature transformation to parentified roles did not entirely come with negative experiences and the researcher finds it an interesting finding of this study. Participants" seem contented that they have agentic abilities to contribute to the survival of their households because of the older age advantage over their siblings and the ability to know the kind of parents they had was a big advantage that they cherished. Although the study participants described that the overwhelming responsibilities of being household heads and bread winners in some cases exposed them to massive amount of worry over the affairs of their respective homes which made them to self-sacrifice and neglect themselves in the process; their wish is to live together as a group. This finding resonated in the study by Okawa et al. (2011) which reported that AIDS orphans cohabitation with biological siblings increased perceived social support (PSS) scores which consequently increased their psychological wellbeing and hence their wish to continue living together.

In contrast however, the participants" in the study by Thupayagale-Tshwenegae et al. (2009), Ogina (2012) and Daniel and Mathias (2012) were absolved into foster homes or other support facilities and did not experience any parenting roles but rather stigma and discrimination in their

foster homes. This underscores that the source of recruitment of AIDS orphans in research can dictate and diversify the type of experience that will be reported by AIDS orphans.

5.4.4 Vulnerability

Although participants' experience of vulnerability was not pronounced in this study, but still their narratives were subtly filled with stories of exposure to vulnerability. One of the participants had a child outside marriage and other female orphans acknowledged that they were targeted by older men for sexual relationship because of their economic and psycho-social needs. Conservative positions of the Nigerian society on sexuality is likely to be the reason for participant's silence on sexual vulnerability and various forms of abuse that they might be exposed to. Even the participant with a child declined to talk about how she became pregnant for an older lover who did not take responsibility for the child. Participants of the study were open to diverse source of information because of the missing parents and this might drive their indulgence in risky behaviours which might compromise their physical, social and psychological wellbeing over time.

This finding of the current study was in line with that of Daniel & Mathais (2012) who found that AIDS orphans experience physical, psychological and sexual abuse which drive their vulnerability. Gregson et al. (2005) added that AIDS orphans are at threefold higher risk of acquiring HIV infection and the authors implicate poverty has the most significant factor that drives orphans involvement in the risky sexual behaviours because of economic survival needs. Since literature on AIDS-orphanhood is concentrated among children under 18 years; it can therefore be expected that risky sexual practices and HIV infections are likely to be higher among the older orphans. This is likely to be as a result of their sexual maturity, need for love and belonging, poverty, repressed feeling, loss of attachment and desperation to ease siblings' worries as confirmed in this study.

A positive finding of this study is the non-reportage of stigma or discrimination by any of the participants. The participants have never been treated differently or shown any type of attitude despite their affiliation to HIV infected parents. This finding differed from those of studies

conducted by Harms et al. (2010), Ogina (2012) and Kumar et al. (2014) which reported that AIDS orphans are often subjected to derogatory stigma remarks and often reminded of their inferior societal position because of parental AIDS illness and death. This difference in finding could be attributed to the developmental age of the participants which afforded them the opportunity to distinguish stigma/discrimination from adversity that comes with their challenges and their personal expectations. The high prevalence of HIV and AIDS in the community which meant that most family has been affected (Hilhorst et al., 2006) and the living arrangement of the participants (not fostered or adopted) can also explain the differences in findings.

The experience of family conflicts in this study emerged from internal quarrel between parents and from participants' anger directed at the extended family members for their inadequate care and distant approaches in relation to their care. This is likely to be a disadvantage of the older age of the participants' and the society's expectation that youths are able to survive on their own due to their energy and abilities. Similar studies such as Evans (2010) have also reported that AIDS orphans are often faced with the additional stressor of family conflicts because of the tendency of extended family members to strip AIDS orphans of their inheritance which often results to bitter quarrel and sometimes legal tussles. This difference in the experience of family conflicts calls for a nuanced understanding of orphans realities and also has to do with the developmental age of the participants', context specific realities, support factors available, wealth of household before parental death and source of recruitment which differs in this study and the ones conducted by Evans (2010).

5.4.5 Continuous grief

Narratives from the participants of this study suggest that some of them were at risk of „complicated grief“ despite that the parental loss has occurred for more than one year before data collection. Some of the participants expressed crying at night, regrets over their current situation, fears over future expectations, dreaming about dead parents and anger directed at dead parents or significant others, at times. Similar studies (Van Rooyen et al., 2012; Thupayagale-Tshweneagae et al., 2010) have also identified anger, fear, pretence, deep pain, wishful thinking as some of the lingering experiences of children orphaned to AIDS. Cluver and Gardner (2007) stated that the

experience of uncertainty, anger and regrets are significant risk factors for psychological wellbeing of AIDS orphaned children. The „continuous grief“ occurring in the participants is consistent with the findings of Thupayagale-Tshweneagae (2012) which reported that grieving is a continuing experience that is always present in the life of AIDS orphans.

When the death of a beloved happens, even when the death is expected as in the case of the participants of this study; participants still experience a wide range of emotions, commonly referred to as bereavement or grief. What is surprising in this study is that none of the participants has ever talked about their experiences of loss with anyone even though the process of acknowledging and discussing their parental death can facilitate their healing process. Bereavement is a distressing but natural, necessary and probably universal experience which is manifested through social withdrawal, crying, anger, guilt, regret, helplessness, hopelessness, low self-esteem and poor concentration among others (Li, et al., 2008).

Based on the attachment theory, Bowlby (1982) postulated that there were four phases in a grieving process:

- shock, associated with symptoms of numbness and denial,
- yearning and protest, as realization of the loss develops,
- despair that is accompanied by many of the manifestations described previously over a longer period; and
- recovery, marked by a general feeling of increasing well-being and acceptance of and adaptation to loss.

Research (Rando, 1984; Li et al., 2008) suggests that if these steps are not successfully completed then individuals will suffer „complicated“ grief. Considering that Cluver et al. (2012) found that the risk of negative outcomes (depression, PTSD) of AIDS-orphanhood increases with the child age in South Africa using structural modelling, it is important that the long term effects of fluctuating episodes of grief among AIDS orphaned youths be explored longitudinally using various research approaches.

In the context of this study, the double blind between participants needs (social and developmental) and parental responsibilities creates ongoing problems for the youths. Some of

the participants seem not to have started grieving because of the costly consequences of caregiving and parentification. Instead they had to repress their own feelings, sacrifice their own career ambition and take substantial risks for the daily survival of their siblings. Sacrificing ambitions, repressing feelings and the experience of overwhelming worry over siblings in the face of adversity and poverty can jeopardize the psychosocial wellbeing and healthy youth development of participants over time.

5.5 THE IDENTIFIED NEEDS OF YOUTHS WHO HAVE LOST A PARENT TO AIDS

5.5.1 Need for parenting skills

In this study, the need for parenting skills aroused out of participants inability to meet the expectations of siblings under their care. Some of the participants expressed lack of skills to make their siblings understand the concept of death in relation to the dead parents and they asked for guidance to fulfil that expectation. The need for parenting skills is supported in studies by Satzinger et al. (2012) and Evans (2010) who reported that AIDS orphans who are responsible for the care of their siblings are unique when compared to other non-bereaved youths of their age group because of self-sacrifice for siblings to get ahead in life. The studies above also disclosed that orphans are faced with psycho-social challenges and are significantly burdened because of the overwhelming responsibilities to fulfil the roles of being a child and a parent at the same time. Some participants of this study discussed feeling under pressure and feeling like failures when they were unable to meet the expectations of siblings. The participants even listed that interventions such as national mentoring programmes and parental modelling approaches would go a long way in assisting them to navigate the tricky sides of parenting

5.5.2 Need for empowerment

Clearly, the participants in this research are disadvantaged due to loss of parental figure and loss of income. In a community where farming is the predominant source of income, participants expressed the need for assistance with farming and education. While some of them described that they were more in need of survival assistance in the form of food stuffs before they could think of schooling or farming. Others sought for social protection against thieves and older men who

may want to take advantage of them. The empowerment needs of AIDS orphans have been actively advocated for in the literature. Some of the pertinent empowerment needs identified in the literature are:

- sexual enlightenment and education to prevent HIV infection (Operario, Underhill, Chuong & Cluver, 2011; Gregson et al., 2005),
- economic empowerment through income transfers for poverty reduction (Arnold, Conway & Greenslade, 2011; Evans, 2010),
- peer mentorship for the prevention of social alienation (Rotheram-Borus et al., 2005, Chitiyo et al., 2008) and
- increased school attendance (Lewin & Sabates, 2012).

All of the above empowerment needs were identified by the participants as important to ameliorate their situation.

Access to resources is undoubtedly a viable means by which AIDS orphans lives can be affected positively. Participants seemed clueless about available resources that might be helpful to them. They expressed frustration at the society's lack of sensitivity to their needs. This finding was also supported by Mnubi-Mchombu et al. (2009) who reported that AIDS orphans did not know about services available or unavailable to them. Mnubi-Mchombu et al. (2009) identified that orphans needed information on financial assistance, child care, psychological support, health services, farming skills, feeding schemes and grants (Mnubi-Mchombu et al., 2009). Mnubi-Mchombu et al. (2009) however reported that despite 82 percent of the participants wanting information on financial and survival services, 65 percent of them could not identify any services that might be of help to them. Of the remaining 35 percent who acknowledged knowledge of some organizations of help, a further 57 percent of them could not name any. This naivety about awareness of services that can benefit the participants might require that OVC stakeholders utilize proactive and grass root strategies such as the social workers (as suggested by the study participants, see page 81) to enlighten them about viable channel of information that can lead them to resources that can be of assistance to them.

5.5.3 Psychosocial needs

Participants were in need of social and psychological interventions because they repressed a lot of emotions. Some of them have verbalized their need for counselling and psychological assistance. This need for urgent psychosocial support is correlated in several studies (Satzinger et al., 2012; Adejuwon & Oki, 2011; Kumar et al., 2014; Cluver et al., 2012) which reported that psychological and physical effects of orphanhood are magnified for AIDS orphans when compared with orphans from other causes and non-orphans. Most of these studies used a wide range of measuring scales and methods to demonstrate the need for psycho-social support in form of counselling, psychologist care, increased contact with extended family, psychosocial support programming, social protection and increased school attendance.

Many of the risk factors for poor psychosocial functioning reported in this study such as anger, regrets, social alienation, anxiety, fear, worry over siblings and the overwhelming exhaustion from their involvement in caregiving roles have good evidence for successful preventive or responsive interventions. There is strong evidence for effectiveness of personal and community-based mental health counselling (Rotheram-Borus et al., 2005; Chitiyo et al., 2008; Kaufman, Zheng, Wang & Zhang, 2013), spiritual modelling through reflection and transformation (Thamuku & Daniel, 2012; Loubser & Muller, 2011) and home visiting (Mikton & Butchart, 2009).

5.5.4 Need for coping skills

Outstanding agency and resilience resourcefulness existed among the participants of this study. This is due to their older age and their readiness to take up parental roles after the demise of their parents. It seems like the participants have co-constructed ambitions through role interactions and attachments formed with parents. All the study participants, save one, are involved in income generating activities and some of them were even contented that their older age saved them from helplessness because they were able to contribute to the survival of their households. This finding is similar to Daniel and Mathais (2012) and Germann's (2006) studies which found the existence of remarkable resilience and extraordinary resourcefulness among AIDS orphans

which assists them to effectively deal with difficult situations of parental loss and the antecedent sequel that follows it. Germann (2006) further advocated for capacity building that is related to resilience development.

5.6 IMPLICATIONS AND RECOMMENDATIONS

5.6.1 Health Policy

The results of this study have several implications for OVC policy in Nigeria. Within the comparatively recent field of research on young people affected by AIDS, a very small but increasing body of evidence (Evans, 2010; Operario et al., 2011; Cluver et al., 2013; Cluver et al., 2012) in the developing world have demonstrated that the risk of both AIDS parental illness and death increases with the child age and that negative health outcomes are maintained and worsen over time, even beyond age 18 years. This study extends the findings of the above listed studies and argues that the effects of AIDS-orphanhood does not abate after orphans cross the boundary of 18 years but rather, their experience and responsibilities become worse and weighty.

Based on the findings of this study, if any category of AIDS orphans need assistance, then it should be the older AIDS orphans because they are acting as buffers for the younger orphans. Young people between the ages of 18-24 who have lost parents to AIDS face specific risks and they require social, economic and political support and intervention in order to realize their full potential. Community intervention program such as the formation of a health professional's network in partnership with youth AIDS orphans can assist in ameliorating the multiple challenges and needs facing them while also assisting them to be connected to various kind of services that might improve their wellbeing in the long run. The OVC policy makers must invest in empowerment programmes such as parenting modelling training, hardiness/resilience training and provision of psycho-social supports for better outcomes.

5.6.2 Future Research

The findings of this study have implications for future research. Research that focus on AIDS orphans above the age of 18 years need to increase in order to inform and guide the OVC policy making in Nigeria. The few emerging studies that are criticizing the strict age criteria used by policy makers to determine AIDS orphans eligibility for support were conducted outside Nigeria. Diverse research approaches especially an „Action Research“ can be used to conduct additional follow-up studies on so that sensitive and context specific community based interventions can be developed for AIDS orphaned youths in Wannune. Participants from diverse populations groups can add transferability value if larger sample size of youth participants were included in a research of this nature. Future research therefore need to take issues of age and developmental peculiarities of youth, duration of orphanhood, context and support factors into considerations when designing research studies. This will facilitate other researchers and policy makers to interpret and utilize research findings more readily. Future research should also explore the quality of the youth’s attachment to lost parents as well as to the post-lost attachment that is significantly directed to siblings in this research so that appropriate interventions can be designed.

Longitudinal studies are also needed to explore the causal relationships between the self-sacrifice of youths AIDS orphans and their delayed grieving to future actualizations, achievements and psycho-social wellbeing and functioning. In addition well-designed qualitative researches are also needed to explore the meaning and reality of AIDS orphaned youths in their given cultural settings. This would help to facilitate the design and development of appropriate cultural sensitive interventions. Future research might also explore whether HIV parental bereavement confer better outcomes and better coping when compared to other types of bereavement since the participants of this study described their preparedness for parental loss.

5.7 LIMITATION OF THE STUDY

Acknowledgement of the limitations of a study and the steps taken to reduce the impact are important considerations within any research project (Murray, 2002). The following is the limitation of this study:

5.7.1 Homogeneity of the participants

All the study participants were from the same tribe in Nigeria, lived in the same neighbourhood, shared the same cultural norms and values and were all affected by the same loss which is attributable to AIDS. This meant that the findings of this research cannot be generalized.

5.8 CONCLUSION

The use of a descriptive phenomenological approach assisted the researcher to explore and describe the lived experience of youths who have lost a parent to AIDS in Wannune. The hypothesis of the study argues that the life-world of participants aged 18 years and older experienced vulnerabilities when they are denied any form of external agency support. The study confirmed that crossing the set boundary of 18 years old does not necessarily confer special immunity for their survival. Despite the small sample size, this descriptive phenomenological study exposed the researcher to the many interconnections between the diverse and complex experiences that constitute AIDS-orphanhood and the process by which they influence the participants' life. What intrigued the researcher most was the participants' description of attachment to the lost parents.

Participants' description of being held back in their emotional, educational and economic development because of the significant sacrifices for the survival of the household for which they were responsible was also very emotional for both the researcher and participants. It was at this juncture that most participants cried and it was deeply touching.

Choosing phenomenology as the appropriate design for this study was daunting for the researcher. At first, the researcher was confronted with deciding which approach of phenomenology to use (descriptive or interpretive) and then having to remain consistent with the

rules of descriptive phenomenology and finally having to think like a descriptive phenomenologist proved very challenging. At one stage during the research, the researcher wished the study would be classified as a quantitative study because the volume of data generated was overwhelming. The stringent requirements of the ethical review board was frustrating and discouraged the researcher from future research on AIDS related phenomenon because of the overly cautious approach of the ERBs. It seems the ERBs were more concerned about the sample size than the actual purpose of the protection of human research subjects.

However, the method utilized and the various difficulties encountered from the study conceptualization, submission for ethical clearance, data collection and analysis and writing the discussion of the study were gratifying at the end. This is because the researcher was able to explore and describe what it meant to be an AIDS orphan at an older age and experienced what life is and can be without parents at a stage when participants needed to form their own niche and chart their own life course. The study therefore concludes with a quotation from the participant Flower who commented on the interference of AIDS in her life and family: “it crippled my life and still cripples it”.

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Appendix 1: Interview Guide: Youths

- 1. How long ago did your parent pass away?**
2. Which of your parent pass away; mother, father or both?
3. Whom did you live with before your parent passed away?
4. During the time of the illness whom were you staying with?
5. Can you share with me how you experienced the time during which your parent was ill?
- 6. How have you experienced your parent's loss to AIDS?**
7. How was life like before your parent passed on?
8. Describe exactly how your parent's loss has affected your life?
9. Do you think your experience would be different if your parent's loss was due to another illness that is not AIDS related?
10. Do you think your experience would be different if you were younger when you parent passed on due to AIDS?
11. What has changed since the passing on of your parent (s)?
- 12. As a young person who has lost a parent to AIDS related illness, what are your needs?**
13. What do you think needs to be done to support young people who have lost a parent to AIDS?

Clarifying questions and probes:

- A. Can you tell me something more about?
- B. What do you mean when you say?
- C. Can you give me an example?
- D. How do you think it might be different?

Thank you for your participation. God bless you.

Appendix 2: Informed consent form



Nursing Discipline
School of Nursing and Public Health
University of KwaZulu Natal
Howard College Campus
5th Floor Desmond Clarence Building
Durban
4041
SOUTH AFRICA
Telephone (SA): +27610886363
(NG): +234 8066493682
Email: 213572789@stu.ukzn.ac.za
fixtosinup@yahoo.com

23 June, 2014

Dear Participant

Informed Consent Letter

Protocol Number: BE227/14

Investigator: Tosin Popoola
Institution: University of KwaZulu-Natal
Telephone: +27610886363
Email address: fixtosinup@yahoo.com

Supervisor: Prof. Gugu Mchunu
Institution: University of KwaZulu-Natal
Telephone: +2731-260 5571
Email address: Mchunug@ukzn.ac.za

Research Ethics Office: Biomedical Research Ethics Committee
Address: University of Kwazulu-Natal, Westville Campus, Govan Mbeki Building
Private Bag X 54001, Durban, 4000, Kwazulu-Natal, South Africa.
Telephone: +2731-260 4769
Email: BREC@ukzn.ac.za

I, Tosin POPOOLA, University of KwaZulu Natal, South Africa, kindly invite you to participate in the research project entitled, „**The Lived Experience of Youths who have lost a parent to AIDS in Wannune, Nigeria: A Descriptive Phenomenological Study**’

This research project is undertaken as part of the requirements of the Master’s degree, which is undertaken through the University of KwaZulu-Natal, School of Nursing.

You have been selected to participate in a study about your experience of losing a parent to AIDS. You have been selected because your age is between the ages of 18 and 24 years.

Purpose of the Study: The purpose of this study is to explore and describe what you have experienced in terms of losing your parent to AIDS related illnesses and to determine what can be done to improve your wellbeing.

Procedures involved: I am interested in your personal history and account of how you have experienced the loss of your parent to AIDS related illnesses. This will involve asking questions in two separate interview sessions. **The expected duration of the first interview is in the region of about 40 minutes to an hour. However, the interview can last more than the estimated time if we have not finished talking about your experience.** The duration of the second interview is expected to be shorter and should not be more than 15 minutes because it only involves verification of how your interview response was described.

This research involves taking audiotapes of your interviews. These audiotapes are being made so that I can make sure that all our discussions are accurately captured and will then be typed out word for word. The tapes will not be linked to your name.

_____ I agree to be audiotaped during my participation in this study.

_____ I do not agree to be audiotaped during my participation in this study.

Potential Risks: There is no physical harm or injury associated with this study. However, the interview questions might open up concealed emotions, feelings and re-open past and current pains of losing your parent to AIDS related illnesses. If this happens during interview sessions, interviews will be stopped and your feelings will be discussed. If necessary, referral to the psychologists will be made. Should you need further counselling after interview sessions, please contact **Dr Victor at General Hospital Wannune.**

Phone: +2348057233169. Email: talk2vicpop@gmail.com

Potential Benefits: Participating in this study may provide you with an opportunity to discuss some of the factors that affects you and that needs attention. This study can also serve as an opportunity for you to be connected with professional services that can further support you.

Confidentiality: If you agree to take part in this interview, the things you tell me will be confidential. That means they will be private between you and me. I am not going to write down your name. The records and recordings of this study will be kept private. None of the information will have your name on it, and it will be impossible to identify you by name. After completion of this study; consent forms, collected data, and audiotapes will be kept securely for at least five years and then destroyed. To help protect your confidentiality, your name will not be on the audiotapes or questionnaires. Only through the use of identification key will the researcher be able to link your response to your identity and only the researcher will have access to the identification key. If a report is written about this research project, your identity will be protected to the maximum extent possible.

However, please note that I am obliged by law to report to relevant authorities“ issues that might be connected with your safety and wellbeing such as neglect and abuse in any form.

Participation in this research project is voluntary. You may refuse to participate or withdraw from the research project at any stage and for any reason without any form of disadvantage. There will be no monetary gain from participating in this research project. Confidentiality and anonymity of records

identifying you as a participant will be maintained by the Development Cluster, at the University of KwaZulu-Natal.

If you have any questions or concerns about participating in this study, please feel free to contact the investigator, research supervisor or **the ethics office using the contact information stated above.**

Thank you for participating in this research project.

I hereby consent to participate in the above study.

Signature of participant _____

Date _____

Signature of investigator _____

Date _____

Appendix 3: Gate keeper permission

BENUE STATE HOSPITALS MANAGEMENT BOARD
GENERAL HOSPITAL, WANNUNE



P.M.B. 1426,
Makurdi
Benue State.

Our Ref: _____

Your Ref: _____

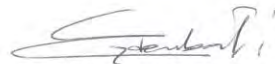
Date: _____
26th May, 2014.

Prof Gugu Mchunu
(School of Nursing)
College of Health Sciences
University of KwaZulu Natal
5th Floor, Desmond Clarence Building
Howard College Campus
Durban, South Africa. 4041
Email: mchunug@ukzn.ac.za
Tel: +27 31 260 1421

Ma,

RE: REQUEST FOR PERMISSION TO ACCESS THE SOCIAL WORKERS AND PSYCHOLOGISTS TO COLLECT DATA FOR MASTER'S RESEARCH WORK

Your letter on the above subject matter dated April 7, 2014 refers, please.
I am directed to convey to you the approval of the Medical Director (MD) to contact the social workers, psychologists and access all facilities of General Hospital Wannune that will assist you in the hitch-free conduct of your research.
While wishing safe arrival to the Wannune, please accept the assurance of the MD's esteem regards.


Ifeanyi Ezeudemba (B.Pharm)
Tel: +2347069795602
For: MD


Appendix 4: Ethical approval letters

BSUTH ethical approval letter

BENUE STATE UNIVERSITY TEACHING HOSPITAL
MAKURDI - NIGERIA.

BOARD CHAIRMAN
Prof Peter O. Obekpa
MB, FRCS, FMCS, FWACS, FICS

POSTAL ADDRESS
P. M. B 102131
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Prof A. O. Malu (OON)
MB, FMCP, FWACP

CHAIRMAN MEDICAL ADVISORY COMMITTEE
Dr. Hembah-Hilekaan S. K.
MBBS, FIIA, FWACS

E-mail: bsuth_estab@yahoo.com

Ref: _____ REGISTRATION NUMBER: NHREC/08/11/2013B Date: 28th August, 2014.

HEALTH RESEARCH ETHICS COMMITTEE

Popoola Tosin (213572789)
School of Nursing and Public Health
University of Kwazulu-Natal
South Africa.

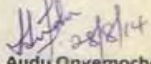
Research Title: The Lived Experiences of Youths who have lost a Parent to AIDS in Wannune, Nigeria: A Descriptive Phenomenological Study.

NOTICE OF FULL APPROVAL AFTER FULL COMMITTEE REVIEW

This is to inform you that the research described in the submitted protocol, the consent forms and other participant information material have been reviewed and given **full approval** by the Health Research Ethics Committee during its 10th meeting held on 27th August, 2014.

This approval dates from August 28th 2014 to August 28th 2015. If there is delay in starting the research, please inform the HREC so that the dates of approval can be adjusted accordingly. Note that no participant accrual or activity related to this research may be conducted outside these dates. All informed consent forms used in this study must carry the HREC assigned number and the duration of HREC approval of the study.

The **National Code for Health Research Ethics** requires you to comply with all institutional guidelines, rules and regulations and with the tenet of the Code including ensuring that all adverse events are reported promptly to the HREC. No changes are permitted in the research without prior approval by the HREC except in circumstances outlined in the Code. The HREC reserves the right to conduct compliance visit to your research site without previous notification.


Dr. Audu Onyemocho
Chairman.

UKZN BREC ethical approval letter



09 September 2014

Mr Tosin Popoola
fixtosinup@yahoo.com

PROTOCOL: The Lived Experiences of youths who have lost a parent to AIDS in Wannune, Nigeria: A Descriptive Phenomenological Study. REF: BE227/14

EXPEDITED APPLICATION

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 01 May 2014.

The study was provisionally approved pending appropriate responses to queries raised. Your responses received on 31 August 2014 to queries raised on 09 July 2014 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 09 September 2014.

This approval is valid for one year from **09 September 2014**. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its meeting taking place on **14 October 2014**.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor D.R. Wassenaar
Chair: Biomedical Research Ethics Committee

Biomedical Research Ethics Committee

Professor D.R. Wassenaar (Chair)

Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban 4000

Telephone: +27 (0) 31 260 2406 Facsimile: +27 (0) 31 260 4609 Email: brec@ukzn.ac.za

Website: <http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx>

1918 - 2018
100 YEARS OF ACADEMIC EXCELLENCE

Ennedai | Ennedai | Ennedai | Ennedai | Ennedai | Ennedai

Appendix 5: The final thematic map

| | |
|---|--|
| <p>Theme one: Disruptive life changes</p> <ul style="list-style-type: none"> • Adversity • Uncertainty | <p>Theme two: Multiple losses</p> <ul style="list-style-type: none"> • Loss of the ideal family • Loss role models • Loss of educational opportunities |
| <p>Theme three: Parenting</p> <ul style="list-style-type: none"> • Caregiving • Positive experiences <ul style="list-style-type: none"> ○ Better appreciation of dying and death ○ Realization and development of agentic abilities • Negative experiences <ul style="list-style-type: none"> ○ Overwhelming responsibilities ○ Overwhelming worry over siblings ○ Self-sacrifice and self-neglect | <p>Theme four: Vulnerability</p> |
| <p>Theme five: Continous grief</p> | <p>Theme six: Multiple needs</p> <ul style="list-style-type: none"> • Need for parenting skills • Need for coping skills • Need for psychosocial support • Need for empowerment |

Appendix 6: Editor's letter

To Whom It May Concern

This is to certify that the Masters Thesis of Tosin Popoola fixtosinup@gmail.com was submitted for language editing. A full language editing was done with comments and recommendations given concerning how the text can be further improved for clarity and the use of language more concise.

Wilhelmina Hewitt (Language and literacy specialist)

hewittwilhel@yahoo.com

0333460917

0793071787

5 Allison Road, Pietermaritzburg 3201

Appendix 7: Turnitin Originality Report

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- ID: 487627807
- Word Count: 41569
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Completed Thesis - 8 December 2014 By Tosin Popoola
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