FACTORS CONTRIBUTING TO ANTIRETROVIRAL TREATMENT NON-ADHERENCE AMONG CAREGIVERS OF CHILDREN UNDER FIVE YEARS OF AGE, VHEMBE DISTRICT, SOUTH AFRICA

By

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DECLARATION

I, **Lithole Takalani Julia,** declare that the dissertation entitled "***Factors contributing to Antiretroviral treatment non-adherence among caregivers of children under five years of age, Vhembe district hospitals***", is my own work and that all the sources that I have used or quoted have been indicated and acknowledged accordingly by means of complete references and that this work has not been submitted before for any other degree at this or any other institution.

Signature …… Date……

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DEDICATION

This study is dedicated to:

- *My supervisor: Dr Ndou N.D*
- *My Co-supervisor: Prof Nemathaga L.H*
- *My mother: Mrs Mutshinyani Thikhathali*
- *My children*: *Phathutshedzo, Anzatshilidzi and Unarine*
- *My husband: Mr Meshack Lithole*
- *My siblings: Agnes and Godwin Thikhathali*

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- **Lefez editorial services** for their effort in editing this dissertation to be user friendly and presentable to the examiners.

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LIST OF ACRONYMS AND ABREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
ART:	Antiretroviral Treatment
ARV:	Antiretroviral
CCCU:	Canterbury Christ Church University
HCUM:	Health Care Utilisation Model.
LDoH:	Limpopo Department of Health
LPAC:	Limpopo Province AIDS Council
MRC:	Medical Research Council
PLWH:	People Living With HIV
PMTCT:	Prevention of Mother to Child Transmission
SA:	South Africa
UNAID:	United Nations Against AIDS
UNICEF:	United Nations Children's Fund
USAID:	United States Agency for International Development
WHO:	World Health Organisation.

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ABSTRACT

HIV/AIDS is the world's leading cause of premature death in children under five years. The promoters of an AIDS free generation predict a situation in which children living with HIV/AIDS readily have access to antiretroviral treatment, care and support. As such children need to remain alive and do well until they reach adulthood. This study seeks to explore the factors contributing to antiretroviral treatment nonadherence among caregivers of children under five years. A qualitative approach with explorative, descriptive and contextual designs were employed in this study. The population were caregivers of children under five years of age, living with HIV/AIDS and on antiretroviral therapy. Purposive and convenience sampling were used to select the hospitals and caregivers. Unstructured in-depth interviews were employed to collect data from 25 caregivers. Creswell's eight steps approach were employed to analyse data. Ethical issues were considered to protect the participants. A myriad of factors was found to contribute to Antiretroviral treatment nonadherence among caregivers of children under five years. The results of the study revealed that Social and personal factors, poor access to medication, medicinal factors and other factors that are beyond the caregiver's control as contributory factors to Antiretroviral treatment non-adherence. The researcher concluded that, although South Africa has been running one of the biggest Antiretroviral Therapy programme, she is facing challenges related to adherence particularly among caregivers of children in rural settings. Recommendations made by the researcher based on the findings of the study focused on improving adherence to ART through training. Future research can be conducted focusing on adherence to ART by caregivers of children in urban areas. It will be interesting to hear what factors influence the caregivers to adhere to Antiretroviral treatment.

Keywords: Adherence, Antiretroviral treatment, Caregivers, Children, HIV/AIDS

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CHAPTER ONE

ORIENTATION TO THE STUDY

1.1. Introduction and background of the study

Several studies acknowledge the complexities that arise in the Antiretroviral treatment (ART) adherence among children and families. These complexities occur as children depend on caregivers for taking medications. This means that all psychosocial issues surrounding HIV/AIDS which affect the caregivers, always have an impact in the management (Penn & Evans, 2011). There is a serious need for HIV positive children to adhere strictly to ART. The situation in resource-limited which requires adequate attention to determine the causes of poor ART adherence, so that effective measures are put in place. According to Fetzer, Mupenda, Lusiama, Kitetele, GolinandBehets (2011), understanding the factors that influence ART adherence in children is very important in developing adequate strategies to help HIV/AIDS positive children. Yeap, Hamilton, Charalambous, Dwadwa, Churchyard, Geisler and Grant (2010) also argue that in South Africa, fewer children than expected have access to HIV care services, regardless of the strong ART therapy rollout.

The level of adherence to ART among children living with Human Immune Virus (HIV) varied from 49% to 100%, depending on the settings and methods used (Biressaw, 2013). Adherence to ART is the key to successful treatment of patients as well as containment of drug resistance. Once a child or an adult is diagnosed HIV positive and put on ART, adherence to medication becomes an important process throughout his/her life. Antiretroviral (ARV) drugs require strict adherence if they are to be effective. It is a known fact that HIV-positive children do not have that knowledge, hence an adult, the caregiver, takes that responsibility. Non-adherence to ART has many potential negative effects, such as viral resistance, antiretroviral regimens that are no longer effective, progression of HIV disease and increased morbidity and mortality. Nonadherence to ART by children living with HIV is due to caregivers not following the programme or regimen and resistance to taking the medications by the children (Merzel, Van Devanter & Irvine, 2008).

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While there have been great developments in the prevention of HIV transmission and care of people living with HIV/AIDS since 1981, when the first case was discovered, HIV continues to overpower populations in developing countries and more gravely in sub-Saharan Africa (Murithi, 2013). This is partly due to the methods of transmission of HIV which present many challenges in the effort to prevent the spread of the viruses well as nonadherence to treatment by those living with HIV/AIDS (Arage, Tessema & Kassa, 2014). Although antiretroviral drugs (ARVs) have a high capability of slowing the progression of the disease dramatically, there is no known cure for HIV/AIDS.

In South Africa, HIV/AIDS related deaths account for more than one third of the total number of deaths in children under the age of 5 years. In 2011, there were 330,000 HIV positive children in South Africa (Arage, Tessema & Kassa, 2014). In the absence of any interventions to prevent Mother to Child Transmission (MTCT), approximately 25-35% of HIV positive mothers are likely to transmit HIV to their infants by 6 months post-delivery (Woldesenbet, Goga & Jacksonp, 2012).

Children infected with HIV live much longer and healthier lives when using Anti-retroviral treatment. However, an estimated 90% of HIV positive children worldwide are deliberately deprived of ARVs by caregivers who do not adhere strictly to ARV programmes put in place or by mere shortages of ARVs (Jo'sean, 2015). In SA, provinces with better health resources have a higher intake of children on HIV/AIDS programmes. Shipalana and Ntuli (2016) in their study conducted in the Western Cape province of South Africa indicate an increase in the proportion of infected children successfully linked to HIV care and treatment. Knowledge and attitude on PMTCT and HIV have an impact on the practice of HIV prevention, counselling and testing, as well as adherence to medication and attitude towards PMTCT interventions.

The psychosocial issues surrounding HIV/AIDS that affect the caregivers, have an impact on the child's care, including how the child's ART is managed (van Dyk, 2012). Despite over 10 years of increasing clinical availability of children's ART in Africa, significant practice challenges remain, with a corresponding need for further research into children's access to and uptake of HIV services, including ART (Belton, 2014). Further research is thus needed to discover, create, and sustain the personal and social factors which can support a massive uptake and usage of HIV care in children.

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When children are diagnosed with HIV infections, caregivers are expected to adhere to antiretroviral therapy in order to reduce the impact of the HIV to immune system of the child. However, in most cases, the situation in some Districts in South Africa is different, as there are problems in adhering to ART by caregivers, resulting in HIV/AIDS deaths. ART seems to have changed HIV infection from a fatal disease to a chronic illness, which can be managed, much like other chronic illnesses (Ross, Aung, Campbell & Ogunbanjo, 2011). However, there still nonadherence to ART in children living with HIV in many SA provinces. Adherence to ART is a principal determinant of virologic suppression (Jo'sean, 2015). Repeated admissions of children diagnosed with HIV/AIDS influence the researcher to conduct a study on the factors contributing to ART nonadherence among caregivers of children living with HIV at selected hospitals in Vhembe District. There are several factors that cause caregivers not adhere to ART, particularly in children living with HIV in developing countries. Qualitative study was conducted to establish factors that contribute to nonadherence to ART by caregivers of children living with HIV at selected hospitals of Vhembe District.

1.2. Problem statement

In Vhembe District, nonadherence to ARV drugs is a challenge encountered in the treatment of children living with HIV. Unlike with HIV positive adults who can undergo the adherence preparation and assessment prior to their own therapy initiation or changing, children are often represented by adults or caregivers. By not adhering to ART, caregivers are exposing HIV positive children to threats on their lives which will eventually prevent them from reaching adolescence and adulthood and many may not reach their second birthday (UNAIDS, 2014).

The researcher is a paediatric unit manager at Messina Hospital, responsible for providing clinical care to children, including those living with HIV/AIDS. Despite the ART rollout, children under five years of age are repeatedly re-admitted with HIV/AIDS related infections. The repeated re-admission of children living with HIV/AIDS in hospital with same problem was an indication of nonadherence to ART uptake by the children and this could be traced to the caregivers responsible with the collection and administration of the medication. HIV positive children can only adhere to ART through caregivers' efforts and beliefs (Coetzee, Kagee & Bland, 2014). Due to repeated readmissions of children under five years living with HIV/AIDS, the researcher decided to conduct a qualitative study to

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explore contributory factors to antiretroviral treatment nonadherence among caregivers of children under five years in Vhembe District.

The South African public antiretroviral treatment programme, which was introduced in 2003, has been running for more than 15 years and is recognised largest globally and for being able to reduce morbidity and mortality rates (Mulqueeny & Taylor, 2019). The ART programme rolled by the South African government is free and it includes HIV/AIDS patients, ARV drugs, ARV clinics and pharmacies, clinical and non-clinical staff (Azia, Mukumbang & van Wyk, 2016; Mulqueeny & Taylor, 2019). In spite the fact that studies have shown that early initiation of infants and children diagnosed with HIV on antiretroviral therapy significantly reduces mortality nonadherence to ART among children of the under the age of five years who rely on caregivers for medication uptake remain a topical issue in rural and poor communities across South African provinces and districts. Full benefits of ART can be achieved through strict adherence to medication as well as following treatment instructions (Eyassu, 2015). UNAIDS/WHO (2013), states that sticking to the treatment instructions for a long-term illness, though very important, is also extremely challenging for children under the age of five. Unlike some diseases, failure to adhere to ART always leads to treatment failure, which in turn leads to drug resistance strains due to viral mutations (UNAIDS, 2016; UNAIDS/WHO, 2011; UNAIDS Global Report 2013).

Table 1. Mortality rate of children under five years of age with HIV/AIDS

NAME OF THE FACILITY	2015/2016	2016/2017	2017/2018
Tshilidzini Hospital	141	109	171
Donald Fraser Hospital	104	93	104
Elim Hospital	90	85	86
Siloam Hospital	59	58	69
Malamulele Hospital	90	123	68
Musina Hospital	62	44	33
Louis Trichardt Hospital	18	10	46

Source: Vhembe District Health Information System

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1.3. Purpose of the study

The purpose of this study was to explore contributory factors to nonadherence ART by caregivers of children living with HIV aged 0-5 years at selected hospitals of Vhembe District.

1.4. Research objectives

The objective of the study was to:

Explore the factors contributing to ART nonadherence among caregivers of children under five years living with HIV/AIDS.

1.5. Research question

The research question for this study was,

What are the contributory factors to ART nonadherence among caregivers of children under the age of five years Vhembe district hospitals of Limpopo province.

1.6. Significance of the study

The findings of the study are intended to elaborate the contributory factors to nonadherence among caregivers of children living with HIV/AIDS for better management and improvement of their health status. The findings may be used by nurses, caregivers and lay counsellors to improve adherence and counselling,

1.7 Definition of terms

1.7.1 Acquired-immune deficiency syndrome

Acquired Immunodeficiency Syndrome (AIDS) is a fatal chronic condition in human beings caused by human immunodeficiency virus (HIV). With time, HIV tends to weaken the immune system and eventually halts the body's ability to fight infections (Murithi, 2013). In this study AIDS is any immune deficiency illness in human caused by the availability of HI Virus in the body.

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1.7.2 Adherence

According to Bello (2011) adherence refers to the patient's behaviour of taking drugs correctly in the right dose, with the right frequency and at the right time. In this study adherence means compliance to prescribed medication (ART) by the caregivers of HIV infected children.

1.7.3 Antiretroviral therapy (ART)

ART refers to the treatment of people infected with HIV, using anti-HIV drugs and the standard treatment consisting of a combination of at least three drugs often called ''highly active ART or HAART, that suppress HIV replication (WHO, 2014). In this study ART refers to the therapy which consists of treatment of opportunistic disease.

1.7.4 Child

A child is a person under the age of 16 in fulltime education under 18 in certain circumstances and a person who has not contracted a valid or annulled marriage (William & Burton, 2007). In this study a child is a human being living with HIV/AIDS on ART under the age of five years.

1.7.5 Factors

Factors mean a substance that functions in or promotes the function of a physiological process or bodily system (Merriam-Webster Dictionary, 2017). In this study factors refer to constituents or elements that cause non-adherence.

1.7.6 Human immunodeficiency virus (HIV)

HIV is a virus that attacks the immune system. If untreated, a person's immune system will eventually be completely destroyed (AIDS info net, 2016). In this study HIV is a virus which spreads through body fluids and attacks the body's immune system, causing HIV infections leading to AIDS.

1.8 Theoretical framework

Considering efforts being made in South Africa to reduce the impact of HIV and improve paediatric ART adherence among children below the age of five years, it is important to understand the factors contributing to nonadherence to ART by caregivers. The socio-

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ecological model based on Bronfenbrenner's Ecological Systems Theory (EST) has been found useful for understanding multifaceted structural barriers related to ART adherence in among caregivers in selected hospitals in Vhembe District. Bronfenbrenner's Ecological Systems Theory (EST) was used the theoretical framework in this study based on its merit in investigating certain behaviours in health by many researchers. The employed in this study is described in detail in chapter 2.

1.9. Summary

This chapter elaborated the background of the study, the research problem, purpose of the study, research objective and question. The significance of the study was also highlighted. Factors contributing to nonadherence to ART by children aged below fives old who are under the custodian of caregivers were being explored using a qualitative study.

1.10 Structure of the Dissertation

The study is presented in separate chapters that reflect different steps of research:

Chapter 1 is an overview and rationale which captures a brief introduction to the study, background, problem statement, purpose of the study, objectives, research approach and designs, data collection and data analysis.

Chapter 2 is literature review which discusses the information related to the title of the study

Chapter 3 is research methodology which describes research approach and design, research population, sample and sampling technique, data collection and analysis, measures to ensure trustworthiness and ethical considerations.

Chapter 4 is data presentation, analysis and description of the research findings presents results obtained after analysis of participants transcripts.

Chapter 5 discussions, limitations, conclusions, recommendations and discussion of the findings in relation to existing literature, provides conclusions of the study and recommendations.

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CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

According to Krathwohl (2012), a literature review serves three important purposes; namely to place research focus of the study within the context of the wider academic community in public health; conduct and report on critical review of the relevant and scholarly literature with regards to barriers in ART adherence in children by caregivers; and Identify a gap within the existing literature that this research study intends to address the contributory factors to nonadherence to ART in children under five years. To achieve such an endeavour, this section includes systematic identification, location, analysis and critiquing of journals and articles containing or those with information related to ARV uptake among children living with HIV. This will help in identifying the existing gaps, to justify the need for this study. Literature was searched from journal articles, internet databases such as ScienceDirect and EBSCOHOST.

2.2. The magnitude of HIV/AIDS in children

Each of the following subsection deals with magnitude of HIV in children a different stage namely, globally, continentally, national and district level.

2.2.1. The global magnitude of HIV/AIDS in children

In 2014 alone, it was estimated that the worldwide rate of new HIV infections was 6300 individuals daily (AIDS, 2014). Among these new infections, more than 1500 were children making up approximately 24% per day. This number is expected to rise by the end of 2016. The majority of these children (more than 90 percent) acquire the infection from their mothers through Mother-to-Child Transmission. Since the beginning of the pandemic, over 5 million infants have been infected with HIV, of whom 90 percent were in Africa (Kamugisha, 2014). This development has made it mandatory that the care of children living with HIV infection worldwide be an area of concern for most health care providers and caregivers, as the number of HIV infected children continues to grow (Klitzman, Marhefka, Mellins & Wiener, 2008). The UNAIDS Report (2014) purports that by the end of year 2009 the cumulative number of children with HIV worldwide stood at 2.5 million

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with Africa being the hardest hit continent accounting for 70% of all the HIV paediatric population.

Globally, majority of HIV positive children are infected through Mother-to-Child Transmission (MTCT). From the estimated 430 000 new HIV infections which occurred in infants and children in 2008, 90% were acquired through MTCT (Motshome, 2011). Most countries have shown good progress by reducing the under-five mortality rate by more than half since 1990. Studies have demonstrated that early diagnosis and treatment can reduce morbidity and mortality among these children (Shipalana & Ntuli, 2016). In Africa 30–50% of all untreated HIV positive children die prematurely before their first birthday, and fewer than 30% survive beyond five years of age (Leshabari, 2007). In countries hardest hit by HIV, the risk of dying from infectious diseases in the first two months of life has been estimated as six times greater for infants who are not breastfed (WHO, 2014).

2.2.2. The continental magnitude of HIV/AIDS in children

Although Sub-Saharan Africa has12% of the global population, it continues to be the region most affected by HIV/AIDS (Rujumba, 2012). Of the 2.7 million new HIV infections in 2010 worldwide, about 70% of the cases were in sub-Saharan Africa (Rujumba, 2012). In Sub-Saharan Africa region, high rates of maternal HIV infection, high birth rates, lack of access to currently available and feasible interventions such as ARV, and the widespread practice of prolonged breast-feeding translate into a high burden of paediatric HIV disease (Kubai, 2011). The trend in Africa is that 30–50% of all ‘untreated’ HIV positive children die prematurely before their first birthday, and fewer than 30% survive beyond five years of age (Leshabari, 2007). The transmission risk for a child born to HIV infected mothers in an African setting without ARV and other interventions is about 30–40%. In most countries in the sub-Saharan Africa region, there are limited paediatric HIV diagnostic techniques and care facilities and most HIV-infected children and adults are diagnosed and managed very late in the course of illness, or not at all (Kubai, 2011).

2.2.3. The magnitude of HIV/AIDS in children in South Africa

United Nations AIDs Data (2018) reports that South Africa has the largest HIV epidemic in the world, with 19% of the global number of people living with HIV, 15% of new infections and 11% of AIDS related deaths. These figures include adults, adolescents and children of all ages. Table 2.1 shows the trend in HIV related from 2010 to 2018.

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Table 2: Trends in Births and HIV related death in South Africa 2010 - 2018

Year	Number of births	Number of deaths	AIDS related deaths	Percentage of AIDS deaths
2010	1207338	572177	175375	30,65
2011	1216711	556684	154752	27,80
2012	1218517	534034	138919	26,01
2013	1218105	529288	135331	25,57
2014	1215890	522779	122139	23,36
2015	1216408	523588	115598	22,08
2016	1214592	523997	117296	22,38
2017	1208934	523560	116110	22,18
2018	1200436	522157	115167	22,06

Source: Statistic South Africa (2018)

The trends in table 2.1 shows a sturdy decrease in the HIV/AIDS related mortality on yearly basis due to a number of initiatives put in place, one of them being ART programmes. Regardless of the trend shown on the table, HIV remains a major cause of child morbidity and mortality in developing countries especially in sub-Saharan Africa (Leshabari, 2007; Petse, Goon, Okafor & Yako, 2018). South Africa is facing both health and social challenges due to HIV/AIDS pandemic. The Department of Health (2004) estimates that over 5.5 million people in South Africa could be infected with HIV and the majority of those infections are in the reproductive age group, new born infants and children under the age of one year. In South Africa, one third of the total number of deaths in children under the age of 5 years is attributed to HIV/AIDS scourge (Woldesenbet, Goga & Jacksonp, 2012). Reason being that: 1) more women of childbearing age are HIV infected in Africa than elsewhere; 2) African women have more children on average than those in other continents, so one infected woman may pass the virus on to a higher than average number of children (Murithi, 2013).

In South Africa, HIV related deaths account for more than one third of the total number of deaths occurring in children under the age of five years. Most of these deaths occur among infants born to mothers who do not receive PMTCT interventions (Woldesenbet, Goga & Jacksonp, 2012). A decline in the transmission of Mother-To-Child infections rate at six weeks has been observed over the past few years, indicating that policy changes in conjunction with improved implementation of the Prevention of Mother-To-Child

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Transmission, authors states that the programme have been effective. Important changes include starting ART for PMTCT at 14 weeks of pregnancy or as soon as possible thereafter, instead of only during the last trimester of pregnancy (Shisana et al., 2014). The Medical Research Council (MRC) of South Africa and the Department of Health conducted their first national evaluation of PMTCT impact and it was found out that HIV transmission from mother to child was reduced from 3.5% in 2010 to 2.7% in 2011 (Pillay, Dinh, Goga et al., 2012).

In a study conducted in South Africa, findings revealed that babies wholly breastfed had significantly less likelihood of getting infected with HIV/AIDS in the first three months compared to babies on mixed feeding (Engender Health, 2007). According to Kanabus and Noble (2008), without treatment, around 15 - 30% of babies born to HIV positive women will become infected with HIV during pregnancy, labour and delivery while 5 - 20% of babies will become infected through breastfeeding. The same authors are also of the opinion that in the absence of preventive intervention, the probability that an HIV positive woman's baby will become infected is approximately 25 - 45%.

2.2.4. The magnitude of HIV/AIDS in children of Limpopo Province

The Health Science Research Council HSRC (2014) report also shows that KwaZulu-Natal had the highest HIV prevalence accounting for 24,8% of the total prevalence, Eastern Cape, 15,6%, Limpopo. 10,1%, Gauteng, 9,0%, Western Cape, 8,9%, Mpumalanga, 8,8%, Northern Cape, 8,0%, North West, 7,5% and Free State 7,3%. The prevalence for all other province were reported to have slightly increased by end of 2015 except for Limpopo which remained almost the same and below the national average of 15.6% (HSRC, 2014; UNAIDS South Africa, 2016). The results signify the importance of PMTCT programmes in different provinces. South African National AIDS Council SANAC (2014) report confirms major progress done in reducing HIV transmission through the PMTCT programme. Dramatic decline in the prevention of PMTCT occurred between 2013/14 and 2014/15 where the response towards HIV born free infants at 6-8 weeks was found to be 2.3 and 2.2% respectively South African National AIDS Council SANAC (2014). The new PMTCT policy guideline was only implemented in 2014/15 financial year initiating every pregnant woman on ART regardless of CD 4 cell count (SANAC, 2014). More HIV+ pregnant and breastfeeding women were also initiated on ART regardless of CD4 count (Option B+)

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(SANAC, 2014). The programme was also expanded to include as many children living with HIV as possible (UNAIDS, 2014).

According to Limpopo province AIDS Council LPAC and Limpopo Department of Health LDoH Annual report (2016) the revised ART guide was intended for: Earlier initiation of ART at CD4 count ≤500 cells/mm$^{3;}$ Providing ART to those with HIV co-infection, regardless of CD4 count or clinical staging; Initiation of ART for all HIV/TB co-infected patients; Providing ART to all children under 5 years, regardless of CD4 count or clinical staging. Earlier ART initiation for children ≥ 5 years at CD4 count ≤500 cells/mm^3 regardless of clinical staging; the report is silent about the ART adherence and how it was to be achieved with those already initiated. Furthermore, the report is silent about prevalence in district, an issue discussed in the next subsection.

2.3. Treatment of children living with HIV/AIDS

There is no doubt that many HIV-positive children in South Africa from disadvantaged communities need treatment. Research has shown that early HIV diagnosis in infants is one of the critical steps to prevent HIV transmission or severe morbidity and mortality (Woldesenbet, Goga & Jacksonp, 2012). In 2018 the number of children newly infected with HIV were 160,000 and is expected to rise if appropriate measures to curb it using appropriate ARVs and adhering to treatment programmes, are not adhered to properly (Haldenwang, 2012).

Currently, children are not a priority of ARV programmes in the majority of developing countries, including South Africa. This implies that many children are likely to continue suffering under the HIV scourge, yet they could have lived longer healthier lives had there been enough ARV programmes for them. The main problem with young children, especially the under three years, is that they ideally need medication in syrup or powder form, and they are in syrup form, this makes it difficult for caregivers to give the correct dose. Under these circumstance HIV positive children ARV treatment will get inappropriate medication, thus leading to side effects and unanticipated complications (De Schacht, Lucas, Mboa, Gill, Macasse, Dimande, Bobrow&Guay. 2014). According to Goliber (2012), the objectives of treatment of HIV/AIDS are to: suppress HIV below the limits of detection or as low as possible, for as long as possible preserve or restore the body's immune function; and prolong life and improve the quality of life.

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Adherence is important, as it reduces morbidity and mortality rates in children living with HIV/AIDS. Results on the ground support that ART reduces incidences of opportunistic infections and other AIDS related illnesses, as it retards and delays HIV disease progression (Nabukeera-Barungi, 2007). The overall outcome is the improvement of the quality of life and life expectancy of children. When children start medication, caregivers are always engulfed by fear and uncertainty on whether the treatment would be effective. However, as time goes on, HIV children on ART start to respond to medication, showing good tolerance to the drugs (Nabukeera-Barungi, 2007).

2.4. Adherence to ART in children

Colombini, Stöck, Watts & Mayhew (2014) define (medication adherence as the patient's conformance with the provider's recommendations with respect to timing, dosage, and frequency of medication taking during the prescribed length of time. Unlike many medications used to treat some chronic illnesses that remain effective with less than perfect adherence, ARTs require strict adherence uptake (Ugwu & Eneh, 2013). This means that adherence is the most important determinant of success of ART. Medication adherence refers to a complex health behaviour that influences the extent to which it is administered (Gross, 2014). Medication adherence can refer to the extent to which a patient takes medication the way it is intended by a health care provider and it is expressed quantitatively as the percentage of doses that has been taken by the patients. Proper adherence determines the biological, clinical and public health outcomes of treatment.

Non-adherence to ART tends to lead to incomplete viral suppression, emergence of resistant viral strains, and treatment failure of AIDS related illnesses and subsequently death (Shittu, Issa, Olanrewaju, Odeigah, Sule, Musa & Aderibigbe, 2013). Although sub-optimal adherence to ARVs is the most common cause of virologic failure of ART regimens, nonadherence to one regimen always results in viral mutations that confer virus resistance to many ARVs in the same class (Shittu et al., 2013). In the case of ART, an adherence level of 95% or more is required in order to obtain a successful treatment outcome (Kubai, 2011). Drug resistance usually prompts medical professionals to change medication, which may be even more expensive and require absolute adherence. Such options are generally limited in developing countries and for children (Müller & Moyo, 2011). The situation of children is even more complicated, as there are fewer treatment options than for adults, due to lack of suitable formulations (Shittu et al., 2013). A study by

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Kikuchi, et al (2012) on the nonadherence to ART by orphans in Kigali found that caregivers were influential in the uptake of medication in correct doses at the correct time and also make sure that children had actually taken the medication. This study also emphasised on how medication was also safeguarded to avoid situations where children took it without the knowledge of caregivers.

Effectiveness of ARV' regimens, require strict adherence. The potential consequences of nonadherence include viral resistance, antiretroviral regimens that are no longer effective, progression of HIV disease and increased morbidity and mortality (Müller & Moyo, 2011).

2.5. ART uptake by children in resource limited settings

ART has substantially changed the face of HIV infection where it has been successfully introduced because HIV infected children can now survive to adolescence and adulthood (Eticha & Berhane, 2014). However, the ART uptake by children has a patchy history, starting in 2004 when ART were introduced, to reduce PMTCT of HIV (Belton, 2014). In many developing countries, access to ART by children remains a major concern because it has been very slow compared to adults (Woldesenbet, Goga & Jackson, 2012). The uptake of ART in children is affected by several factors, some of which have to do with the inability of children to access the ARTs directly as they depend on adults, yet others have to do with unavailability of the medication itself due to shortages. In poor communities a number of factors tend to interfere with the uptake of ARTs, compared to those well-resourced settings.

Research studies frequently report great progress in prevention of new paediatric HIV infections in general. However, the provision of adequate treatment to HIV infected children, or the support to vulnerable children and orphans affected by HIV/AIDS, remains a major concern in developing countries. This is because there is little progress for ART for many HIV positive children in developing countries due to inaccessibility of ARVs (Kubai, 2011). For example, in South Africa, Early Infant Diagnosis (EID) is still way below the expected target due to the fact process is a routine practice (Woldesenbet*et al*., 2012). Williams, Van Rooyen & Ricks (2016) also observed that despite efforts made by various governments health departments to increase access to ART, particularly at primary health care (PHC) facilities, medication continues to be out of reach in sub-Saharan Africa because of many factors and barriers. Many children in South Africa cannot access ARV's

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(Wienand, 2015). Children are not always the first priority for ARV programmes. ARVs for children are different from those of adults as they should be in powder form (Kubai, 2011).

South Africa has the world's largest ART programme which accounts for 20% of people on antiretroviral therapy globally (Hodes, Cluver, Toska & Vale, 2018; Petse, Goon, Okafor & Yako, 2018). South Africa also has one of the largest domestically funded ART programmes for close to 80% of the AIDS response being funded by the government (Hodes, Cluver, Toska & Vale, 2018). Antiretroviral treatment is offered free of charge at public health facilities throughout South Africa (Colombini, Stöck, Watts and Mayhew, 2014). In 2017, it was estimated that close to 280,000 children (aged 0 to 14) were living with HIV in South Africa and only 58% of them were on treatment (United Nations AIDS Data 2018) and close to 42% not having been initiated into the programme. According to Petse, Goon, Okafor and Yako (2018), South Africa still faces a surmountable challenge of ensuring and sustaining the quality of ART service, including the prevention and management of side effects of drugs, and improving drug adherence, very critical determinants for the success of the ART programme. This implies that the availability of ARVs in poor settings should increase to sustain drug availability among the poverty-stricken rural populations. However, children's ART uptake still has not improved to the point where it is amenable with availability. In most cases, caregivers may be the main contributors to poor ART uptake by children whom they look after. Factors that contribute to ART nonadherence by caregivers are briefly discussed in the subsections.

2.6. Factors contributing to ART nonadherence among caregivers of children.

Adherence to ART in children has proved to be a complicated process due to factors such as child characteristics, caregiver and family characteristics and regimen characteristics (Eticha & Berhane, 2014). In sub-Saharan Africa, Children on ART and their families face many similar ART adherence challenges to those in richer countries (Belton, 2014). Each of the subsequent subsections briefly discusses the factors that are likely to affect ART adherence in children in general. It is against this background that it becomes imperative to identify factors associated with adherence among HIV infected children, in order to reduce the risk of developing treatment failure or drug resistance through interventions.

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2.6.1. Child Factors

In a study by Reddington in (Nabukeera-Barungi, 2007), it was noted that children with undisclosed HIV status had lower adherence levels, compared to the disclosed ones (Brown, Oladokun, Osinusi, Ochigbo, Adewole & Kanki. 2011). World Health Organization (WHO, 2011) identifies stigma and poverty as one of the major hindrances to children' adherence to ART. Among child related factors, a study conducted in Ethiopia by Gultie, Amlak and Sebsibie (2015) revealed that adherence to ART was significantly associated with the age of the children and the types of ART drugs. The reports on children less than a year old were more likely to adhere to ART programmes than those of three years and above due to the fact that the caregivers were worried about the vulnerabilities of the younger children than the older ones (Gultie, Amlak & Sebsibie, 2015). Unlike other studies, Akahara, Nwolisa, Odinaka and Okolo (2017) state that drug side effects were not a major contributory factor to effective ART nonadherence. According to Kim et al. (2016) mothers were always concerned about the side effects that the medication had on their children and they reduce the dose or stop temporarily. The study reports that when HIV positive children developed side effects such as fever, feeling ill or very exhausted, blistering of the skin, mouth ulcers or breathing difficulties, caregivers would get scared and stopped medication to allow the child to get better.

2.6.2 Caregiver' Factors

According to Reddington (Nabukeera-Barungi, 2007), the relationship between the child and a/the primary caregiver was not seen as a factor affecting adherence levels (Lachman et. al, 2014). The perceptions of caretakers and the concerns about privacy were significantly associated with nonadherence (Kuo, Operario, Cluver, 2012). Sustaining adherence depends on social factors (Kubai, 2011). Nabukeera-Barungi (2007), affirmed that the level of education and socio-economic status do not affect adherence. The caregiver's knowledge and perceptions on ARV use in children, household composition, cultural practices and lack of caregiver's knowledge, were factors mostly pronounced in sub-Saharan African region, where HIV/AIDS is more prevalent. In Kenya stigma is seen as common in most communities and HIV victims and those on ARV are viewed as outcasts and sometimes denied treatment, essential services and sometimes isolated (Kubai, 2011).

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A study by Akahara, Nwolisa, Odinaka and Okolo (2017) on ART adherence in Nigeria found that close to 60% of the parents were afraid of stigmatization from colleagues and relatives while disrupted administering ARVs in the presents of relatives. This was particularly prevalent among parents who did not disclose their HIV status to the families or partners. This supported by a study conducted by Williams, Van Rooyen, Ricks (2016) in Nelson Mandela Bay in South Africa which revealed that fear of stigmatisation by health care staff and other community members in many healthcare facilities caused caregivers to avoid their local PHC clinics to access ART, particularly parents of the HIV-children. A study conducted in Lilongwe, Malawi on ART adherence by Kim, Zhou, Mazenga, et.al., (2016) also found that caregiver mothers were not prepared to adhere to ART before they discussed the matter with their partners particularly those who were married.

2.6.3 Psycho-social factors

Often when a child is infected with HIV, it might be an indication that one or both parents in the family are infected. In situations where the child has perinatal HIV infection, both the mother and child may be on ART. This makes HIV the number one enemy which most families are fighting. However, this does not mean that HIV is the only pressing problem within families. There are other challenges that contribute to an unstable or chaotic home environment, such as substance abuse, poverty, inner-city stressors, and denial of the diagnosis, secrecy, depression and mental illness. Also, a parent/caregiver and family may lack understanding or parenting skills or might be too ill to manage the complex care of a sick child. Another pressing challenge could be caused by the death of parents, leaving many children and adolescents with HIV infection under the care of elderly grandparents (Daskalopoulou Lampe, Sherr, Phillips, Johnson, Gilson, Perry, Wilkins, Lascar, Collins, Hart, Speakman & Rodger, 2016).

Stigma is also observed by managers of health care institutions in a clinical setting, if stigma is present in the home or community and parents are reluctant to disclose their status to the family, then the prognosis for adherence and a favourable response to the ARV treatment by parents and children is poor (Michaels, Eley, Ndhlovu & Rutenberg, 2006).

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2.6.4 Health factors

Chronic illness usually persists for an extended time, leading to infected children and their caregivers going through psychosocial stages which can be sources of great stress. These might include the following: Initial diagnosis, disclosure of disease status to the child and difficulties resulting from long-term care, including financial and emotional strains. In long-term care situations, adherence to HIV medication regimens is extremely taxing on the child and his or her family. To prevent resistance, the child must take the medications with a greater than 95% rate of adherence. This task can be difficult for an adult patient and becomes increasingly difficult when the patient is a child or adolescent (Weaver, Pane, Wandra, Herlina, Samaan, 2014).

It is a very difficult regimen to manage ARVs for a child under most circumstances. All these unresolved or complex psychosocial issues within the family only add to the difficulty of treatment adherence. However, a coordinated, comprehensive, family-centred system of care can often address many daily and long-term problems that families face and may affect adherence to complex medical regimens (Weaver et al, 2014). The community, family attitudes and structures affect access and continuity of care for children at many levels. In some settings, people are not aware of the benefits of ARVs. This negatively affects referrals to the paediatric ARV programme. Some problems are caused by lack of clarity regarding the guardianship and authority over children. This increases the reluctance of health care providers to test children for HIV. In the Free State province of South Africa, the programme manager noticed that the switching of caregivers contributes to children being stuck in the drug readiness programme.

2.7. Barriers to ARV treatment for children

According to the UNAIDS (2014), children's disadvantages in accessing life-saving treatment stems from a series of programmatic gaps and shortcomings, extend across each stage of the paediatric treatment continuum.

2.7.1. Barriers to timely diagnosis of HIV in children

Children born to mothers living with HIV carry maternal HIV antibodies for up to 18 months. In order to identify the presence of viral DNA or RNA, more sophisticated tests are required to diagnose HIV for these very young children. The tests primarily rely on centralized

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laboratories, where dried blood spots are used and then transferred to laboratories for analysis. The HIV tests for children under 18 months are not widely available. Early diagnosis and treatment are crucial because mortality is high in the first few years of life. In places where the test kits are not available, children under 18 months are given antibody tests and start ART if eligible, even before they get confirmation of their diagnosis. This is done in order to reduce the mortality rate among young children. The tests are repeated after 18 months and if the child is found negative, ART is stopped. It therefore remains a challenge to health workers issuing children ART before confirming the diagnosis (Nabukeera-Barungi, 2007). HIV tests of infants born of women with HIV need to be done as early as possible to curb for mortality rates of infants which occurs at 6-8 weeks. Testing should not be a once off event but an ongoing process, until the risk of HIV transmission is still substantial. WHO recommends virological testing at 4-6 weeks or at the earliest opportunity thereafter, noting that the algorithms for infant testing are currently being reviewed (UNAIDS, 2014). However, breastfed children often do not receive a conclusive HIV test after breastfeeding has stopped (Weaver et al. 2014).

According to Plazy, Newell, Orne-Gliemann, Naidu, Dabis and Dray-Spira (2015), HIV testing in South Africa has undergone many changes making it easier for individuals to conduct the tests and for the children born HIV negative. However, according to the findings by Plazy et al. (2015) a large population of children remains with an undisclosed HIV status which only be discovered when they develop symptoms of the disease. This implies that parents and caregivers from disadvantaged backgrounds prefer to remain with undisclosed HIV status as they are scared to take the test. A study by Koirala, Deuba, Nampaisan, Marrone, Ekström (2017) conducted in Bangladesh, Indonesia, Lao, Nepal, Pakistan, Philippines and Vietnam also report delayed HIV testing disclosure as a serious problem, among children in their country as it affects the ART programmes and the assistance from health care providers. According to Koirala, et. al. (2017) patients were afraid of getting tested or disclosing their status but still try to seek medication for HIV and this made it difficult for health care staff to assist them with such medication.

2.7.2. Service delivery challenges

The main challenge for paediatric HIV/AIDS care and ARV treatment in developing countries relate to the health system infrastructure, particularly the lack of adequate and skilled health staff within existing health services, as well as the availability of adequate

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laboratory facilities. Furthermore, it is crucial to provide paediatric HIV/AIDS children with a continuum of services and family support (Kubai, 2011).

There are also substantial delays in linking children diagnosed with HIV infections to treatment and care services. In a study carried out in Botswana, the median time taken from birth until initiation of HIV treatment was 23 weeks and substantially beyond with an average of three-week interval between receipt of test results and treatment initiation (UNAIDS, 2014). In the same research it was found that out of the 79 children who died, 56 died before receiving HIV treatment (Kubai, 2011). Also, several health care workers are reluctant to recommend HIV testing to children due to lack of knowledge regarding the importance of early infant diagnosis and treatment initiation (UNAIDS, 2014).

Colombini, Stöck, Watts and Mayhew (2014) assert that human resource problems experienced in developing countries cause congestion and long waiting times in ART centres and thus deter many ART users from accessing treatment. Poor healthcare provider practices, such as inadequate counselling sessions, abuse of patient confidentiality, lack of adherence follow-ups and drug stock-outs have been demonstrated as major health systems barriers to adherence (Colombini, Stöck, Watts and Mayhew, 2014).

A study by Williams, Van Rooyen, Ricks (2016) in Nelson Mandela Bay established that 12 592 HIV positive children access ART at centralised hospitals instead of other small units scattered all over the district due to shortage of ARVs or staff in those units. The same study also identifies many challenges being faced by caregivers when accessing medications for their HIV positive children including the cost of travelling to collecting points. Shortage of trained staff at PHC lead to overcrowding and ARVs running out (Williams, Van Rooyen & Ricks, 2016). A study by Mafune, Lebese and Nemathaga (2017) in Limpopo, also report that caregivers of HIV positive children were giving up seeking support from government and community structures as this was not forthcoming. According to Mafune, Lebese and Nemathaga (2017) caregivers in their study hardly receive support from family members, the community or even from the government. There are also report that fear of disclosing the HIV positive status of children in Limpopo province led to the delay of financial assistance from the government and this resulted to unbearable financial problems on caregivers particularly the unemployed ones or grandparents.

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2.7.3. Inadequate spectrum of antiretroviral medicines for children

There is a major challenge regarding children who have difficulties in swallowing tablet pills due to their age. This has led to some children being overdosed while others are given little. It is a well-known fact that young children ideally need medication in syrup or powder forms for better intake. The current challenge is that most ARVs are only available in tablet forms, Regardless of the children's age. Measuring the right dose thus makes it a very huge challenge for caregivers looking after children living with HIV. This means that children are given too little or too much of the medication. Apart from those children born with HIV, there are thousands who are affected by HIV because of loss of caregivers and family members who did not disclose their status before they died (Kubai, 2011).

Some ART-producing companies are sceptical about the future market for new paediatric antiretroviral medications, regardless of the confirmation by UNAIDS and WHO (UNAIDS, 2014). Paediatric drug formulations can cost up to 10 times higher than adult formulations, making it even difficult for children to access these drugs (Belton, 2014). Paediatric medication takes a mere 7% of the global antiretroviral market, with virtually no demand for paediatric antiretrovirals in high-income countries (UNAIDS, 2014). The prices available in low-and middle-income for paediatric antiretroviral (US$ 230 per patient per year) remain higher than those for adults US$ 177 (UNAIDS, 2014).

The cost of buying ART can be a barrier in accessing the medication, especially in situations where one or both parents are also HIV positive and may need to pay for their own ART as well. Some of the children living with HIV may be orphans with no financial support for their ARTs (Kubai, 2011). The shortage of age-disaggregated data might also contribute to less-than-optimal service delivery for children living with HIV. It is therefore crucial to collect data and ensure that data is of a high quality, in order to improve forecasting and programme planning. In order to improve the collection of age-disaggregated data, monitoring and evaluation tools will be needed (UNAIDS, 2014). A study by Meyers, Zuliger, Black, Pienaar & Bekker, (2012). also report that ART adherence was affected by ART regimens, that are too complicated for caregivers to understand, particularly those who are illiterate; and lack of paediatric drug formulations. Akahara, Nwolisa, Odinaka and Okolo (2017) also report on other factors to adherence to ART such as drug exhaustion at home due to sharing of the patient's ARV medication with other siblings.

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2.7.4. Discontinuity of ART for children living with HIV

In a pooled analysis of results from 16 paediatric HIV treatment programmes in sub-Saharan Africa, substantial loss to follow-up was found (Maughan-Brown, Lloyd, Bor & Venkataramani, 2016; Arrey, Bilsen, Lacor and Deschepper, 2015). According to a study involving 17 000 children receiving antiretroviral therapy in four African countries, 51% of children who were enrolled in HIV treatment before their first birthday but lost to follow-up within 24 months (UNAIDS, 2014). These follow-up losses across the paediatric HIV treatment continuum greatly worsen health outcomes for children living with HIV. In Kenya, for example, estimates show that only 14% of the children living with HIV are virally suppressed as a result of gaps in the continuum of care. Substantial loss to follow-up appears to occur among children who were not referred for care at the centre where they received their positive test result (UNAIDS, 2014). Poorly-run clinics also contribute to loss to follow-up. These clinics can be characterised by the following; long waiting period, understaffing, loss of early infant diagnostic tests results, lack of standardised and well-developed patient information systems and support (Keenapan, 2011).

2.8. Theoretical framework

The theoretical framework provided a grounding base for a literature review, the research methodology, techniques and data analysis, as suggested by Grant and Babitsch, Gohl& von Lengerke (2012). Among the plethora of frameworks and theories available, the Bronfenbrenner (1997) Ecological Systems Theory (EST) is conceptualised to be more suitable for this study, as it can be used to explore a given behaviour such as adherence to ART by care givers of HIV/AIDS children under five years of age. The Framework is presented in a simple form, and its underpinnings are explained to justify its suitability in this study.

2.8.1. Bronfenbrenner's Ecological Systems Theory

The EST, in Figure 1.1, is one of the most popular theory used to investigate certain behaviours in health by many researchers. This theory was promoted by Bronfenbrenner in 1997, theorising that the socio-ecological environment played an important role in the psychological and social aspects of human development (Berk, 2000; Coetzee, 2015). Since then, the theory has gained popularity in use in various fields due to its simplicity and ability to be integrated with other models and research methodologies (Kagee,

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Remien, Berkman, Hoffman, Campos & Swartz, 2012). According to the EST, the ecological environment comprises of four important levels of interrelated systems, usually depicted as concentric circles, where all of the systems interact with one another (Coetzee, 2015). To explain the levels of context in the model, Bronfenbrenner (1979) places the child at the centre of the model, where levels are nested inside each other. Bronfenbrenner (1979) uses distinct names to refer to each in the model; namely the microsystem, mesosystem, exosystem, and macrosystem (Coetzee, 2015; Kagee, et al., 2012).

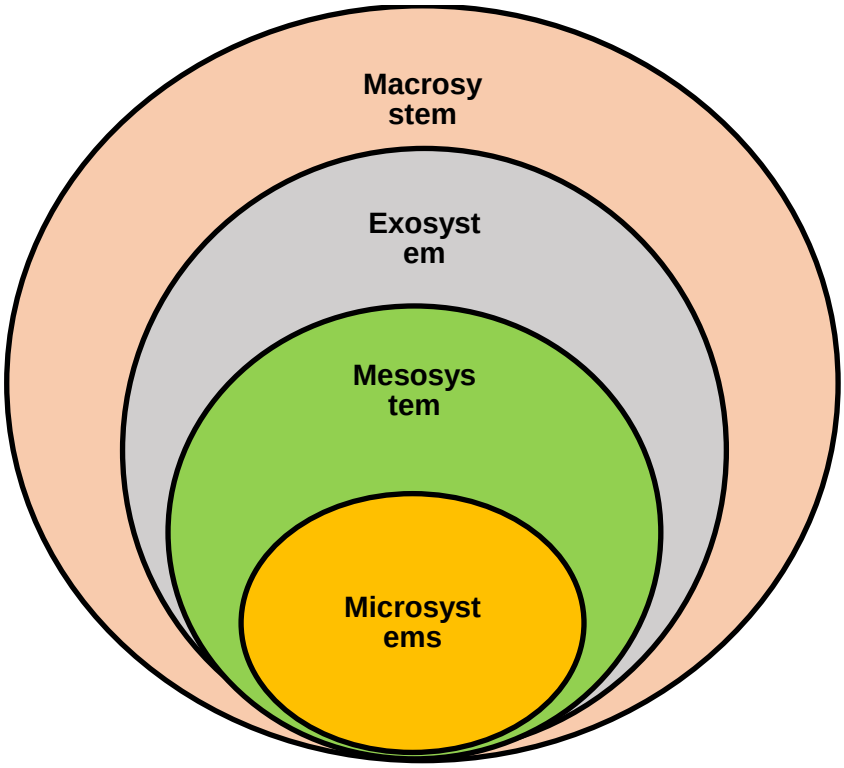

Figure 1. The four systems model of Bronfenbrenner's EST

Berk, (2000); Coetzee, (2015)

In the present study, Bronfenbrenner's EST (1979) will be used as a framework for understanding the factors affecting adherence to ART by caregivers of HIV/AIDS-infected children under the age of five years, borrowing most of the ideas from researchers such as Kagee, Remien, Berkman, Hoffman, Campos and Swartz (2012) and others, who have successfully implemented the model in the South African context.

The advantage of Bronfenbrenner's model over other models is that it places the child at the centre of the nested arrangement, with parents/caregivers and household factors

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situated at the next level, followed by community factors and ethnic group factors at the level after that, as well as the healthcare system related factors at the outmost level.

The study focuses on children under five years of age living with HIV/AIDS, whose ART uptake depends on the caregivers. In this model, a helpless HIV/AIDS child is at the microsystem space. In this model, the microsystem denotes the immediate environment of the child's life. The microsystem is the most important environment because the child grows and develops under the care of adults, who spend much of their time with these children. The child is in the hands of caregivers and parents who are responsible and accountable for all the needs of the child, including ART adherence Coetzee (2015).

The microsystem nests with the mesosystem, which defines the various types of interactions that take place between the members of the microsystem. Culturally, children do not directly interact with strangers. These levels signify the interactions that take place between parents/caregivers. As a result, when children are ill, they may not be able to describe their conditions to healthcare staff, hence they are represented by parents and caregivers (Coetzee, 2015).

A child lives in an even bigger environment called the community, represented by the Exosystem in the model. In the Exosystem level, there are more advanced interactions from extended families, family networks, media, workplaces, family friends, and community health services, legal and social welfare (Coetzee, 2015). The child does not have a direct contact with any of the Exosystem, yet these systems determine how the child will develop and socialise eventually. Social and economic factors in the family always determine how the family members will interact with other members of this system and eventually impact on the adherence to ART.

Lastly, the macrosystem forms the most outer level, made of attitudes, beliefs, ideologies, values, laws and customs of a specific culture or subculture of people from which the child comes from. These would have a bearing on who will care for the HIV/AIDS infected children under the age of five.

Children under five years of age living with HIV/AIDS in South Africa face many complexities that affect adherence to ART. In this study, the Bronfenbrenner's theory is appropriate in that the researcher could use it to design and interpret the research for determining the contributory factors contributing ART to nonadherence in children under

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the age of five years. As depicted by the EST model and the explanations given, the present researcher argues that adherence to ART behaviours of children living with HIV/AIDS under the age of five years are nested within a complex environment, where the caregivers are predominantly in-charge.

2.9 Summary

Literature reviewed revealed many aspects about the extent of HIV/AIDS in children under five years globally, nationally and in South Africa. Adherence and ART in children, ART uptake by children in resource limited areas, Factors affecting adherence to ART in children under five years of age and barriers to ARV treatment for children under five years. Chapter 3 describes research methodology in detail.

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CHAPTER THREE

RESARCH METHODOLOGY

3.1. Introduction

Research is an investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts (merium-webster, 2014). Research methods are the techniques the researcher use to conduct a research study and they represent the tools of the trade, and provide ways to collect, sort and analyse data so that one can come to some meaningful conclusions (Walliman, 2016). The purpose of research methodology is to address the objectives of the study through exploration and description of the research question. The research methodology is also important in that it informs readers on how the researcher carries out an investigation in order to solve the identified research problem. This chapter addresses research design, population, sampling procedure and technique, sample size, data collection methods, data management and analysis.

3.2. Qualitative research

The researcher employed a qualitative research since Antiretroviral treatment nonadherence needs to be explored and hear the voices of the participants. It is also conducted because the researcher needs a complex understanding of the factors affecting antiretroviral nonadherence among caregivers of children under five years of age. The researcher wanted to empower the caregivers to share their stories (Creswell & Poth, 2018). Goldkuhl (2012) and Myers (2011) encourage the use of a qualitative research approach when the research study is designed to understand or promote knowledge construction through social meanings attached to human experiences.

Qualitative research is the systematic inquiry into social phenomena in natural settings (Teherani, Martimianakis, Stenfors-Hayes, Wadhwa & Varpio, 2016). As a process, research entails emerging questions and procedures; collecting data in the participants setting; analysing the data inductively, building from general themes, and making interpretations of the meaning of the data (Bhattacherjee, 2012; Creswell, 2014). According to Rahman (2017), qualitative study focuses on persons' lives, lived experiences, behaviours, emotions, and feelings as well as about organisational

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functioning, social movements, cultural phenomena, and interactions between nations. The experience, emotions, socio and cultural beliefs of caregivers in ART is vital to unlock the contributory factors to their nonadherence to the programme. A researcher who uses qualitative research is interested in analysing subjective meaning or the social production of issues, events, or practices by collecting non-standardised data and analysing texts and images rather than number and statistic (Rahman, 2017).

Grove, Gray and Burns (2015) also regard qualitative research as a systematic, interactive subjective approach that describes life experiences and give them meaning. In this study, qualitative research approach denotes a wide range of research designs and methods that was used to study phenomenon of social action and of which do not have an understanding. From the given definitions, qualitative research would thus refer to the meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things. This implies that qualitative researcher focuses on the meanings, traits and defining characteristics of events, people, interactions, settings/cultures and experience.

In qualitative research, the researcher can collect data in a variety of ways including narrative (non-numeric) form, such as dialogue from transcript of an unstructured interview (Polit & Beck, 2012). Based on this notion, the researcher utilises qualitative approach as it is appropriate in the exploration and description of the experiences of caregivers regarding factors contributing to nonadherence to ART in HIV positive children under five years of age.

3.2.1. Benefits of qualitative approach

Qualitative approach has a lot of benefits when applied to health contexts. One of the major advantages of qualitative approach is that methods used provide more emphasis on interpretation and providing reader with complete views, looking at contexts, environmental immersions and a depth of understanding of concepts (Tewksbury, 2009). Lasch et al. (2010), regard the interactive relationship as a benefit as it offers the researcher first-hand insights into the experiences of participants about factors. Choy (2014) states that qualitative research raises more issues through broad and open-ended inquiry and seeks to understand behaviours of values, beliefs and assumptions. Another benefit for qualitative research is that of producing detailed description of participants' feelings, opinions, experiences and interprets the meanings of their actions (Donmoyer, 2012; Flick,

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2014). When a qualitative research is used, the researcher can discover the participants' inner experience and opportunity to work out how the meanings are shaped through in culture (Crano, Brewer & Lac, 2015; Maxwell, 2012). Furthermore, qualitative research methods such as participant-observation, unstructured interviews, direct observation, describing records are most commonly used for collecting data making it possible for the researchers to interact with the participants directly (Cohen, Manion, & Morrison, 2011). This implies that data gathering is both subjective and detailed (Flick, 2011). In this study, the researcher collected deep information about nonadherence to ART from the caregivers. Table 3.1 Shows the advantages and disadvantages of using qualitative research.

Table 3: Advantages and disadvantages of using qualitative research

Advantages	Disadvantages
Rich, in-depth detail is possible because participants can elaborate on what they mean	Not always generalizable due to small sample sizes and the subjective nature of the research
Perceptions of participants themselves can be considered (the human factor)	Conclusions need to be carefully hedged
Appropriate for situations in which detailed understanding is required	Accusations of unreliability are common (different results may be achieved on a different day/with different people)
Events can be seen holistically	When the subject is highly sensitive, participants may be inhibited in exchanging beliefs
They clarify questions that are to be incorporated in a subsequent quantitative survey	They are subject to bias from dominating participants
Spontaneous comments are encouraged	In a similar way to the above point, they are subject to the herd instinct (everyone agreeing)

Adapted from Ferdinand (2016); McCulloch (2016)

3.2.2. Rationale for choosing a qualitative approach

Most of the caregivers in Vhembe district are adult women who may only volunteer to give information through interviews basis rather than questionnaires. In this study, caregivers were given an opportunity to raise issues and topics which the researcher is unlikely to include in a structured reductionist research approach. By use of qualitative methods, the researcher was able to systematically captured caregivers' experiences and interpreted the events and circumstances pertaining factors contributing to nonadherence to ART in caregivers of children. Brink (2011) states that a qualitative study is an investigation of

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phenomena, typically, in a holistic fashion through the collection of rich narrative materials using a flexible research design. Qualitative research is a way of finding out what people think and feel through observing and interviewing and reading documents. Qualitative approach was chosen for its potential to give useful insights to factors contributing to ART nonadherence among caregivers simultaneously improving the skills and experience of the researcher healthcare issues related to HIV among children.

3.3. Research design

Creswell (2014) defines a research design as a plan and procedures for research that span the decisions from broad assumptions to detailed methods that can be used for data collection and analysis. According to Polit and Beck (2012) research design refers to an overall plan for addressing a research question, including specifications for enhancing the study's integrity.

The researcher used qualitative research approach with explorative, descriptive and contextual designs in order to explore and describe in-depth understanding of factors that contribute to ART nonadherence among caregivers of HIV positive children at the selected hospitals in Vhembe District. Qualitative research design is flexible and interactive in structure because it can be constructed and modified as the researcher sees fit (Maxwell, 2012; Mohan, 2012).

3.3.1. Exploratory

Exploratory design is used when the researcher does not know what to expect, how to define the issues, or lack an understanding of why and how population is affected or impacted by the problem (Hancock, Ockleford & Windridge, 2010). The purpose of exploratory research design in this study is to gain insight into the problem and situation about factors contributing to nonadherence to ART in caregivers of children, Vhembe district hospitals. With an exploratory design, the researcher also aimed to gain insight to develop new ideas, concepts and theories regarding a problem.

The researcher gathered the in-depth information by means of conducting in-depth interviews, that revealed the problems and experiences that caregivers face in their quest to assist HIV positive infants to adhere to ART uptake. Exploratory designs have been widely used in health to solicit data used to give answers in different ways about how

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phenomena and process occur as understood by the participants (Polit & Beck, 2012). In-depth interviews with caregivers have the potential to provide detailed information that are vital to this study.

3.3.2. Descriptive

This design describes the variables in order to answer the research question. Descriptive designs are concerned with gathering information from a represented sample of the population. It is used in studies where more information is required for a specific field through the provision of a picture of the phenomenon as it occurs naturally (Brink, 2014). The purpose of qualitative descriptive design is to enable the researcher to provide a comprehensive summary, in everyday terms, of specific events experienced by individuals or groups of individuals (Lambert & Lambert, 2012). Generally, the design enables hearing, seeing, feeling, remembering, deciding, evaluating and acting in a natural setting where the participant and the researcher may interact. In this study, descriptive research presents a picture of specific details of situation, social setting or relationship, and focuses on ‘’how’’ and ‘’why’ ’questions, the researcher therefore begins with a well-defined subject and conducts research to describe it accurately (Brink, 2014). The caregivers described the factors contributing to nonadherence to ART among caregivers of children living with HIV/AIDS.

3.3.3. Contextual

By using contextual research design, the researcher seeks to explore and give answers into different ways about how the phenomena and processes take place (Polit & Beck 2012; Lambert & Lambert, 2012). Contextual research design enables the researcher to describe and understand events within a concrete, and natural context as they take place (Brink, 2012). A contextual inquiry is an observational qualitative research technique where the user is observed performing a task or using a product or service in the context of the environment that they would normally do this in their workplace or home (O'Neill, 2015).

The contributory factors explored required the researcher to have an insight into context to which caregivers operate, and the challenge they must overcome in order to adhere to ART uptake when providing care to children. In this respect, the caregivers described the factors that contribute to nonadherence in the natural settings, which are the hospitals.

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3.4 Research setting

Research setting is a specific place or places where data was collected, real life situation or environment (Brink, 2012). Limpopo province is one of the nine provinces in South Africa. It has five districts Mopani, Sekhukhune, Capricorn, Waterberg and Vhembe district. Vhembe district lies in the northern part of Limpopo province. Vhembe District has four Municipalities namely Thulamela, Makhado, Mutale and Musina. Musina stretches to the Beit Bridge border with Zimbabwe, and Mozambique.

The study was conducted in Vhembe district hospitals of Limpopo province. The selected hospitals in Vhembe district, of Limpopo province included Donald Fraser, Siloam and Musina. Figure 2 shows the hospitals in Vhembe district.

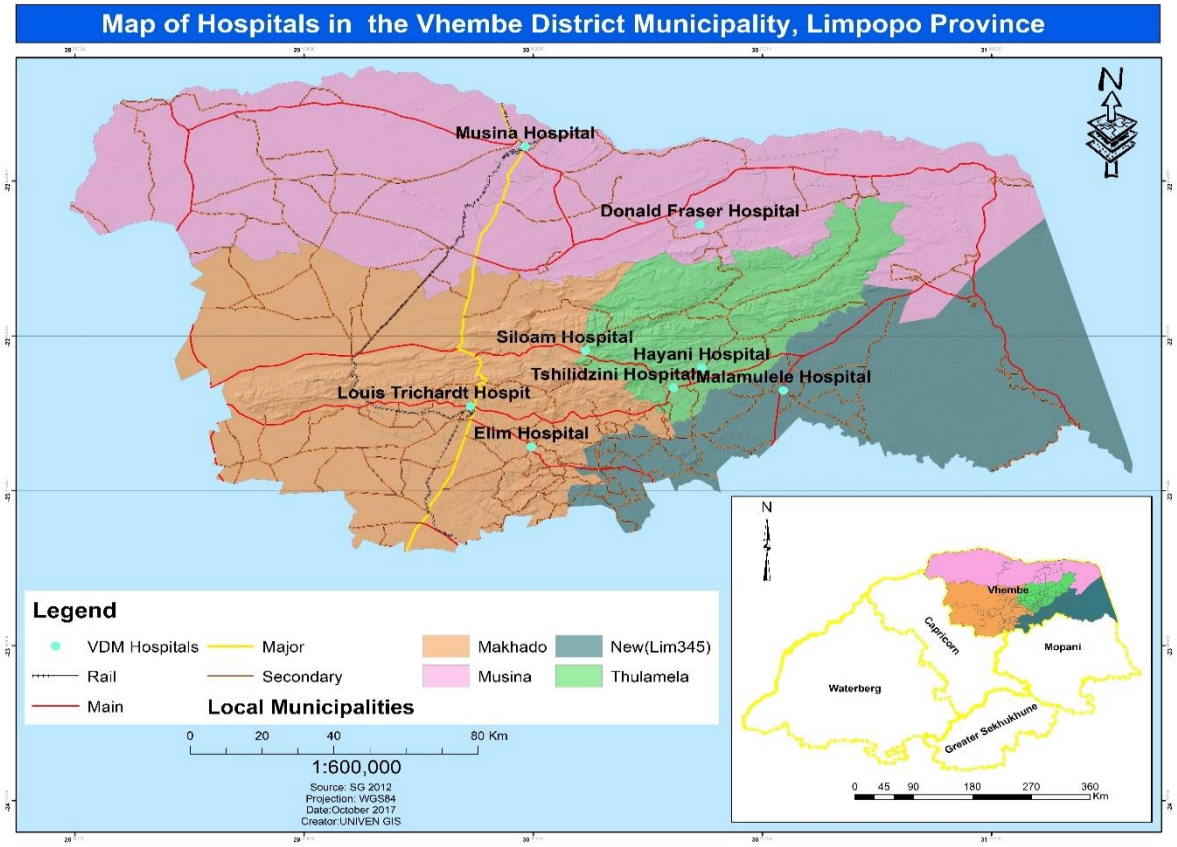

Figure 2: Vhembe District, Municipalities and Hospitals Map

There are seven public hospitals in Vhembe District; namely: Musina, Siloam, Louis Trichardt, Elim, Donald Fraser, Malamulele and Tshilidzini. The hospitals serve rural and urban communities.

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3.5 Research method

Polit and Beck (2012) refer research methods as the steps, procedures and strategies for collecting and analysing data in the research process. Research population, sampling method and sample size, data collection and data analysis are described in this section

3.5.1 Research population

A research population is the entire individuals having common characteristics that are selected by researcher to meet the purpose of the study (Brink, 2012; De vos et al, 2012). Research population is generally a large collection of individuals or objects that is the focus of a scientific enquiry (Hancock et al., 2010). The population consists of all caregivers of children under five years of age who are on ART.

3.5.1.1 Target population

A target population refers to the entire group of individuals or objects to which researchers are interested in generalizing the conclusions (Cresswell, 2011). Target population is described as the entire set of cases about which the researcher would like to generalize (Lobiondo & Haber, 2014). In this study the target population is the caregivers whose children are repeatedly admitted diagnosed with opportunistic conditions and infections.

3.5.1.2 Accessible population

Accessible population refers to the population that meets the target criteria that is available (Loboindo & Haber, 2014). An accessible population is a subset of the target population and is also known as the study population. An accessible population were the caregivers whose children under five were admitted in the hospitals' paediatric unit and those who were at the ARV clinic for review and collection of medication for their children during the time of the study.

3.5.2 Sample and sampling technique

The main purpose of a qualitative research study is to understand the subjective reality of the study participants from within or their point of view and experiences (Elmusharaf, 2012). The consensus among qualitative researchers is that, one continues to sample until one no longer gets any new information which is referred as data saturation (Elmusharaf, 2012; Creswell, 2014).

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Brink, (2014) views a sample as a subset of the population that is selected to represent the population. This study utilises a sample from which data will be collected. The main function of the sample in this study is to allow the researcher to conduct the study with individuals from the population, so that the results of their study can be used to make conclusions that will apply to the entire population (Luffman, 2014, Loboindo & Haber, 2014). The researcher will thus select a sample.

A sample is the selected group of participants or elements included in the study (Grove et al. 2013). The main reason for selecting a sample instead of studying the entire population is to make an accurate conclusion about the whole study population (Polit and Beck 2010). Once the population is identified, sampling techniques are employed.

Sampling technique is a process whereby a group of individuals are selected in order to obtain information regarding a phenomenon in a way that represents a population of interest (Grove, Gray & Burns, 2013). Lincoin and Guba (2010) indicates that qualitative research purposively sample participants who have experience and can best answer the research questions.

There are several sampling techniques used in qualitative research studies each with its strengths and weaknesses. In order to select a sampling technique, the researcher is obliged to have a deeper understanding of what the technique entails, how it is used, merits and demerits as well as the suitability to the issues being researched. The researcher will use non-probability sampling technique. Non-probability sampling allows sampling to be conducted so that samples are selected based on the subjective judgement of the researcher, instead of random selection (Gentles, 2015).

There are both theorical and practical reasons for adopting a non-probability sampling technique (Maxwell, 2013; Rahman, 2017). Non-probability sampling requires the researchers to use their subjective judgements, drawing on theory or academic literature, their research practice or experience and the evolutionary nature of the research process (Maxwell, 2013). Non-probability sampling is preferred because the procedures used to select units for inclusion in a sample are much easier, quicker and cheaper when compared to those used in probability sampling (Elmusharaf, 2012).

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Generally non-probability convenience and purposive are cheaper and faster to obtain the required sample for the study (Gentles et al., 2015). Therefore, this study utilises non-probability sampling technique to select a sample of the hospitals from Vhembe District and the sample of participants from the entire population of caregivers of HIV positive children in selected hospitals. By using non-probability sampling, the researcher selected individuals and sites because they were available, convenient, and represent some characteristics the researcher wants to study. Although non-probability sampling may not accurately represent the population being studied, it is usually more convenient than random sampling. The relevant authorities of the selected hospitals had given the permission to access the hospitals (see annexure B). The types of non-probability sampling used in this study are convenience sampling and purposive sampling.

3.5.2.1 Sampling of the hospitals

Vhembe district is comprised of seven hospitals of which the researcher used purposive sampling method to select the hospitals with paediatric units that refer their HIV infected children to ARV clinics within the hospitals. The researcher used judgement to select hospitals which admitted large numbers of caregivers with HIV/AIDS children under five years of age who are repeatedly admitted with HIV opportunistic infections. Purposive sampling technique relies on the judgement of the researcher in selecting study units needed (Gentles et al., 2014; Elmusharaf, 2012; Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood, 2015). The following criteria were considered in selecting the hospitals:

- A public hospital with HIV/AIDS clinic
- A hospital with paediatric unit with high rate of AIDS children readmission

3.5.2.2 Sampling of participants

The researcher used both convenience and purposive sampling to select the participants. Convenience sampling method was used to select all caregivers of HIV infected children under five years of age who were available in the unit and at the hospital clinic during the time of collecting data. The researcher further used purposive sampling to select Caregivers:

- Whose children are repeatedly admitted with opportunistic
- Who collect ARVs from the hospital AIDS' clinics.

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Qualitative researchers rarely pre-specify the sample size. All caregivers were residents in the Vhembe District and the children were registered on the official registers for HIV/AIDS in the selected hospitals and clinics

Purposive sampling is widely used in qualitative research for the identification and selection of information-rich cases related to the phenomenon of interest (Palinkas et al., 2015). This involves identifying and selecting individuals or groups of individuals that are knowledgeable about or experienced with a phenomenon of interest (Cresswell & Plano-Clark, 2011). For the sampling technique to be successful, the researcher became aware of the need to have knowledge and experience and also importance participants' availability and willingness to participate, and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner (Palinkas, et al., 2015).

Researchers often believe that they can obtain a representative sample by using a sound judgment, which will result in saving time and money (Alvi, 2016). Purposive sampling technique is effective when only limited numbers of participants are to serve as primary data sources due to the nature of research design and aims and objectives (Black, 2010). Various studies discuss the advantages and disadvantages of using purposive sampling (Cresswell and Plano-Clark, 2011; Alvi, 2016; Saunders, Lewis, Thornhill, 2012). Purposive sampling is one of the most cost-effective and time-effective sampling methods available. It may be the only appropriate method available if there are only limited numbers of primary data sources and this sampling technique can be effective in exploring situations where the discovery of meaning can benefit from an intuitive approach.

Disadvantages of purposive sampling as discussed by Creswell and Plano-Clark (2011). Alvi (2016), Palinkas, Horwitz, Green, Wisdom, Duan and Hoagwood, (2013) and Saunders, et al. (2012) include: Vulnerability to errors in judgment by researcher, low level of reliability and high levels of bias, and inability to generalize research findings.

Kemper, Stringfield and Teddlie cited in Palinkas, et al., (2013) describes seven principles of purposive sampling that the researcher needs to consider, namely the need for: the sampling strategy to be logically derived from the conceptual framework and research questions that the research study is answering; the need for the sample to be able to generate a thorough database on the type of phenomenon under study; the sample to at least allow the possibility of drawing clear inferences and credible explanations from the

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data gathered; the sampling strategy to be ethical; the sampling plan to be feasible; the sampling plan to permit the researcher to transfer/generalize the conclusions of the study to other settings or populations; and the sampling scheme should be as efficient as practical.

3.5.2.3 Sample size

Sample size is the number of the participants who are likely to give the consent and participate in a research study (Groove, Gray & Burns 2013). Myers (2012) purports that due to the nature of qualitative studies, smaller samples can only be studied. Qualitative studies emphasise on quality of data collected rather than the quantity of such data (Bryman, 2012). 25 caregivers were interviewed.

3.6. Unstructured in-depth interviews

In real life situations, an interview is a conversation intended to extract descriptions of how the interviewee experiences, understanding and interpretation of the meanings of the issues being discussed (Gunawan, 2015; Moon, et al, 2016). Four types of interviews are usually utilised in qualitative studies namely, structured, open-ended (unstructured), semi-structured and focus group (Moon, et al. 2016; Berg, 2007). Structured interview is mainly organised around a set of predetermined direct questions that require immediate predetermined answer such as yes or no (Alshenqeeti, 2014). When using a structured interview, the interviewer and interviewees normally have very restricted freedom (Berg, 2007). There is generally a thin dividing line between structured interviews and self-administered quantitative questionnaire forms and underlying assumptions (Alshenqeeti, 2014). This type of interview is not appropriate for this study as it will restrict the participants to the researcher's predispositions. For the caregivers to be free, the researcher asked a central question that led the participants to give information on the topic under discussion.

Data in a qualitative research study is collected by means of an instrument (Zohrabi, 2013), a device used to collect data in research studies (Brink, 2012). In this study the researcher collected data through an unstructured in-depth interview that gave caregivers an opportunity to narrate and explain factors that contribute to nonadherence to ART among HIV positive children under five. The root of unstructured in-depth interview is focused in understanding the experience of other people and the meaning they make of that experience (De Vos, 2010).

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The most appropriate data collection method often used in qualitative studies is in-depth interviews' process and observations (Creswell, 2014). Oltmann (2016) refers to an interview as negotiated accomplishments of both interviewers and respondents are shaped by the contexts and situations in which they take place. Interviewing is a method of collecting important data and information the researcher needs in order to analyse the phenomenon or issue being studied with the intention to understand it (Creswell, 2014; Maxwell, 2013; Miles, Huberman and Saldana, 2014).

Unstructured in-depth interviews were used as a means for data collection from a sample of caregivers for HIV/AIDS children aged below five years. As means of data collection, unstructured in-depth interviews allow the participants to share their opinions and views about a topical issue freely and without bias from other participants and gain extra knowledge and insight than focus group discussion and it can enable the recruiting and scheduling process easier and faster. Miles et al., (2014) encourage the use of unstructured in-depth interviews due to their flexibility which allows the researcher to follow the direction determined by subjects. Unstructured in-depth interviews were designed to explore factors that contribute to caregivers' nonadherence to ART among children under the age of five.

In-depth interviews are the means by which the researcher accessed caregiver's views and interpretations of their actions and consequences. The researcher gathered data by means of unstructured in-depth interviews which intended to lobby information about the factors contributing to ART nonadherence among caregivers of children under five years at the selected hospitals in Vhembe district.

3.7. Interviews

This study adopts an unstructured in-depth interview as the sole method of data collection. Interviewing is described as a natural and socially acceptable way of collecting data as it can be used in various situations covering a variety of topics (Dornyei, 2007). The interview process is recommended by various researchers as a tool for social research as it facilitates obtaining direct explanations for human actions through a comprehensive speech interaction (Alshenqeeti, 2014).

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A central question was asked to all participants (See annexure G)

English: *"You are caring for a child living with HIV, may you please share with me the factors contributing to nonadherence, as you can see that the child is repeatedly admitted with HIV-related infections".*

Tshivenda: *"Vha tshi khou thogomela nwana wavho a no khou tshila na tshitzhili tsha HIV ndi khou humbela u kovheliwa/talutshedziwa zwiitisi zwi vha swikisaho kha u sa fha nwana mishonga nga ndila yo teaho sa izwi vha tshi khou zwi vhona uri nwana wavho u dzulela u adimitiwa a na malwadze a yelanaho na a tshitzhili?*

3.8. Pretesting

A central question was pre-tested using 5 caregivers from the hospitals not included in the study. Corrections were made in order to improve the central question. Time management was also observed.

The unstructured interview provides an open situation and has a great flexibility and freedom for both the interviewees and the interviewers (Berg, 2007). The interviewer can ask follow-up questions for clarifications on certain unexplained issues. This type of interview was appropriate for this study as it assists the researcher and gave an opportunity to unearth various underlying issues in the factors contributing to nonadherence to ART by caregivers.

3.9. Data collection and management

Data collection involves applying the instruments to the sample or cases selected for investigation (Merriam-Webster, 2014). Studies in qualitative research indicate that most of the qualitative data are non-numeric (Mouton, 2009). Consequently, qualitative research relies on data collected from a small number of individuals or sites through interviews, observational, fieldwork and archival research techniques. Permission to use voice recorder was asked before commencement of the interviews.

Data was collected from Donald Frazer (see annexure H and Siloam Annexure I hospitals in November 2018. The researcher explained the purpose of the study and protection from human rights to the participants. One participant was interviewed for 30 to 45 minutes. One central question was asked to all interviewees. Probing questions were asked

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determined by the response from the participants. The researcher interviewed the caregivers until data saturation is reached (Groove, Gray & Burns 2013; Polit & Beck, 2010). Ten (10) participants from the hospital units and 15 from ARV Hospital clinics were interviewed.

Data management involved keeping data and storage devices secured from destruction and exposure or unauthorised access by people who were not intended to. Immediately after data collection, the tapes and notes were secured by locking them in a safe place. All data collected through audio tapes were transcribed verbatim. After recording, the tapes and other data sources were stored under lock and key for safety while the researcher was doing data analysis. Only the researcher could access the tapes that will be disposed for incineration after a period of five years.

3.10. Data analysis

Data analysis is the process of making sense out of the data by consolidating, reducing and interpreting what people have said and what the researcher has seen and read (Merriam-Webster, 2014). According to Brink (2014) data analysis involves categorising, ordering, manipulating and summarising the data and describing them in meaningful terms with the aim of highlighting useful information, suggesting concussions and supporting decision making. Qualitative data analysis consists of three concurrent flows of activities namely data reduction, data display and interpretation or conclusion drawing (Miles and Huberman,2014). In this study, data analysis involves the researcher examining data for completeness and accuracy by listing individually each piece of data collected. Transcribed data was methodically organised according to themes and sub-categories based on research questions. Creswell (2014) provides a detailed approach to analysis of unstructured data. The steps for data analysis proposed by Creswell (2014) guided analysis for this study:

Step 1. Transcribe, sort and arrange the data for analysis

Reading through the transcript helped the researcher to arrange the transcripts carrying the same information

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Step 2. Read through all the data

The researcher reviewed the transcripts to get a general sense of information and possibly their overall meaning.

Step 3. Make a list of topics

Similar topics were clustered together, from these clustered topics into columns.

Step 4. Abbreviate the topics as codes

The researcher used a checklist to write the codes next to the appropriate segments of the text. Additional groups of categories were added throughout data analysis to refine the data.

Step 5. Categorize the topics

This is where the total list of categories reduced by grouping topics that related to each other.

Step 6. Abbreviating the topics as codes

Make a final decision on the abbreviation for each category; find the most descriptive wording for your topics and turn them into categories. Look for ways of coding and alphabetize these codes.

Step 7. Assembling similar categories of data

Data material belonging to each category assembled in one place and a preliminary analysis performed.

Step 8. Recode the existing data

It is at this stage where the existing data was recorded to ensure that all data was considered. Themes and sub-themes identified by both the researcher and the coder were compared by one external reviewer who was not part of the initial analysis

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3.11. Measures to Ensure Trustworthiness

According to Pilot and Beck (2012), trustworthiness refers to the degree of confidence qualitative researchers have in their data, assessed using criteria of credibility, transferability, dependability, conformability, and authenticity. Trustworthiness is usually subdivided into credibility, which corresponds to the positivist concept of internal validity; dependability, which relates more to reliability; transferability, which is a form of external validity; and conformability, which is largely an issue of presentation (Gunawan, 2015). Each of the criteria for ensuring trustworthiness in this study were discussed in subsequent subsections. Trustworthiness was applied in all study phases, so that the study outcomes represent an accurate experience of participants. A study has been evaluated in relation to the procedures used to generate the findings. The researcher used the following criteria to ensure trustworthiness

3.11.1. Credibility

Botma *et al*. (2010) state that credibility means that the researcher reports the perspectives of the participants as clearly as possible. Credibility refers to confidence in the truth of the data and interpretation thereof. Qualitative researchers must strive to establish confidence in the truth of the findings for the participants and contests in the research (Polit & Beck, 2012). In this study, credibility dealt with the quality of data collected and the richness of the information gathered. The researcher avoided preconceived ideas about the participants being studied during data analysis and concentrated on the empirical data gathered during the research. The researcher collected information until data saturation occurred. The researcher engaged with participants and informed them about purpose of the study so that they signed an informed consent form during an interview. The researcher spent a month with participants collecting data in order to establish trust, rapport and understanding of the participant's experiences.

3.11.2. Transferability

Transferability refers to the extent to which the findings can be transferred to or have applicability in other setting or group (Polit & Beck, 2012). In a qualitative study, transferability determines the degree to which the phenomenon or findings described in study are applicable or useful to theory, practice, and future research or other contexts

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(Moon, *et al.,* 2016). Research transferability is enhanced by thoroughly describing the research context and the assumptions that are central to the research.

It is the responsibility of the researcher or person who wishes to transfer the results to a different context to make the judgment of the applicability of the results in other contexts. Data was collected from three different hospitals where the researcher had spent a month collecting data and has given enough description of the context and assumptions that guided the research process and the findings.

3.11.3 Dependability

Dependability is the ability of a research study to account for the ever-changing context within which the research occurs (Myers, 2011). Dependability can also refer to the stability of data over time and conditions. It refers to the provision of evidence such that if it were to be repeated with the same or similar participants in the similar context, its findings would be similar (Polit & Beck, 2012). To ensure dependability the researcher examined the research process continuously. In this study, the researcher has taken responsibility of describing the changes that occurred in the setting and how those changes affected the way the researcher approached the study. For this research, measures for maintaining dependability involve systematically gathering data by means of prior identified non-key items. The researcher kept a detailed record of the decisions made before and during the research, description of the research, and documented -verbal communication observed during in-depth individual interview. The researcher shared the transcript with another experienced researcher who independently did the analysis and compared the notes.

3.11.4 Confirmability

Confirmability is concerned with establishing whether data represents the information provided by the participants and that the interpretations are not fuelled by the researcher's imagination (Pilot & Beck 2012; Brink, 2014). The findings must reflect the participant's voice and the condition of the enquiry, not the researcher's biases, motivation or perspectives. In this study research confirmability was achieved by documenting all the procedures for checking and rechecking the data throughout the study. Those documents allow the researcher to conduct and examine the data collection and analysis procedures and make judgements about the potential for bias or distortion. Alternatively, the researcher made the data available for scrutiny by research participants. Participants should have access to data collected, so that they confirm the credibility of the data. To

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ensure confirmability, the researcher made an audit trial detailing the data collection, data analysis and interpretation of the data. During analysis of data, major themes, themes and sub-themes identified by both the researcher and an independent coder were compared by an external reviewer and they arrived to the same conclusion.

3.12. Ethical Considerations

Conducting a research with human beings as subjects brings forth ethical issues that must be addressed from the onset (Cresswell, 2014). Denzin and Lincoln in Polit and Beck (2012) define ethics as what is not legitimate to do, or what a “moral” research procedure involve asserts that ethical considerations in research “mostly affect stages of planning and data collection.” The researcher conducted a research in a responsible and morally defensible manner. People were used as subjects; great care has been exercised to ensure that human rights are protected.

3.12.1 Permission to conduct a study

The research proposal was presented to the University of Venda’s higher degree committee for approval to conduct the study for quality purpose (see Annexure A). Permission to conduct research was sought from the provincial Department of Health Research committee (Annexure B) and the chief executive officer of the selected hospitals in Vhembe district of the Limpopo province. Informed consent was obtained from participants. In this study ethical considerations were regarded as the core principle because credibility in trustworthiness was ensured.

3.12.2. Informed consent

In research, voluntary participation means that participants make an informed choice while informed consent means that participants have adequate information about the study, comprehend the information, and have power of free choice, enabling them to consent or decline participation voluntarily (Polit and Beck, 2014). Obtaining informed consent from human participants is essential for conducting ethical research. In the informed consent form, the researcher elucidated the following important items: research activities, benefits, assurance of anonymity and confidentiality, researcher’s willingness to answer questions and option to withdraw (Burns and Grove 2011). Before participating in the study, all relevant information was presented to the participants and after that they were left to make

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informed decision regarding participation in the study. Rights of the participants were protected by following the principles:

3.12.3 Beneficence

The principle of beneficence was ensured by making provision of benefits and good to the participants. It required the researcher to weigh risks and benefits and take decisions which provide maximum benefit to the participants (Chagani, 2014). The principle of beneficence in the study covered the right to freedom from harm and the right to protection from exploitation. During and after the interview participants were protected physically, psychologically, emotionally, spiritually, economically, socially and legally. Furthermore, they were protected from experiences that cause temporal or permanent harm.

3.12.4. Anonymity

Throughout the interview, the researcher addressed each interviewee with a pseudo name. These pseudo names were used for the purpose of the interview, after which they were discarded. This ensure that every participant's personal information remained unknown. The participants' names do not appear on any document used in this study. The participants remained anonymous (Brink, 2012).

3.12.5 Confidentiality and privacy

Each individual participant in a study is entitled to privacy and confidentiality on ethical grounds (Burns & Grove, 2011) and in terms of the protection of their personal and sensitive data under the Data Protection Act. In a study, confidentiality is maintained by the researcher's management of private information shared by a participant and must not be shared with others without the authorization of the participant (Burns & Grove, 2017). Participants remained anonymous and the information was kept confidential. The researcher ensured that personal rights and privacy of participants were adequately protected, by not including their names in the research report.

3.12.6 Rights of the institutions

Permission to conduct research in the institutions was obtained. The researcher promised the nurse manager that the study findings will be published without reference to the

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hospital name and disseminate research findings to the professional nurses, and manager of the selected hospitals in Vhembe district.

3.12. 7 Protection from Human rights

Freedom from harm

During the data collection stage, the researcher ensured that no harm or discomfort are caused to all participants. To ensure this ethical aspect, the researcher selected venues for interview where participants felt comfortable and safe.

Protection from exploitation

In this study, caregivers were protected from exploitation through asking them to participate voluntarily. This implies that the researcher explained to the participants that they may withdraw from the interview at any moment should they wish to, without penalty and without an explanation

Justice

Justice means fairness and equity for all participants and ensuring that no individual or group is neglected or discriminated against in research (Cantebury Christ Church University, 2014). In this respect, the principle of justice imposes obligations on the researcher towards participants who are vulnerable and unable to protect their own interests. To ensure justice, they are not exploited for the advancement of knowledge (Chagani, 2014). According to Burns and Grove (2011), the right to fair treatment is based on the ethical principle of justice which holds that each participant should be treated fairly. To achieve, this critical ethical aspect, participation in this study was voluntary.

3.12.8 Human dignity

Respect for human dignity requires that research involving humans be conducted in a manner that is sensitive to the inherent worth of all human beings and respect their values and beliefs. (CCCU, 2014). Participants were respected and treated equal and they were listened to. The researcher informed the participants of their right to participate in the study or not.

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3.12.9 Respect for persons

According to Cantebury Christ Church University (2014), vulnerable individuals (the old, young, sick and mentally impaired) are entitled, on grounds of human dignity, caring, and fairness, to special protection against abuse, discrimination, deception or exploitation. Ethical obligations to vulnerable individuals in the conduct of research should necessitate special procedures to protect the interest of the vulnerable. This study does not include vulnerable participants.

3.12.10 The right to self determination

This means that the prospective participants have the right to decide voluntarily whether to participate in a study, without risking penalty or prejudicial treatment (Polit & Beck, 2014). Therefore, in this proposed study, respect for individuals were expressed through recognising that their autonomy and right to self-determination which underpins their ability to make judgements and decisions for themselves. Accordingly, the right to self-determination is based on the ethical principle of respect for persons and it indicates that human beings should control their own destiny (Burns & Grove, 2017). The right to self-determination is based on the ethical principle which gives people the right to make their choices. In the present study the researcher avoided any form of coercion. To cater for autonomy, all participants signed the informed consent form.

3.13 Summary

This research is designed to establish factors that contribute to nonadherence to ART in children living with HIV at selected hospitals of Vhembe District, Limpopo Province. The rationale of the study and the problem statement have been stated to justify why the study is necessary. Literature was also reviewed on issues affecting ART adherence and its effects among infants. The research methodology will describe the choice of the technique, approach and designs. Unstructured interview was used as the data collection technique. Justification for the selection of research methods was pinned on the research problem. The population of the study consist of caregivers of children under five from the selected hospitals who are admitted and collect ARVs from the hospitals in Vhembe District. Non-probability purposive sampling was used for selecting both hospitals and caregivers. Ethical issues were also considered.

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CHAPTER FOUR

DATA PRESENTATION, ANALYSIS AND DISCUSSION

4.1 Introduction

The purpose of this study was to explore the contributory factors to ART non-adherence among caregivers of children under five years of age living with HIV/AIDS from selected hospitals of Vhembe District, Limpopo province. The critical question that the study sought to explore is “What are the factors that contribute to ART nonadherence among caregivers of children under five years of age living with HIV/AIDS from the selected hospitals of the Vhembe District, Limpopo province?”. Data was collected from a sample of 25 caregivers who were conveniently and purposively selected on their visit to the hospital HIV/AIDS clinic. In-depth interviews were conducted with all the 25 participants, recorded and then data was transcribed verbatim. The transcripts were scrutinised three times identifying codes to main ideas using computer application called Atlas Version 8. Data expressing similar ideas were grouped together into themes and sub-themes from which patterns were qualitatively identified before tabulating for final analysis. The previous chapter focused on research design and method used in this study. The current chapter focuses on data presentation, analysis and discussion about factors that contribute to ART nonadherence in caregivers of children under five years.

4.2. Factors contributing to non-adherence to ART in caregivers of children

This section presents factors that contribute to nonadherence to ART in caregivers of children under five years of age, living with HIV/AIDS at the selected hospitals of Vhembe District. Numerous factors contributing to nonadherence to ART in caregivers of children under five years of age came out of this study. The factors were grouped into four main themes, namely: social factors, personal factors, information related factors, access to medication by caregivers, psychological factors and medicinal factors. The four themes and their corresponding sub-themes are shown on table 4.

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Table 4: Themes and sub-themes on contributory factors to nonadherence

MAJOR THEME	THEMES	SUB-THEMES
Factors contributing to ART non-adherence among caregivers of children under five years of age in the selected hospitals of Vhembe district of Limpopo province	**Social factors**	Fear of disclosure of HIV status of the child
		Traditional and religious beliefs
		Forgetting to give the child medication
	Personal factors	Lack of knowledge and understanding of ART
		Deliberately giving ARTs inconsistently
		Confusing information from medical staff on HIV/AIDS
		Non-adherence due to stress
	Poor access to medication	Distance between mother and child
		Shortage of medicine in Health Facilities
		Economic problems
	Medicinal factors	Negative effect of medicine on baby
		Positive effect of medication

4.2.1 Social factors

Factors grouped under this theme involved different social issues which prevented caregivers from adhering to ART. The factors include fear of disclosure of HIV status of the child, traditional and religious beliefs, and forgetting to give the child medication.

4.2.1.1 Fear of Disclosure of HIV Status of the Child

Caregivers in this study are failing to tenaciously adhere ART for children under the age of five because they are afraid of disclosing the HIV status of their infected children. They hide the HIV status of their children from the husbands by avoiding giving children medication. The caregivers are afraid of ruining their marriages leading to a divorce if they disclose their children's HIV status or seen by the husband giving a child ART. Participant 1 said:

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> *"I found it difficult to inform him (the father to the child) that I was sick, and his son was infected with HIV/AIDS. I was afraid that he might divorce me after concluding that I am the one bringing sickness in the household".*

Another caregiver who could not disclose her child's HIV status due to fear of an impact that could have on her marriage said:

> "*my husband is playful, and he despises me. If I tell him that the child is HIV positive, he might reject me because he is only coming for his child." Similarly, another participant said "I am just scared. I just think he may divorce or reject me accusing me of infecting him with HIV. He will conclude that I have been sick for a long since my children are HIV positive."*

Posse, Meheus, van Asten, van der Ven and Baltussen (2008) contend that fear of divorce is one of the main reasons why there is nonadherence to ART as one partner does not want the other to know that he/she is HIV positive. If the child is infected with HIV, one parent may keep it from the other as a way of safeguarding their marriage. Nonadherence will eventually come because covering the secret could be a challenge sometimes. Azia, Mukumbang and Van Wyk (2016) argue that one of the unintended consequences of disclosing someone's HIV status is divorce.

Some of the caregivers do not want to disclose the HIV status of their children as they are afraid of being divorced by their husbands and end up not being able to look after the children alone. Participant 9 said:

> *"I cannot be able to look after these children if this man says he does not want to be with me anymore. I cannot tell him the HIV status of the child."*

Women are generally afraid of consequences of sharing the HIV status of their children to their husbands. This was reiterated by Participant 14 who said:

> *"After disclosing the pregnancy, the father of the child refused to take responsibility. Following the birth of the child, he agreed that the child was his and he begun to take responsibility. As he wished to see his child, I could not deny him the opportunity. However, if the time for medication arrives, I stop giving the child*

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if the father is around. I do not want the father of the child to know that the baby is HIV positive as that may have negative consequences."

Participant 21 indicated fear of being labelled a careless woman if her relatives discover that the child is taking medication for HIV/AIDS. She would have to devise a plan to hide the medication and only give the child medication when no one was watching her. The Participant 21 says:

"*My mother and brothers keep on talking about how careless I am for being pregnant while in high school. They dislike my child and mock and laugh at me for giving birth to a sick child. My Mother always shouts at me for no reason and wants me to take the child to her father's place. I am afraid that if I leave my child with the father, she may not take medication completely. No one supports me in looking after the child so I hide the child's medication from the family members in fear that they can throw it away."*

Most caregivers are afraid of being discriminated by family members. A study by Wasti, Simkhada, Randall, Freeman and van Teijlingen (2012) conducted in Nepal concludes that the fear of being victimised and/or rejected by their family or community patients and resulted in caregivers did not disclosing HIV status and tended to flout instructions on ART adherence for themselves and those they took care of. Findings of this study agree with what was found by Kheswa (2017) that in South Africa, there is non-adherence to ART because of fear of the consequences of disclosure. People are generally afraid of what could possibly happen if other people learn that they are infected with HIV or their children are suffering from the disease. They end up not going to health facilities to collect drugs or to go for counselling session as they do not want anybody to know that their children are HIV positive.

Mahlalela (2014) argues that fear of what could happen after people learn about another person's HIV status is a hindrance to ART adherence in South Africa. If adults who are responsible for ensuring that children under five years are taking ART are afraid of consequences of disclosure, they are likely to keep away from where ARTs are obtained. Kahema, Mgabo, Emidi, Sigalla and Kajeguka (2018) asserts that in Tanzania, non-

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adherence to ART was common among women or men who did not disclose their HIV/AIDS status as they were afraid of taking medication in the presence of their partners. Similarly, in this study, some caregivers who had not disclosed the HIV status and that of their babies to their spouses and family members felt that it was proper to stop ART or change medication with a view to conceal HIV statuses of the children.

In a situation where a woman does not live with the husband, but a child often goes to visit the father during holidays or weekends, the mother makes sure the child stops taking ART. This is because the mother does not want the father of the child to know that the child is HIV positive. Participant 14 states,

> *"I cannot let the child go with medication to his father's place because he (father of child) thinks that the child has no virus. The father has no virus. Only the child and I are infected with the virus."*

Participant 13 said the same thing saying*:*

> *"When the child visits the father, I do not give him the medication because he does not know that the child and I are HIV positive. So, he will be surprised what the medication is for and how come his child is HIV positive".*

Another participant whose child often goes to his father for holiday concurs that she does not give the father ARTs as she does not want him to know the status of the child: "No, the medication I keep here at home." Nonadherence to ARTs does not only occur when a child goes to visit another parent, but also when he is taken to grandparents. One participant took her child to her grandparents and decided to interrupt medication in order to avoid disclosing the child's status: "I have established that when I give her grandmother the medication, she will want to know the purpose of medication." Similarly, Participant 11 was reluctant to disclose the status of the child as she did not want the mother in law to know the purpose of ART and said:

> *"I am always gripped with fear of my child being HIV positive. This problem starts when the child gets sick. My mother in-law shouts at me and concludes that it is because of the medication I am giving the child every day and wants to know its use. I am still confused how a child born without HIV got positive. If I tell my mother in-law about the purpose of the medication, I will be*

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> *humiliated or embarrassed in front of the whole family… can end up being chased away from home. I have nowhere to go. My step mother will not accept me and my sick child into her house."*

This means, whenever the child is with the mother, there is adherence to ART, but when he/she goes to his father, grandmother, mother-in-law or another relative, there is nonadherence as one parent does not want to disclose the HIV status of the child to the other.

The situation of nonadherence to ARTs among caregivers of children under five years is not only because they do not want the other partner to know the status of the child. They do not want partners, relatives, friends and other people to know about the status. One participant said, If I am seen giving my child HIV medication, "this makes us exposed to people you may not want to know that you are infected."

One participant who lives with a man who is not the father to her child does not adhere to giving the child ARTs as she does not want the man to know that the child is infected with HIV/AIDS. Participant 11 further said:

> *"I stay with another man who is not the father of this child. The house is just one room. I am afraid the child will see what is not proper and when I give the child medication the man, I am staying with will want to know what it is for as I did not tell him anything. He does not know anything. He does not know that the child and I are HIV positive."*

Caregivers will go to extremes to make sure that their partners do not know their HIV statuses along with that of children who are on ARTs. One participant went as far as taking ARTs in the toilet and stop giving the child to make sure that the partner does not know. The participant said

> *"I can even take my medication in the toilet. For the child I gave the medication the first month. This other time I had stopped."*

In most of the caregivers interviewed in this study, it was the mother who knew the HIV status of the child and she kept it from the father. In two cases, fathers knew that their

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children were HIV positive, but, they did not want the mothers to know that their children were taking ARTs. In the first case, Participant 1 said:

> *"when the mother is present, the daughter who is infected with HIV will not take ARTs because she (mother of child) will know that they are meant for HIV patients even though I did not tell her."*

In the second case, the father did not disclose the HIV status of the child to the mother as he was afraid that "she will no longer take care of the child properly if she knows that the child is HIV positive. Is better to be suffering from HIV/AIDS, Participant 24.

Parents of the child who takes ART are very particular about non-disclosure of their child's HIV status. They rather skip times and days of giving the child ARTs in order to maintain his/her status secret. Parents do not want people to know the HIV status of their children as that would result in discrimination. Sometimes, parents are reluctant to go to collect ARTs because they are separated by health practitioners according to medication which they come to collect. Participant 2 said, "sometimes when I think of going to the clinic, I get bored because they (medical practitioners) separate us as consulting patients." Similarly, Participant 2 went on to say:

> *"When you arrive at the clinic, they speak loudly indicating that those who came for service like: such as bandaging and chronic medications must be on the other side. This arrangement exposes us to people you may not want them to know that you are infected with HIV."*

In other words, caregivers of children under the age of five who are HIV positive are unenthusiastic to go to clinics as there is a risk of other people knowing that they are at a medical facility for ARTs.

Participant 12 expressed fear of nurses when she took back the ill child to the clinic she said:

> *"I never informed the nurses about my status. I was afraid that nurses might rebuke me like what they do to other women who they call careless mothers. I am a weak person. I do not like to be shouted at because I easily become emotional and cry. I*

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become so confused and at times forget to give the child medication. When I look at my child, I fear for his life."

Similarly, participant 11 was afraid of going to clinic because nurses would yell at her:

"I did not go to the clinic because I was afraid that the nurses will shout at me for being lazy to give my child medication."

Kheswa (2017) contends that in South Africa, some people are reluctant to go and collect ART from hospitals because of poor service they get from staff members. This includes treating all patients in a way that makes people at the hospital know that this person has HIV/AIDS, or he is collecting medication for a child who is infected with the diseases. As caregivers prefer keeping the status of their children or themselves a secret, they end up not going to collect medication and that results in non-adherence to ART (Posse et al. 2008). Mahlalela (2014) concurs that treatment which people who goes to health facilities for ART get is poor as they are sometimes made to wait long hours to get the medication and other relevant service. This deters caregivers from frequently visiting hospitals for ART for their children who are HIV positive. Care givers are afraid of being discriminated along with their children.

Wasti, Simkhada, Randall, Freeman and van Teijlingen (2012) postulate that HIV parents and caregivers often experience some form of discrimination and HIV-related stigma which negatively affect ART adherence behaviours. Young et al. (2014) argues that non-adherence to ART was due to individual-level barriers related to patients such as fear of disclosure and its consequences, denial of HIV diagnosis for children by parents. Boyer Clerc, Bonono, Marcellin, Bile and Ventelou (2011) also argues that most of the disruptions to ART adherences were unplanned by patients or those who provided services but were circumstantial. In this study, some of the nonadherence are planned as the caregiver particularly the mother tries to avoid repercussions and sanctions from the communities for having given birth to a child infected with HIV.

4.2.1.2 Traditional and Religious Beliefs

Traditional and social beliefs were identified by participants in this study as causes of nonadherence to ART in caregivers of children under five years of age. Some caregivers would adhere to HIV medication prescribed by health practitioners. However, they stop at

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some point as they go to traditional healers who are also known as *Sangomas* for advice. Participant 6 whose child was taken to a *Sangoma* said:

> *"I have been made a fool by my mother in law who is very fond of Sangomas. We started to sort advice from the Sangoma and a culprit was identified who was accused of bewitching the child. The child was then given medication. The Sangoma gave her medication to stop the ailment. Looking directly at the place where the child was sleeping, mmm … if the child was not sleeping you would be seeing her, the child has been incised all over the body. "*

When a child who is HIV positive taking ARTs is taken to a *Sangoma,* that literally means stopping ARTs and replace them with African herbs prescribed by traditional healers. Grandmothers are accused of disregarding ARTs and prefer African herbs they get from *Sangomas.* Participant *6,* who was giving her child ARTs consistently blamed her grandmother for discarding the medication in preference for something else from *Sangomas*:

> "*I showed her the medication, they say a child is for grandmothers, not medication from the West. She took the child to a Sangoma. I can see I allowed them to make me a fool whereas I knew my actual story."*

Some mothers may not agree with grandmother's idea of discontinuing ARTs. But, they will be forced to comply as the grandmother will be looking after the child on their behalf. A participant whose child was living with a grandmother who took the child to a *Sangoma* said, "you have to follow all her (grandmother) instruction so that she may not decide to stop looking after the child. As a mother you have nothing to say."

Similarly, another Participant 13 whose child was living with a grandmother who believed in traditional medication not ARTs said:

> *"She does not know that one is not supposed to stop taking medication because she never gave a chance to explain and she personally believes on traditional medication, the same applies to me when I get sick, I start by consulting the traditional*

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doctor. When I come here it is after they have established that their medication does not work."

Sometimes caregivers do not adhere to ARTs because they consult old people to find out what the child is suffering from, they consult even if they know that their children are HIV positive and they are on ARTs. When they consult traditional healers or old people, their children will be diagnosed with another disease where they will be forced to stop giving ARTs. This was explained by Participant 13 who stopped giving her child ARTs *and attend to other traditional diseases diagnosed:*

This child is always sick most of the time, initially her grandmother thought she had gokhonya, I took her to a certain old lady, we came back with medication to sprinkle on soft porridge. Her grandmother then instructed me to stop giving her medication. She then got better, suddenly she got ill again, and she said she had Ngoma and I again stopped giving her medication."

Posse et al. (2008) posit that tradition makes it difficult for people in developing countries to access ART. Some people in African countries believe in traditional approaches rather than clinical ways of treating some diseases. The same argument is taken to HIV where caregivers are reluctant to adhere to ART and prefer to consult traditional healers and use herbs that they get from there. Peltzer, Preez, Ramlagan, Fomundam, Anderson and Chanetsa (2011) postulate that in the South Africa context, some HIV patients have a tendency of complementing ART with some traditional medicine while others stop taking ART completely in preference of some alternative cultural medication. That subsequently result in non-adherence of ART by HIV adult patients or caregivers who are responsible for giving medication to a child. Azia et al. (2016) echoes the same sentiment that in numerous developing countries, non-adherence to ART by both adults living with HIV/AIDS and children they care for is a result of traditional medication. Some people prefer traditional medication compared to Western (Peltzer et al. 2010).

Some caregivers do not adhere to ARTs because of religious related beliefs. They stop giving ARTs and give the child church related medication. If that does not work, they seek medical attention again. One participant whose child is looked after by her mother said,

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> *"She goes to the church with the child where she gets tea and drink as medication or remedy of the condition she is experiencing at that time. It then gets worse and ultimately she will call me to take the child to the hospital."*

Another participant whose mother looks after her child who is HIV positive does not believe in ARTs, but prayer. The participant said, "she (her mother) does not believe that there could be a problem beyond her prayers." In other words, she believed that prayers are more important that adhering to ARTs. Another participant is not adhering to ARTs with her HIV positive child because of where she stays with mother in law who strongly believes in prayer. The Participant 18 said:

> *"I have just one problem, where I stay is a large family of my mother in law, who attends Zion Christian Church. I have told her that I am HIV positive and my child was HIV positive and she just acknowledged my disclosure. However, it is not easy to find yourself taking treatment and the child as well."*

Wanyama, Castelnuovo, Wandera, Mwebaze, Kambugu, Bangsberg and Kamya (2007) state that a belief in divine healing among HIV/AIDS patients in Uganda prevented them from adhering to ART. An adult who cares for a child who is HIV positive is likely to avoid giving the child ART if he/she believes that prayer or any other form of divine intervention is better than ART.

4.2.1.3 Forgetting to give the child Medication

The researcher found that one of the factors that contribute to nonadherence to ART in caregivers of children under five years of age, living with HIV is forgetfulness. Some caregivers forget to give medication to their children. One participant said:

> *"sometimes I simply forget and when the time passes and then just tell myself that I will give the medication to the child the following day." Two other participants reiterated the same view saying, "I just forget" and the other said.*

The situation of caregivers' forgetting to give children medication was cited as one of the barriers to adhering to ART in India (Mehta, Ekstrand, Heylen, Sanjeeva and Shet 2016). Parents and other caregivers who had the responsibility of ensuring that children who were HIV positive and were supposed to take ART consistently forgot to give them medication

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in India (Mehta et al. 2016). Similarly, in the South African context, Azia et al. (2016) contend that people taking ART in the Western Cape province had a tendency of forgetting to take medication in order to reduce viral load in their bodies. In a situation where an adult forgets to take his own medication, one can just imagine what would happen if that same person has a responsibility of ensuring that a child who is under five years adheres to ART. The situation of nonadherence to ART renders the medication ineffective as there is no continuity which is essential when a person takes that medication (Biressaw, 2013).

Sometimes caregivers forget to pack children's ARTs when they travel to their relative's homes. Participant 7 said,

> *"For the first time it was because I had visited the child's aunty for the whole month, and I had left the medication at home. It was then that the child experienced diarrhoea which never stopped, and I came, and the child was admitted here at the hospital."*

Some parents forget to give medication to someone who will be looking after the child at the time. One participant who is separated with the father of her child explained that sometimes nonadherence to ARTs happen because she forgets to give medication to the father when he takes him for weekends. Participant 15 also said:

> *"I often forget to give medication to the father of the child when he picks up the child if he is not working on weekends and this makes her to skip medication."*

Another participant reported a different experience. She does not forget to give the child ARTs, but the father does. The participant, Participant 15, said, "*I often leave before the right time to give the child medication. If I request his father to give him, he often says he forgot each time I ask him."* Another participant experienced a similar situation where she went to work and ask other people at home to give her child ARTs, but they forget. Participant 15 said, "sometimes when I am attending workshops far away or when I am working far away from home, they often fail to give him medication." This is similar to what Niilonga and Maano (2017) found in their study that due to some work-related responsibilities where a person travels for a conference or workshop, adherence to ART by adults and children becomes a challenge. In order to overcome this challenge, Mehta et al. (2016) recommend that caregivers responsible for ensuring that HIV positive children

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adhere to ART have to make that a priority. Otherwise, the whole process of giving a child the medication, interrupt it and resume again renders the drug ineffective towards controlling the virus in a human body. This is because strict adherence to ART is paramount to a successful treatment outcome (Okoronkwo, Okeke, Chinweuba and Iheanacho (2013). In another scenario, Niilonga and Maano (2017) state that some adults forget to take ART to give them to their children because of alcohol abuse. A person could drink alcohol excessively and end up forgetting the obligation of giving ART to children who are HIV positive.

As a result of different duties and responsibilities that caregivers have, they tend to forget to give ART to children. Sometimes it is grandmothers who forget. This was stated by one participant who said"

> *"the issue is I take the child to crèche in the morning and after school the child goes to her grandmother where I pick her up after work. Sometimes I forget to give the child medication and sometimes it is grandmother who forgets to give ART to the child."*

Another participant, Participant 9, who is very preoccupied with work responsibilities gives her elder son ARTs to give to the child, but he forgets.

> *"I have four kids. Two are HIV positive. Their father is dead. When you see me here as I am, I am a father and a mother at the same time. I notice that for children to grow well with adequate food and clothing, I should go out and look for a job. Now I got a job far from home. I come back home every weekend. I leave medication with the elder brother to give the child and sometimes he forgets to give the child."*

One parent acknowledged that it is her responsibility to make sure that a child takes ART but he is failing to adhere to the schedule of medication because of work. Participant 5 said, "it is mine (responsibility of giving child ART), but mmm…. Remember I will be at work working for the very same children."

In another case, the mother reported that the child is not consistently adhering to ARTs because of the father's selfishness and forgetfulness. The father is shy to go and take his

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own ARTs from the local clinic. As a result, he takes ARTs which the mother collects for the child and he sometimes forget to give the child. Participant 7 also said,

> *"If I am given two prescriptions, my husband takes one container from me for himself. He is just shy to go to the clinic and he sometimes forgets to give the child."*

Okoronkwo et al., (2013) and Bauleth, Van Wyk and Ashipala (2016) conducted studies in Nigeria and Namibia respectively and came up with a common finding of forgetfulness as one of the main barriers to adherence to ART. When caregivers forget to give children ART, it poses a great risk to the health of the child and often make the viral load difficult to control (Demeke and Chanie 2014).

4.2.2 Personal Factors

The researcher found that personal factors are among elements that contribute to nonadherence to ART in caregivers of children under five years of age, living with HIV in selected hospitals of Vhembe District. These personal factors include caregivers' lack of knowledge and understanding of giving ARTs to their children and deliberately giving ARTs inconsistently.

4.2.2.1 Lack of Knowledge and Understanding of ARTs

Some of the participants state that they lack comprehensive knowledge and understanding of giving ARTs. Participant 3 said,

> *"Nurses said I was not giving medication to the child in a proper way. The medication they are talking about I do not know them because the medication they give for the child I make sure that the child gets it up to the end".*

Another participant openly declared that "It is because of lack of knowledge" of how to give ARTs to children that makes it difficult for her to adhere to the medication. Another participant, Participant 13 showed a misunderstanding of the way ARTs should be given to the child:

> *"I thought that the child would get better quickly than the way he felt, and I will then continue with the medication thereafter*."

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This means the caregiver stopped giving the child ART because of deteriorating health. The caregiver hoped the child would recover so that she would resume the course of ART with the child.

Lack of information about ART was the common barrier cited among the 19 studies conducted about barriers to accessing ART in developing countries (Posse et al.2008). Care givers require comprehensive information about ART, how they work, why they should be given to someone infected with HIV/AIDS, how often they must be taken and the aspect of adherence. If caregivers are not made aware of that basic information, they may not see the perceived benefits of giving the medication to their children and they will end up not adhering to the drugs (Kheswa 2017). If caregivers are given the information, that reduces the rate of nonadherence of ARTs.

Adherence of children to ART in South India was attributed to the fact that caregivers had received comprehensive information through counselling sessions at their respective centres (Mehta et al. 2016). This was in accordance with recommendations laid down by the Indian national guidelines that caregivers who give ART to children must be given enough knowledge. Vreeman, et al., (2018) postulate that ART adherence among children in Kenya improved significantly because of knowledge and skills about HIV/AIDS which was taught to people. Several studies have identified the importance of giving caregivers and patients the correct information about the disease, its medication and instructions of using ARTs (Ahmed et al. 2017; Mehta et al. 2016). In this study, information related factors caused caregivers to disrupt or even stop children from taking ART. Care givers are misinformed and they lack good understanding of giving medication to their children living with HIV.

As a result of lack of correct information about ART, caregivers in this study ended-up making wrong decisions which led to the disruption of the medicine process. This was exemplified by Participant 6 who says that:

> *"My mother in law said we should stop for a while since it might amount to overdose." The mother in law in this case lacked knowledge about adhering to ART and that resulted in caregivers making a wrong decision of not continuing to give the child ART."*

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Participant 8 also lacked knowledge and that resulted in making a wrong decision based on what friends say rather than following what was prescribed by health staff at the clinic:

> *"Looking down in shame. I have been misled by friends who told me that if you are HIV positive and once you start taking medication you reduce your life expectancy. The medication contributes to people's ill health, so they said. It is then that I decided to give my child medication once after 2 or 3 days. I realised later when I took the child back to the clinic that I have made a wrong decision. This information I had was wrong and made me risk the life of my child …. there is nothing else I could have done. It was just a matter of ill advice from friends".*

This shows lack of knowledge about the disease and ART programme as expressed by Participant 12 when asked about the effects of the disease on the child, "I did not understand. It is also because of lack of knowledge in the programme and disease." In another related incident, Participant 12 took a wrong decision and changed the medication of the child. The participant said,

> *"I never thought that it was necessary for medication to be changed for the others." Participant 13 made a wrong decision based on misunderstanding of ART where she thought that the medication is not taken routinely. She thought that they should recover naturally."*

Participant 13 said*:*

> *"Nothing. I had thought that the child would get better quickly on what the child was feeling, and I will then continue with the medication thereafter."*

In a different case, a caregiver lacked knowledge and understanding of the importance of checking medical records in order to gain knowledge of the HIV status of the child. This was stated by Participant 10 who says:

> *"I remained with this child without knowing anything until the time the child got sick and I brought the child to the hospital. Following medical examination, it was then that it was*

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confirmed that the child was HIV positive. When they asked for the child clinic card, I did not have it by then. They asked where the child was born. And I said in this very same hospital. When they checked the records, they established that the child was born with HIV and now the child is taking medication to that effect".

Some of the family members were influencing caregivers to make wrong decisions on ART medication knowingly or unknowingly, particularly grandmothers. This behaviour by family members is consistent with what Coetzee (2015) states that a child is in the hands of caregivers and parents who are responsible and accountable for all the needs of the child about ART adherence. Whether a caregiver makes a right decision (adhering to medication) or wrong decision (discontinuing medication), he/she takes full responsibility of what happens to the child

Merzel, Van Devanter and Irvine (2008) argue that caregivers deliberately or unknowingly discontinued the programme for medication when they thought the medication was not bringing desired changes within a short time or when the child's health deteriorated. Sometimes caregivers are misinformed by other people and they end up making wrong decisions. Such wrong decisions will be normally taken without consulting health staff. Consequently, the child's condition will not improve, but there will be complexities caused by lack of consistency in the way ARTs will be taken.

Vedhanayagam, Rajagopalan, Rajendran, Sengodan, Sengodan (2016) argue that in India, nonadherence to ART by people living with HIV/AIDS resulted in complexities in medication and that resulted in those giving care to decide either alteration of the medication programme or discontinuing it with the intention to ease the suffering of the patient. Azia et al. (2016) contend that side effects of medication on patients led caregivers to seek for alternative medication to get the patients well or relieve the suffering. This misconception is reflected in this study when grandmothers instead of adhering to ART they seek for alternative medication which disrupts the programme and worsen the situation. All these problems are caused by a lack of understanding of the HIV medication.

Kahema, et al. (2018) emphasise the importance of understanding of ART and the HIV/AIDS diseases by caregivers by arguing that the inability to understand and follow instructions related to the treatment supposed to be given by health providers reduces the

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chances of adherence among patients and caregivers. Lack of understanding of ART led to some of the caregivers giving children increased dose than prescribed. This caused the medication to finish sooner than expected. This lack of understanding is illustrated by Participant 5 who says that, *"I have demonstrated to them as to how they should measure the medication, but I am now surprised why the medication is finished now at this time."* This reaction shows that the participant did not follow the instructions that is why the medication got finished way before schedule but tries to cover up for the lack of understanding.

Similarly, when Participant 18 was asked whether she still remember what she was advised to do when given medications. The participant indicated that she really could not claim to know everything about the ART: "Part of it I remember. I cannot really say I know everything." In the same vein, Participant 19 who did not know what to do when tablets were finished says, "No. It is just that he had no medication … I was not aware that when they get finished, I have to go and take more." The same lack of understanding of ART was expressed by Participant 25 saying,

> *"I did not know that I had to go back to the clinic to collect medication when the first lot got finished. I only knew when the child got ill long after the medication was finished."*

These assertions confirm that some caregivers did not understand the ART programme and the detriment of HIV/AIDS to the children. In some cases, those care givers who were aware of replenishing medication were ignorant of who should collect. For example, Participant 25 confirms this by saying:

> *"I thought pills are taken by elderly people only. They gave me the requisite medication I just forgot to go back and collect more when they got finished."*

The assumption by Participant 25 brings to light how misinformed caregivers can improve adhering to ART and putting the life of children at risk of HIV/AIDS. According to Najjar, Amro and Kitaneh (2015) nonadherence in Israel was linked to knowledge of patients or caregivers. It was concluded that patients and caregivers with good knowledge of chronic diseases were likely to adhere to the treatment programmes than those who lacked knowledge. This concurs with the view of Wachholz and Ferreira (2007) who postulate that

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children who are looked after by educated people or caregivers who are knowledgeable about HIV/AIDS and ART are likely to adhere to medication compared to those looked after by uneducated caregivers. When a caregiver lacks comprehensive understanding of the way ARTs work, that results in nonadherence which was very prevalent in this study.

4.2.2.2 Deliberately Giving ARTs Inconsistently

Some participants were aware of how ARTs work. They knew that consistently adhering to the medication was an important factor, but they deliberately skipped giving medication because of reasons which include laziness and burdensomeness. Participant 20 said,

> *"After finishing the medication, I then stopped collecting more from the clinic because I was lazy to walk with two kids when it is hot and because one is still very young, he needs to be carried on the back."*

Participant, 19 said:

> "*After giving birth to the last born, I thought that the issue of gi ving medication to this child was a burden to me, more especially when I noticed that the younger one has HIV virus as well.*

"Participant 15 echoed the same sentiment that it is burdensome and troublesome to administer ARTs:

> "*You know you are always troubled by administering medication timeously."*

As a result of the perceived laziness and burden of giving ARTs, caregivers either do not consistently give medication to children with HIV or they stop giving completely. In Namibia, Niilonga and Maano (2017) state that one of the barriers preventing male adults who were HIV positive from adhering to medication was because it was not easy for them to stick to the routine of ART as it felt burdensome. In a context where adults fail to adhere to ART because they are lazy or the routine of taking medication is burdensome results possess a great risk to children who depend on those adult caregivers to take ART. The situation results in nonadherence to ART which makes viral load more active in the children's body and more difficult to control (Posse et al. 2008). The findings were also consistent with the findings in a study by Mehta, Ekstrand, Heylen, Sanjeeva and Shet (2016) on nonadherence among caregivers, claimed to forget giving medication, but upon

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being interviewed, they revealed that they were always busy with other schedules and did not prioritise giving medications to children.

Further investigations also revealed that such situations were more prominent where the child was either an orphan staying with distant relatives (Mehta, Ekstrand, Heylen, Sanjeeva and Shet, 2016). Similar findings were also made by Mutwa, Van Nuil, Asiimwe-Kateera, Kestelyn, Vyankandondera, Pool, Ruhirimbura, Kanakuze, Reiss, Geelen, van de Wijgert, and Boer (2013) qualitative study on nonadherence to ART in Rwanda in which they established that orphans under the age of five years given medication on an irregular basis on the excuse of busy schedule by caregivers who always blamed the deceased parents on the HIV state of the child. John (2013) also report discrimination among children as cause to nonadherence to ART among children in Namibia in which caregivers gave preference to some children when giving medication. This was usually prevalent in families where there were more children living with HIV and were from parents with different financial statuses or where some children received grants and others did not. Children with parents with better financial statuses or were receiving social grants were more likely to receive better treatment and more attention than those who had poor parents.

4.2.2.3 Confusing information from medical staff on HIV/AIDS and ART programme

At times misunderstanding by caregivers is due to the way the information is communicated to them by health staff members when their children are initiated to ART. Participants 3 and 25 shared confusing information which they received from health staff. Participant 3 says:

> *"one will come and say the child is sick because of hunger, another one will say it is stunted growth, another one will even talk about the sickness which attacks matured people, on the other hand the child has soars on the bums and cannot sit, are these sicknesses many for a small child like this."*

Participant 25 says:

> *"They gave me medication. They might have told me to come back but I did not go back because I never heard the pharmacist saying, I should come back and collect medication."*

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These two views indicate the gravity of poor communication between the health staff and caregivers. Health care staff take it for granted that caregivers understand everything their say. With the prevailing stress and anxiety of caregivers particularly mothers on the news of their children being infected by HIV, it is expected that the confusion should be cleared before they leave the health care facility.

Storey, Seifert-Ahanda, Andaluz,Tsoi, Matsuki and Cutler (2014) argue that comunication with HIV/AIDS patients, parents and caregivers is important in promoting the uptake of ART and its adherence as well as promoting good behaviour free from further risk. Health care providers should communicate information about HIV/AIDS to the patients or care providers in an unambiguous manner so that right decisions and actions that promote understanding of the disease, risks and its medication can be taken (Storey et al. 2014). Contrary, this study found that several caregivers confessed ignorance to some important processes and treatment by saying that they were not given enough information at the clinic. Some also claim that if such information was communicated, they might not have understood it as it was communicated in a manner that did not make any sense to them. According to Storey et al. (2014) communication by health care providers is intended to assist in creating and sustaining a positive, supportive environment within which positive HIV-related behaviours can take place while promoting required behaviour among the patients and stakeholders.

Although communication may have effect on the virus itself, it can however, have major effects on knowledge, attitudes, social norms, risk perceptions, and behavioural decisions that affect the audience when the virus is transmitted, where and when testing and care is sought, how care is delivered, and how well adherence to ART is maintained (Storey *et al*. 2014). According to Population Council (2001), communication difficulties among health care staff and HIV/AIDS patients or care givers can arise from language and cultural differences as well as when the patients or caregivers' attitudes and expectations regarding HIV and treatment are different from those of the providers. In this study, problems of communication between the health providers and caregivers are caused by several factors such as being defensive about their lifestyle leading to negative attitudes towards adhering to ART.

Caregivers from marginalised communities are often conscious about stigmatisation and this would also interfere with how they understood what was said by nurses. The findings of this study are consistent with what was found by Mulqueeny and Taylor (2019) that

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many patients expressed dissatisfaction with communication and treatment provided to them by some health workers. According to Mulqueeny and Taylor (2019), communication failed due to various staff members' attitudes when addressing and answering patients or care providers' questions and concerns about processes and treatment.

4.2.2.4 Non-adherence Due to Stress

According to Azia et al. (2016) emotional distress can disrupt peoples' moods and their ability to concentrate on taking their ART. In this study some participants expressed their lack of effort in adhering to their children's ART which was prescribed due to their emotional distress resulting from a number of factors such as stigmatisation, victimisation by spouses or relatives, financial burdens, rejection by family and societal members, the deteriorating status of the child as a result of the HIV status of the child. Several extracts from participants confirm this:

Participant 20 says:

> *"I had an acute stress which led to a cul-de-sac. I also looked at the point that the child was going to suffer due to continuous medication for the rest of his life. Initially, the child become more seriously ill that I spent sleepless nights by the bedside. When the breathing of the child decrease, I screamed and called my mother, and this was too bad at night. During the day, it was better as I would rush to the clinic with the child, I suspected that I was given a wrong medication and stopped giving it to the child."*

Also, Participant 7's utterances indicate psychological stress due to what happens between her and the father of the child as well as the families:

> *"Sometimes I feel so bad about the condition of the child and what happens between me and the father, I am not married to him but he wants to bully me as if I am the one to blame, he is also HIV positive, he is the one who first had the virus, it is my family who keep forcing me to stay with him, I will leave him alone, if they keep on forcing me, I will go and stay alone far from them. This man is a problem, at times he gives the child too much medication and this affects the child every time and I have to go*

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back to clinic where nurses insult me for attempting to kill the child by giving too much medicine."

Participant 8 explained how taking of medication for the rest of the life by the child stressed her and disrupted the administration of ART to the child:

"I just felt that they could be right when I think of taking pills for the rest of my life and to give medication to the child and this really stressed me. I did not expect to be in this situation in my life. What stresses me is that this was my first pregnancy with someone I trusted, but look, for the whole of my life and my baby on HIV treatment. … the counselling programmes were fine but still, it does not make sense to me that my life is upside down like this, stress will kill me and not HIV."

This extract shows the appalling conditions in which caregivers particularly mothers find themselves and the challenges they must overcome. This usually led to stress which also impinge negatively on how the caregiver adhers to ART of the child. According to Mthiyane (2013) the consequences of disclosure of HIV status include stress due to perceptions of discrimination by family, community and friends, which becomes a barrier to health care and social support, and this may subsequently cause serious disruptions on the adherence to medication instructions and programmes. According to Kheswa (2017) nonadherence was caused by the fact that adults taking ART and their children could be distressed by a lot of things which include stigmatisation and denial by family members.

4.2.3 Poor Access to Medication

Access to drugs by caregivers was found to be as one of major factors to nonadherence to ART among children below the age of five years in Vhembe district. This factor has been described under four sub-themes namely, distance between the mother and child, shortage of medication in health facilities and economic problems.

4.2.3.1 Distance between mother and child

In this study, it appears that most of the caregivers were mothers of the children living with HIV/AIDS and they were staying in different locations with their children who stayed with relatives particularly mothers-in-law. Mothers kept medications with them instead of giving to the mothers-in-law and the children will only get medicine when they are sick and

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brought back to their mothers. Participants 1, 16 and 5 alluded to this fact. Participant 1 says;

> *"I do not stay in the same place with this child. The child is brought to me when he is sick. When the child is healed, they take the child back."*

Participant 16 are confirming the same situation with that of Participant 1:

> *These other children stay with my mother. I stay with the last born and his father. I have a problem when these children visit. I am unable to go and get medication for them."*

This shows that the ART programme is seriously disrupted because the caregiver is not the one who stays with the child and the guardian of the child is also ignorant of the HIV status of the child. Participant 5 also faces the same challenges to those of Participant 1 but is a foreign national. For Participant 5, the child stays in Zimbabwe being looked after by siblings:

> *The child remains in Zimbabwe with her elder siblings what they do is to call me, or phone and I will then come and take the child as now the child is sick. … most of the time I send the medication in time …., it is just that if I am not staying with the child there would be many obstacles*."

Besides being separated from the HIV infected child on ART, the caregiver faces another challenge of delegating her duty to siblings who do not have knowledge and skills in caregiving. The children are unnecessarily put at risk when separated from their mothers and the duty of caregiving shift to those who are ignorant. This disrupts the ART adherence as caregivers are not doing their duties as agreed during the initiation programme. Among factors documented in reviewed literature, little has been said about the link between delegation of responsibility of ART giving and adherence among under the age of five years.

4.2.3.2 Shortage of Medication in Health Facilities

Participant 17 who stays very far from the hospital collects her medication from a local clinic which usually runs out of supplies of medication particularly during the raining season

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when the whole district runs out of ARTs. She waited for weeks to get the drugs for the child. She says:

> *"Our clinic usually runs out of drugs due to many people who collect from it. I once waited for drugs for two weeks when they got finished. The nurses at the clinic could not assist as they were not able to go to the next hospital to collect ART due to damaged roads. I could not get help from other patients as I was not sure whether the drugs were like those my child used."*

Participant 22 also faced a similar situation when the clinic ran out of supply of ART:

> *"This has been the worst part of my life; I was afraid that my child would fall sick and die. I was in a queue to collect the drugs when the nurse told us that the drug has been finished and we should come back after two days. The following day it rained heavily, and the bridges were washed away making it difficult to go to the clinic. The child did not have medication for three days, just imagine three days, I was afraid that something bad was going to happen to him...but thank God, I finally got the drugs. From that time, I learnt that I have to collect the medication before it got finished."*

Participant 19 said:

> *"In most cases nurses at the clinic give me a medication for the child which lasts three months, but on this occasion, I was surprised to be given a very small supply of 10 days and they told me to return when the clinic got more supplies. They told everyone who was there that the clinic has run out of stock of one type of drug and could not give us the other. They were not sure when it will be supplied, she asked us to check every day, but I stay very far from the clinic. When there were two days drugs left, I went back to the clinic, and the nurse told me that I was late I should come back the following week as the drugs*

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were not supplied during weekends. On the following week my mother got ill and I had to visit her... I only got drugs a week after. The child had already stopped taking a drug. At times we face these problems, and no one seem to care."

Sokutu (2018) alluded to the short of ARV drugs in several rural parts of South African districts. ARV drugs in South Africa are usually supplied to clinics and hospitals by a contracted supplier and their availability depended on the efficiency of the supplier (Sokutu 2018). Similarly, Okoronkwo et al. (2013) postulate that some HIV patients in Nigeria could not adhere to ARVs due to the unavailability in some health facilities. supply of medication is sometimes inadequate to cater for all the patients who require medication (Posse, 2008).

4.2.3.3 Economic Problems

Economic hardships among the population in Vhembe district have been identified as a major contributory factor in nonadherence to ART by caregivers who were interviewed. The economic factors identified to be interfering with adherence to ART include poverty, unemployment and lack of money for transport. Unemployed caregivers depend on government grants which can hardly support a small child. Poverty and unemployment led to financial constraints among caregivers. Participants pointed out that unemployment meant that they were not able to raise money to travel to clinics to collect drugs leading to nonadherence of ART. Therefore, under such problems it became the caregivers who failed to collect the medication or missed important review meetings with health staff. In some cases, the caregivers had to walk long distances to the hospitals as they could not afford the cost for transport which they described as being exorbitant. Poverty stricken caregivers have no option but to walk long distances to collect ARVs. The following extracts from the selected participants confirm the economic hardships faced by caregivers which prevented them from getting ARVs from the clinics.

Participant 2 who fails to let her child adhere to ART because of acute financial constraints says:

"I stay in a remote village very far from the hospital. It is close to Limpopo River and I always struggle to make my way to the hospital. The taxi price is high, and I am supposed to use two. One leaves me half way and the other takes me to the

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destination. I pay close to R60 and if I miss the first taxi, I will have to hike which becomes even more expensive and unsafe. Even if I have money in the (SASA) grant card, the taxi drivers will not accept it, they want cash. In this rural place it is difficult to get cash. What should I do… obvious, either I walk or skip the collection until I get cash to travel to the hospital? Even if you explain this to the father of my child, he does not care, but blames me for everything."

Participant 14 also agreed that the lack of money to travel to distant clinics to collect ARVs for the child was the main cause for nonadherence:

"It is not that I do it on purpose not to collect ARVs for the child, No one will believe me if I tell you that I do not have cash to pay for transport. I want my child to live, but at times money problems force me to act like this. In my village, there are very few people who can lend you money, everyone is suffering from this financial problem. We cannot even buy enough food due to poverty. The grant money is too little to meet all our needs. At least I am trying, my friends have given up, I will not give up for the sake of my child. I do not want God to punish me."

Participant 15 experienced financial problems as well. She said:

"Things are getting worse and worse. My child will die. What is happening in our province is not good. It seems they want all people to die as we walk very long distance, it is just less than a year when taxi fares from my village to the hospital was R12, but now it is R35 one way. This is too much for unemployed people like me. I cannot afford a good meal. I missed a review and the nurse was unkind about it, they do not care whether you have money or not."

Participant 24 who experienced the same problem of lack of transport money states:

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> *"The father of my child used to support me before he knew that the child was HIV positive, but now, he gives a lot of excuses if I ask for money to go and have refilling of ARVs. I spend all the little money I get in buying food for the child. I buy everything to sustain myself and my child. My parents are dead, my only brother went to look for a job in Johannesburg and no longer talks to me. I do not know when this problem will end. What makes me angry is that even if you explain to the nurses that you did not have transport money, they do not listen."*

These extracts show the extent to which financial challenges have become a major contributory factor to nonadherence to ART among children under the age of five years of age. A study by Najjar, Amro and Kitaneh (2015) in Malawi found that financial problems were among the main problems that rural caregivers and people living with HIV/AIDS in Malawi faced and these severely affected the ART programmes for the patients. In the same study, Najjar. (2015) argue that some unemployed mothers of HIV positive children were deprived of financial support of their husbands or fathers of their children. The mothers were left to bear the burden of looking after the children using meagre financial resources, Kheswa, (2017) confirm financial challenges as a contributory factor to ART nonadherence among patients and care providers in South Africa. Azia et al. (2016) concur that economic factors particularly lack of finance and unemployment were prevalent in disadvantaged communities in the Western Cape province. Mulqueeny and Taylor (2019) affirm that lack of finance leads to the inconsistency in following the ART programme among HIV/AIDS patients.

Poverty and unemployment among the communities from which the caregivers come does not only affect transport money but also the ability of the families to get enough food which is needed for HIV/AIDS patients. Participants 4, 20 and 23 expressed how poverty and unemployment lead to nonadherence to ART among children below the age of five years old.

Participants 4 says:

> *"Even if the medication is there, at times one stops giving the child medication because there will be no food in the house. It is not all the time that we get food. The drugs are not good in*

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an empty stomach especially for the child. It is because of poverty in the village that we sometimes go without food for a long time and you cannot expect me to give the child medication in such a condition, but if there is enough food, I always follow the programme."

Participant 20 also concurs by saying:

"Before I lost my job, I was able to buy food for the baby and I. Now it is difficult because I am not working, and things are a bit difficult. The child is supposed to eat before taking medication, now with only one meal per day, I am forced to skip the afternoon medication so that the child does not suffer from the effects of the medication. I know that this is not good, but I need to protect my child from suffering taking medication on an empty stomach. If she does so, she vomits a lot."

Many respondents reported that they sometimes failed to take their ART because they are poor and unemployed. They live on shoe string budgets and they do not have enough basic food to eat with their children. Participant 23 who is struggling to adhere to ART because of poverty and unemployment says:

"I am not employed, my daughter the mother of this child also does not work and now she stays with another man in the township far from us. She is not sending any food or money for the child. My grandchild and I no longer eat proper meals because there is no food at home. I have no money to buy food. When the nurses gave me medicine, they said I should give the child good food before taking the medicine. I do not know where I will get all that food with the money problem I am having."

The findings of this study on poverty as a contributory factor to nonadherence to ART in children under the age of five is consistent with the findings made by other similar studies; Kumwenda (2011) confirms that one of the main factors which prevented HIV patients from adhering to ART was poverty as they struggled to get food. Shortage of food forced some patients not to continue taking ART drugs as taking medication without having good food upsets the stomach and become a cause of concern (Kumwenda, 2011). Kheswa (2017)

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stresses the importance of proper feeding if the ART is to be adhered to consistently. Similarly, Ehiemua (2014) argues that some patients were given their medication only once per day particularly in the evening the only time they would have food.

In a worst-case scenario, Kumwenda (2011) and Ehiemua (2014) reported malpractices by care providers of HIV/AIDS patients selling the medication to those who have not disclosed their status in order to buy food for the children to avert starvation. This proves that lack of food due to poverty and financial woes among the local communities was a contributory factor to nonadherence to ART in general and to children who depended on adults for their medication. Young, Wheeler, McCoy and Weiser (2014). study also concludes that food insecurity in families occurs when people do not have physical, social, and economic access to enough safe and nutritious foods that meet their dietary needs and food preferences for an active and healthy life and this is becoming a crucial barrier to adherence to care and treatment recommendations for various groups of patients living with HIV and AIDS. Poverty in among people in Vhembe District leads to shortage of food needed by patients on ART.

4.2.4 Medicinal factors

Participants reiterated that they were not adhering to ART because of the negative side effects which they had on their HIV positive children.

4.2.4.1 Negative or side effects of medicine on baby

Participants described medicinal factors that hindered adherence to ART as side effects and sense of feeling better after starting treatment. Participant 11 felt like discontinuing the ART programme due to side effects of the medicine, she says;

> *"I collect medication from the clinic every month however when I give my child to drink, my child vomits. At times I must skip a day to allow the child to recover and continue. At times I feel like giving the child more doses of the medicine."*

Similarly, Participant 4 expresses the same views:

> *"I am hesitant to give the child medication because each time I give the child medication it does not go well with him… this child has to take three medical prescription, two from big bottle*

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containers, and one from the small container from the refrigerator. I start by big containers and the small one is given at the end and one the child finishes, the child just starts crying and vomit at the same time."

According to participant 4, the child loses weight after several days of vomiting due to the medicine: "Yes. I noticed that when the child vomits, she starts to lose weight but if I stop giving the child medication, she gets better, and you feel happy when you look at the child." It is evident that the medication has side effects on the child, but it is also wrong for the caregiver to discontinue medication without the advice from the clinic.

Participant 5 whose child experienced problems because of medication says:

"Most of the time when I send the medication, I find them still available. When I ask them am told that sometimes the child refuses to take medication because they make him feel like wanting to vomit. The child tries to induce vomiting."

Participant 12 was convinced that medication contribute to the nonadherence to ART programme:

"Mmm… these medications also have their own issues you know. At times after giving the child medication, nothing happens. The other times the child would cough and ultimately vomit, then the child becomes calm and keeps quiet... at times when the child does not vomit, she often starts sweating and sleep to an extent that you may even forget that the child is there."

Participants 13 and 22 expressed that they discontinued giving medication when the condition of their children deteriorated and after some time, resumed.

"*I had thought that the child would get better quickly on what the child is feeling, and I will then continue with the medication thereafter*",

Participant 13 and Participant 22 said:

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"…. looking at the child, sometimes the child vomits and get fever when I give medication to the child."

These extracts illustrate how the caregivers based their decisions to disrupt the ART programme in children because of the medication they gave. Report of arbitrary decisions of stopping medication by patients living with HIV/AIDS and care provider are reported in many studies. Azia (2016) maintain that patients could stop taking medication because they believed that the disconformity was due to the medication. Kioko and Pertet (2017) concur that care providers and people living with HIV/AIDs tend to disrupt the medication programme by either stopping the intake of the medicine or not following the instructions due to side effects such as dizziness, loss of appetite, vomiting, headaches, skin rashes and fever. This was prevalent among young children who could not take decision for themselves. A study by Xu, Munir, Kanabkaew and Le Coeur (2017) also confirm that some parents particularly those with low educational level, were more likely to disrupt ART programme upon seeing deterioration of the health of the child after taking medication for a month or so. The tendency was either to reduce the quantity of the medication, give on selected times convenient to the caregiver or stop it completely without advice from the clinic (Xu, et *al.,* 2017).

According to Semvua , Orrell, Mmbaga, Semvua, Bartlett, Boulle (2017) caregivers especially in child-headed families were more likely to disrupt ART programmes on the pretext of negative effects of medication on the health of the child particularly where the medicine induced vomiting, coughing and fever. This was also prevalent among caregivers who stayed farther away from the collection points. The caregivers feared that if health of the child get worse, they were not likely to get immediate medical assistance (Semvua et *al.,* 2017). According to Schachter (2013) negative effects can also be referred to as side effects and these can lead a patient or caregivers to stop medication especially when they are adverse. In this study, participants were worried about the side effects of the children's medication and decided to disrupt the ART programme to avert the negative effects of the medication without consulting health care workers. In their study on ART adherence in Tanzania, Bukenya, Mayanja, Nakamanya, Muhumuza and Seeley (2019) confirm that negative side effects of medicine on children contributed to high prevalence of nonadherence to ART as children either refused to take the medication when they became

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ill and refused to eat food afterwards. The caregivers were afraid of complicating situations that may lead to the premature death of the children.

4.2.4.2 Positive Effect of Medication

Like negative effects, some of the caregivers stop giving ART to their children because they see positive effects of medication on the child. This perception was detrimental to the adherence to ART as caregivers either stopped giving the medication completely or reduced the quantities. Participants in this study were found to have stopped adhering to ART when the child seemed to have improved or the signs of HIV/AIDS disappeared. This study regards feeling better by a sick child as contributory factor to medication nonadherence in some cases. Extracts from three participants (9, 10 and 21) confirm this view:

> **"***One thing that comes to my mind is to speed up the recovery of the child by giving her more doses, this is where I made the first mistake, the child worsened after that and I took her to the clinic where I told the nurses what I did. After a while, when the child recovered. I stopped*" (Participant 9).

> *"… when the child gets better, and the medication is finished I leave the child to allow the child to rest. Initially, I was very happy to see my child getting better and better every time she took medication until her grandmother asked me not to collect more drugs. I thought the medication was too much for the child. However, happiness disappeared after a month when the child start getting ill again" (Participant 10).*

> *"It was when my mother-in-law called me to come and see her at her house that I realised the child who was playing the day before was now seriously sick. I had stopped giving her medication because I thought everything was fine and I was going to start giving the following week. If you ask me, I will not repeat the same mistake again, it's better when there are no drugs then you can blame that not intentional" (Participant 21).*

These findings are confirmed by findings made in other studies conducted in other places where patients did not adhere to ART because they thought they had been healed. Li,

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Marley, Ma, Wei, Lackey, Ma, Renaud, Vitoria, Beanland, Doherty and Tucker (2017) have also found out that patients or care providers had misconceptions of disappearing of symptom and the healing of HIV/AIDS patients in that they regard the easing of signs and symptoms and healing and they stop adhering to medication instructions. Bukenya, et *al.* (2019) also reiterate the negativity of the positive effects of medication on the adherence of ART among Tanzanian children under caregivers who lack proper understanding of the treatment.

According to the findings by Bukenya et *al.* (2019) caregivers looked for the slightest improvement of HIV positive children to use as an excuse not travel to clinic to collect medication particularly among elderly caregivers or those caregivers who did not want to disclose their HIV status. In the case of the latter caregivers, early recover of the child would be a big relief as they will not be caught giving medication and asked to justify. This was done for selfish reasons rather than on assisting the child. The finding by this study was inconsistent with that of Wasti, et *al.* (2012) which established that caregivers continued to give medication regardless of the improving condition of the babies and other patients. Wasti, et *al.* (2012) attributes this to high level of counselling to caregivers that emphasised on the importance of good adherence to ART and the knowledge of HIV/AIDS among the caregivers. This implies that caregivers with good understanding of HIV/AIDS were more likely to continue adhering to ART even when the condition of the babies improved.

4.3 Summary

This chapter focused on data analysis of the data collected regarding the contributing factors to nonadherence to antiretroviral therapy in caregivers of children under five years of age. Data expressing similar ideas were grouped together into themes and sub-themes from which patterns were qualitatively identified before tabulating for final analysis. Four major themes were identified from data analysis, namely: social factors, personal factors, poor access to medication and medicinal factors. Findings were further discussed by explaining the themes and sub-themes. The next Chapter will cover the recommendations and the conclusion of the study.

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CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1. Introduction

The previous chapter presented, analysed and discussed findings of the study under themes and sub-themes which emerged. In this chapter, a summary of key findings of the study is provided together with conclusions and recommendations made. The chapter also has limitations of the study.

5.2. Summary of the Key Findings

The purpose of this study was to explore contributory factors to nonadherence to ART by caregivers of children living with HIV aged between 0-5 years at selected hospitals in Vhembe District. The study was guided by one critical research question: What are the factors that contribute to nonadherence to ART by caregivers of children under five years of age, living with HIV, at selected hospitals of Vhembe District? Factors contributing to non-adherence have been categorised into four main themes:

i) Social related factors, ii) Personal related factors, iii) Access related factors, and iv) Medicinal related factors. Each of these main themes have sub-themes.

5.2.1 Theme 1: Social Related Factors

Social related factors that came out of this study were grouped into three: Fear of disclosing the HIV status of the child, traditional and religious beliefs and forgetting to give medication to the child. Caregivers of children who are below five years living with HIV/AIDS are failing to adhere to ART because they want to keep the child's status a secret. They do not want to disclose the status of the child to their spouse because of fearing that they may be accused of infecting the child with HIV. Most of the women could not disclose the HIV status of their children to their husbands as they were afraid of ruining their marriages by getting divorced. A parent who was aware of the HIV status of the child would not give ART to the minor when the spouse is around. The ending result is non-adherence to ART. This finding is similar to what was found by other scholars: Posse et al

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(2008) and Mahlalela (2014) who reiterates that one of the main reasons why adults and children do not adhere to ART is fear of consequences of disclosing the HIV status. Parents are afraid of getting divorced because of revealing a child's HIV status. Okoronkwo et al (2013) concur that fear of divorce among Nigerians living with HIV prevents them from disclosing their status. That results in non-adherence to ART by adults and children living with HIV. Non-adherence to ART by caregivers of children living with HIV in Vhembe district is done to safeguard marriages.

In some instances, non-adherence is happening because a caregiver does not want the HIV status of the child to be known by other people such as relatives and friends in the community. This is because they do not want to be discriminated and stigmatised in the community. Boyer et al. (2011) concur that as a result of stigma associated with HIV, people are afraid of letting their status be known by other people. In South Africa, adults and children avoid stigmatisation by not disclosing their HIV status even if it means they must temporarily stop taking ART (Kheswa 2017).

Traditional and religious beliefs is a sub-theme that came out from social related factors. Caregivers took their HIV positive children to traditional healers. In most cases, they did so unknowingly that the children were HIV positive as the mothers had not disclosed to them. In other cases, they deliberately sought the aid of these unscientific methods. Caregivers in this study were not adhering to ART because of traditional beliefs that HIV/AIDS can be cured using African herbs. This resulted in caregivers not giving their children treatment but take them to traditional healers where they often get different diagnosis, for example, a caregiver was told that the child had *gokhonya,* not HIV. In that case, there is nonadherence to ART as Peltzer et al. (2011) postulate that some people deliberately stop taking Western medication (ART) in preference of traditional medicine. In some cases, caregivers do not adhere to ART because of religious beliefs. Caregivers are not consistently giving their children ART because they believe in divine intervention. This finding tallies with what was found in the Ugandan context where people abandoned ART as they believe in divine healing (Wanyama et al. 2011).

Forgetting to give medication to a child is the third and final sub-theme among social related factors. Caregivers forget to give medication to their HIV positive children. They forget to give medication to the child because of pressure of work. Sometimes children are

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taken for holiday, caregivers forget to give the person who will be looking after the child ART. That means, a child stops medication for the whole school holiday or weekend when he is away with his aunty, grandmother or any other relative. The situation of forgetting to give medication is very common in different countries – Bauleth et al (2016), Mehta et al (2016) and Azia et al (2016) argue that forgetfulness was one of the barriers to non-adherence to ART in Namibia, India and South Africa respectively.

5.2.2 Theme 2: Personal Related Factors

Personal related factors contributed to caregivers' nonadherence to ART. These include lack of knowledge and understand of ART by care givers, deliberately giving ART inconsistently to children, confusing information given to caregivers by medical staff on HIV/AIDS and non-adherence to ART due to stress. Caregivers could not let their children adhere to medication as they did not have comprehensive knowledge and understanding of the ART programme. They did not know the importance of adhering to ART let alone procedures to follow when giving medication to the child. This resulted in wrong administering of the medication which flouted the procedures and requirements. Some did not know that they were supposed to give the child ART consistently as they thought they would overdose the child, or it is only given when a child's condition deteriorates. A situation of nonadherence to ART is common in Southern African countries because people lack knowledge and understanding of how the medication works (Posse et al 2018).

Some caregivers reported that they were too busy to keep up with the routine of medication or they were lazy to do it. The result was nonadherence. This finding is like what was found by Niilonga and Maano (2017) who reported that some HIV patients could not adhere to medication as its routine was interfering with some of their programmes and it was becoming burdensome. Poor communication between clinic staff and caregivers contributed to nonadherence to ART. Caregivers claimed that they missed the part where nurses told them to adhere to ART. In some cases, caregivers understood the aspect of adhering to ART, but failed to do that because they are stressed by the fact that their child must take the medication for the rest of his/her life.

5.2.3 Theme 3: Access Related Factors

This study found that poor access to medication was one of the major contributory factors to nonadherence to ART among children of age below five years in the Vhembe district.

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There were three main issues which contributed to poor access to medication namely, distance between the mother and the child, shortage of medication at collection centres and economic problems.In several situations, children living with HIV/AIDS were separated with their mothers who kept the medication with them to avoid disclosure or for other reasons such as going to work to another location, or the child was left with very young siblings who could not give medication or child was left with grannies. Due to this separation, the children only got access to ART medication only when their mothers returned from their errands or were available at home.

Besides the distance between the mothers and children, this study also established that shortage of medication in health facilities was a cause for nonadherence to ART. Medication usually ran out at most of the remote collection facilities forcing caregivers to go back home to wait for the supply, meanwhile starting to disrupt ART programme by reducing the quantity of medication or stopping giving medication completely. At times, the medication ran out when it was stolen by other relatives who were HIV positive but did not to disclose. In some cases, medication for the children was sold to raise money for other household needs particularly in poverty-stricken areas. The overall effect was disruption of the ART programme.

As majority of caregivers who participated in this study were unemployed, they were facing acute economic challenges. They could not raise money to pay for transport to go to a nearby clinic to collect ART. That subsequently resulted in nonadherence to the medication. Several scholars have reported that in poverty-stricken areas, non-adherence to ART is mainly caused by lack of funds, shortage of ART in some rural health facilities and parents living far away from their children (Makua 2015; Azia et al 2016; Okoronkwo et al 2016; Posse et al 2008).

5.2.4 Theme 4: Medicinal Related Factors

This study found that nonadherence to ART was because that medication had on children. The caregivers disrupted the ART programme after noticing negative effects which were caused by the medication. Caregivers reported that ART caused some side effects such as vomiting, restlessness, crying, loss of appetite, weight loss and passiveness among children. As a result, they stop giving ART to children fearing that it would deteriorate their health. Kioko and Pertet (2017) concur that some HIV patients stop taking ART because

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of side effects they experience such as dizziness, vomiting, headache, skin rash and fever. Some caregivers were worried about negative effects of ART to an extent of going back to the clinic to request for change of medication. In cases where caregivers were grannies, they used this as an excuse to stop ART and visit prophets and traditional healers, only to return to clinic when the children got worse.

Positive effects of ART were also a contributing factor to nonadherence. Caregivers who sees positive signs on their children thought that it was pointless to continue giving ART. They immediately stop giving the medication thinking that the child is cured.

5.3. Integration of findings related to theoretical framework

Factors which contributed to nonadherence to ART by caregivers of children under five years in the Vhembe district fit well in the Bronfenbrenner's social ecological theory which was selected as a theoretical framework for this study. The theory consists of five interrelated systems – microsystem, mesosystem, exosystem, macrosystem and chronosystem.

5.3.1. Microsystem contributing factors

The microsystem which entails the relationship that a developing child has with proximal settings such as family, school and peers (Bronfenbrenner 1994) was evident in this study. Children under five years where depending on caregivers who according to the Bronfenbrenner's theory are family members who would give ART to the infected child. Although this study found that caregivers were not adhering to ART, the relationship and interaction which took place between caregivers and children who were HIV positive forms the microsystem.

5.3.2. Mesosystem contributing factors

Mesosystem which is an interaction of family, peers and school (Bronfenbrenner 1992) was evident in this study as caregivers of children with HIV were interacting among themselves at the clinic when they were collecting medication. Some mothers would interact with their grandmothers or mothers in law about the child concerning taking his/her ART. That interaction forms part of the mesosystem as was stated by Bronfenbrenner (1992) that mesosystem is an interaction of microsystems.

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5.3.3. Exosystem contributing factors

The exosystem was very prominent in this study. Bronfenbrenner (1979) conceptualises exosystem as: “One or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person.” Children under five years in this study were affected by exosystem. They were not affected directly by what was happening in their communities, but by events taking place around their caregivers. For example, when caregivers could not cope with work at their workplaces, that indirectly affected children as caregivers would not adhere to ART. Bronfenbrenner (1986) reiterates that exosystem occurs when a developing child is affected indirectly by what happens to his/her caregiver’s place of work or social gathering. Some caregivers in this study reported that they were stressed at work that they get home tired and fail to give medication to their children. Masten and Obradovic (2008) state that often, when caregivers are distressed by whatever happens in their work or social places, that falls in the exosystem as it subsequently has a negative effect on the developing child.

The influence that a community has on a developing child also falls under the exosystem (Bronfenbrenner 1986). This is inclusive of what the community values as norm, principles and general social networks (Masten and Obradovic 2008). Caregivers were worried about discrimination and stigmatisation in their communities. That is why they deliberately decided not to disclose the HIV status of their children It can be argued that although an exosystem happens indirectly to children, its effects can be very detrimental (Kail & Cavanaugh 2010). An HIV positive five-year-old child who depends on caregivers to adhere to ART may be very vulnerable to opportunistic infections caused by nonadherence to ART. That non-adherence could have been caused by what a caregiver experiences in his/her day to day life in the community. Caregivers in this study were very unhappy about many things, including stress with their fellow acquaintances and dissatisfaction with services they got from local clinics. Those are exosystem factors which do not involve the child at the centre stage, but he/she will be affected anyway (Kail & Cavanaugh, 2010).

5.3.4. Macrosystem Contributing Factors

The macrosystem consists of the overarching patter of micro-, meso-, and exosystems characteristic of a given culture or subculture, with reference to the belief systems, bodies

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of knowledge, material resources, customs, lifestyles, opportunity structures, hazards, and life course options that are embedded in each of these broader systems (Bronfenbrenner 1994).

The macrosystem occurred in this study when caregivers cited macro factors such as unemployment, cultural and religious beliefs as reasons for nonadherence to ART. Bronfenbrenner (1979) postulates that macrosystem involves large factors related to employment, culture, religion and ideologies of people in a given society. In other words, macrosystem is a blueprint of a culture (Bronfenbrenner, 1979; 1992; 1999) and it was evident in this study as it affected children's adherence to ART. The shortage of ART in some local clinics which was cited by some participants falls under the macrosystem. Economic problems experienced by caregivers where they claimed that they do not have enough money to pay taxi fare to the nearest ART collection point falls under the macrosystem. Bronfenbrenner (1979) argues that the macrosystem is broad and it encompasses various large-scale aspects such as the economic issues.

5.3.5. Chronosystem Related Factors

The chronosystem which summarises the length of time and how it relates to the interactions between micro, meso, exo and macro system (Swart and Pettipher 2011) was experienced by children through a passage of time when they go for some time without getting medication. Children went for some time without adhering to ART due to various reasons which shortage of medication in some local health facilities.

5.4. Recommendations

Recommendations made in this section focused on practice, training and future research

5.4.1. Recommendations for Practice

This study recommends that the South African government increases the practice associated with ART programmes in rural settings. Although South Africa is one of the countries that runs a large ART programme in the world, the practice is not fully experienced by people who come from poor rural backgrounds like the Vhembe district where local clinics sometimes run out of ART supply. The study also recommends hospital and clinic authorities deploy staff at the ARV collection point understand the plight of caregivers by not discriminating them. The clinics should put in place follow-up programme

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for nonadherent caregivers either by sending text messages as reminders. A refresher course should always be given to update caregivers on existing techniques for caring.

5.4.2. Recommendations for Training

As various caregivers attributed their nonadherence to ART to lack of knowledge and misunderstanding, this study recommends that training sessions related to HIV and ART needs to be increased particularly in rural areas. Studies conducted by different scholars (Posse et al 2008; Mehta et al 2016 and Vreeman et al 2018) unanimously state that when people are educated about ART, they are likely to adhere to the medication when they give it to their children. Caregivers in the Vhembe district can benefit from training sessions which focus predominantly on teaching about the importance of adhering to ART. Such training sessions will help obliterate misconceptions which caregivers may be having about the medication. It also helps demystify misconceptions around curing HIV/AIDS using traditional methods and religious beliefs. Training sessions will assist caregivers develop a comprehensive understanding of how ART works in human body and why infected people must tenaciously adhere to the medication in order to reduce viral load. Training sessions can be done in wards or villages where people can attend in numbers as opposed to clinics where some may not be able to attend because of lack of transport money.

This researcher recommended increasing awareness campaigns about HIV in rural areas. People in the Vhembe district are lagging as far as accepting and respecting people with HIV/AIDS is concerned. Awareness campaigns will help people know that stigmatisation and discrimination are not ways to deal with HIV.

5.4.3. Recommendations for Future Research

Future research can be done focusing on adherence to ART by caregivers of children in urban areas. It will be interesting to hear what factors influences or prevents them from adhering to ART. Since this study was done as a small qualitative case study of Vhembe district only, no generalisation can be made. Future research can be done using quantitative approaches focusing on various rural districts and many participants so that generalisation can be made about adherence to ART by caregivers in South African rural areas.

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5.5. Limitations of the study

This study was limited to caregivers of children who are between zero- and five-years old living in the Vhembe district of Limpopo province. This site was purposively selected as it was convenient to the researcher who works in the area. Only 25 caregivers were selected to participate as the researcher wanted to interact with them extensively in order to collect rich textual data about factors contributing to non-adherence of their children to ART.

5.6. Conclusion

The purpose of this study was to explore contributory factors to nonadherence to ART in caregivers of children under five years living with HIV/AIDS from selected hospitals of the Vhembe District, Limpopo province. The study concludes that despite of the fact South Africa has been running one of the biggest ART programs globally (Azia, et al 2016) it still faces challenges related to adherence particularly by children in rural settings. A myriad of factors, some which are beyond the control of caregivers befall them and subsequently prevent them from giving ART consistently to their children. For example, shortage of ART in some health facilities in rural areas. This is beyond a caregiver's control and can only be addressed successfully by the intervention of the government in order to tighten the ART programme.

There is a risk of children developing a resistance to the medication (because of non-adherence) thereby increasing the viral load. That subsequently make them more vulnerable to some opportunistic infections.

Vhembe District is mainly rural and the population generally poor making it difficult to achieve the required level of ART adherence in general and worse particularly to children who depend on adults. Smith, Gengiah, Yende-Zuma, Upfold and Kogieleum Naidoo (2016) support this finding based on their results in KwaZulu Natal in which they conclude that achieving optimal adherence to ARV's in a rural paediatric population was a big challenge.

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Annexure A: Permission to conduct research from UNIVEN

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mrs TJ Lithole

Student No:
15012727

PROJECT TITLE: **Factors contributing to non-adherence to antiretroviral therapy in care givers of children under five years of age, Vhembe district hospitals of Limpopo province, South Africa.**

PROJECT NO: SHS/18/PDC/07/0307

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr ND Ndou	University of Venda	Supervisor
Prof LH Nemathaga	University of Venda	Co - Supervisor
Mrs TJ Lithole	University of Venda	Investigator – Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: July 2018
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: .....
Name of the Chairperson of the Committee: Senior Prof. G.E. Ekosse

UNIVERSITY OF VENDA
DIRECTOR
RESEARCH AND INNOVATION
2018 -07- 04
Private Bag X5050
Thohoyandou 0950

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950, LIMPOPO PROVINCE, SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060
"A quality driven financially sustainable, rural-based Comprehensive University"

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Annexure B: Permission to conduct research from Limpopo province

P.O. Box 1837

SIBASA

0970

Provincial Department of Health

Research ethical committee

Polokwane

0700

Request for permission to conduct research.

Topic: Factors contributing to non-adherence to antiretroviral therapy in caregivers of children under five years of age, Vhembe District hospitals of Limpopo province, South Africa.'

Dear sir/ madam

I am Lithole Takalani Julia a registered professional nurse at Messina hospital and a student at the University of Venda in the School of Health Sciences. I am presently in a research study entitled **contributing factors to non-adherence to antiretroviral treatment in caregivers of children under five years of age, Vhembe District of Limpopo province, South Africa.** This study is to be conducted under the supervision of Dr Ndou N.D and Professor L.H Nemathaga from the School of Health Sciences at the University of Venda.

The objective of this study is to explore the contributory factors to poor adherence to antiretroviral treatment by care givers of children living with HIV/AIDS at selected hospitals in Vhembe District Limpopo province, South Africa. In order to complete my degree, I need to conduct interview with caregivers of HIV positive children on antiretroviral treatment. The interview will be audio taped and the taped information will be erased after five years, to ensure confidentiality. Anonymity will be safeguarded by using pseudo names and information related to the interviews will only be accessible to the researcher and the independent coder. The results of the study may assist health workers to understand the factors that affect adherence and improve the quality of care rendered to HIV positive

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children. The results of the study may be escalated to the hospital authorities and help in reduce mortality and morbidity rate in Vhembe district Limpopo Province.

For further information contact the researcher on the following numbers: (015)534 0446 (WORK), 076 664 7813 (CELL).

Thank you

Lithole T.J

…… ….. …….. ……..

Signature Student no Date

…… ……..

Signature of supervisor Date

……. ……..

Co-supervisor's signature Date

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ANNEXURE C: Approval from Department of Health

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: LP_2018_10_001

Lithole TJ
University of Venda

Greetings,

RE: **Factors contributing to non-adherence to antiretroviral therapy in care givers of children under five years of age, Vhembe district hospitals of Limpopo Province, South Africa**

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

Date 23/10/2018

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

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ANNEXURE D: Letter seeking consent from the hospital

P.O. BOX 1837

SIBASA

0970

The Chief Executive Officer

Hospitals in the Vhembe District

Limpopo Province

Request for permission to conduct research.

I, **Lithole Takalani Julia** a master's in nursing sciences' student at the University of Venda request permission to conduct research as a requirement for my study.

My research topic is: **Factors contributing to ART non-adherence among caregivers of children under five years of age, Vhembe District hospitals.**

The purpose of the study is to explore contributory factors to ART non-adherence among caregivers of HIV positive children. The findings of the study will be disseminated to the hospital authorities to improve the of care rendered to HIV positive children and motivate the caregivers to improve on adherence.

Thanking you in anticipation

…… …… ……..

Lithole T.J (Researcher) Student no Date

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ANNEXURE E: Information relating to informed consent

Request for consent from participants

I am a registered professional nurse and student at the University of Venda in the School of Health Sciences. I am presently conducting research under the topic: **Factors contributing to antiretroviral non-adherence among caregivers of children under five years of age, Vhembe District hospitals of Limpopo province, South Africa.'**

The purpose of the study is to explore the contributory factors to antiretroviral treatment non-adherence among caregivers of children. The findings of the study may assist health workers to improve the standard of care rendered to HIV-positive children, while reducing morbidity and mortality rate. Adherence to antiretroviral treatment may also improve.

You are invited to join a research study. The decision to participate is voluntary. You have the right to withdraw at any stage of the study without penalty. There is no harm or threats expected for participating in the study and all the information shared will be kept confidential. The interview will be audio-taped. The taped information will be erased on completion of transcribing the tapes, to ensure confidentiality. Your anonymity will also be safeguarded by using pseudo names. The information related to the interview will be accessible to the researchers and independent coder. No data will be linked to your name.

For any information on your participation, contact researcher on the following number (015)534 0446 (Work) ; 076 664 7813(Cell).

Thanking you in advance

Lithole TJ. Signature…… Date…….

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ANNEXURE F: Consent for participation in research

I…… voluntarily participate in the study titled, 'Factors **contributing to non-adherence among caregivers of children under five years of age, Vhembe District hospitals of Limpopo Province, South Africa.'**

I understand that my participation is voluntary and that I may withdraw at any time.

…… ……..

Signature of participant **Date**

…… ……

Researcher 'signature **Date**

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ANNEXURE G: Central and probing questions

English: *"You are caring for a child living with HIV, may you please share with me the factors contributing to poor adherence, as you can see that the child is repeatedly admitted with HIV-related infections".*

Tshivenda: *"Vha tshi khou thogomela nwana wavho a no khou tshila na tshitzhili tsha HIV ndi zwiitisi zwifhio zwi vha swikisaho kha u sa fha nwana mishonga nga ndila yo teaho?*

Probing questions

Tell me more of the factors and explain how they contribute to ART non-adherence

Please explain various factors to non-adherence

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ANNEXURE H: Permission to conduct the study from district

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OFHEALTH
VHEMBE DISTRICT

Ref: S5/6
Enq: Muvari MME
Date: 09 October 2018

Dear Sir/ Madam:

PERMISSION TO CONDUCT RESEARCH
LITHOLE TJ

1. The above matter bears reference
2. Your letter received on the 09/10/2018 requesting for permission to conduct research in our facilities is hereby acknowledged
3. The District has no objection to your request.
4. Permission is therefore granted for the request to be conducted within Vhembe District.
5. You are however advised to make the necessary arrangements with the facilities concerned.
6. Wishing you success in your research in the Vhembe health facilities.

..... 09/10/18
CHIEF DIRECTOR DATE

Private Bag X5009 THOHOYANDOU 0950
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623
Old Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962 2373, (015) 962 227

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ANNEXURE I: Permission to conduct research from Donald Frazer

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
DONALD FRASER HOSPITAL

Ref: 4/2/2
Enquiries: Mphephu V.F
TELL NO. 0721880436;
Ext. 9306/9348
23.10.2018

To: Lithole Takalani Julia
University of Venda
Thohoyandou
0950

RE: Permission to conduct research study at Donald Fraser Hospital.

Topic: Contributing to non-adherence to antiretroviral therapy in caregivers of children under five years of age, Vhembe District hospitals of Limpopo province, South Africa

1. The above matter refers.
2. Permission to conduct the above mentioned study is hereby granted.
3. Kindly be informed that:-
   - In the course of study there should be no action that disrupts the services.
   - You to give report to quality assurance manager of Donald Fraser Hospital after the completion of research study at Donald Fraser Hospital.
   - After completion of the study, a copy should be submitted to our institution to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - You are therefore requested to contact nursing audit office number 5, OPD basement for logistic arrangements
4. Please bring along the following documents:
   - Permission letter granted from department of health
   - Permission letter granted from educational institution.
   - This letter

Hoping you will find this in order.

SIGNED _____ Date: 29/10/2018

CHIEF EXECUTIVE OFFICER

Private bag X1172, Vhufuli 0971
Tel: 015 963 1778/9, 015 1783 1791/2 • Fax: 015 963 1773, 015 963 1796
Cell: 083 248 0184

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ANNEXURE J: Permission to conduct the study from Siloam

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
SILOAM HOSPITAL
Confidential

Ref : S4/2/1/1/3
Enq : Mushaphi N.T: HRD
Date : 19 October 2018

DEPARTMENT OF HEALTH
SILOAM HOSPITAL
HUMAN RESOURCE
2018 -10- 23
P/BAG X 2432.
MAKHADO. 0920
LIMPOPO PROVINCE

To: Lithole T.J

RE: PERMISSION TO CONDUCT RESEARCH: YOURSELF.

1. The above matter refers.
2. The Hospital highly acknowledges the receipt of your letter dated 08/10/ 2018 regarding the above matter.
3. Kindly note that the institution is granting you permission to come and conduct research in Factors contributing to non-adherence to antiretroviral treatment in care givers of children under five years of age in the Vhembe District Hospitals in Limpopo Province.
4. You are kindly requested to adhere to the conditions as set out in your approval from the Provincial Office.
5. Hoping you will find the above in order

Chief Executive Officer

22/10/2018
Date

Private Bag X2432. Makhado, 0920
Tel (015) 973 0004/5/6, 015 973 1447/8, 015 973 1977, 015 973 1892/4/9 Fax (015) 973 0607.

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ANNEXURE K: Proof of editing

Proof of Editing

LEFEZ EDITORIAL SERVICES
Flat 101 Zethushof
620 Park Street
Arcadia, Pretoria
E-mail: statshelp66@gmail.com

Date: 9 May 2019

This is to certify that I have edited the draft dissertation for the following candidate:

Name and Surname: Ms. LITHOLE TAKALANI JULIA

Student No: 15012727

Title: FACTORS CONTRIBUTING TO ANTIRETROVIRAL TREATMENT NON-ADHERENCE AMONG CAREGIVERS OF CHILDREN UNDER FIVE YEARS OF AGE, VHEMBE DISTRICT HOSPITALS

Dr. S. Sargu
Acting Director
Lefez Edotirial Services

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ANNEXURE L: Interview transcript

Interviews transcript

Researcher: Good morning, how are you doing together with your child?

Participant: We are fine. What about you?

Researcher: I'm fine thank you for asking, since you know that your child is living with HIV and that your child must regularly take medication every day. What are the factors that might be contributing to ART non-adherence?

Participant: Nothing. She looked aside. Scratching her fingers.

Researcher: Is there no any cause really? You just felt that you no longer want to give your child medication. You no longer want your child to have a good health like other children?

Participant: Looking down sobbing with tears. I collect medication from the clinic every month however when I give her medications she vomits.

Researcher: Ever since you started to give the child, has that always been the case?

Participant: Yes

Researcher: Is that what made you to stop giving the child medication?

Participant: Sometimes when I think of going to the clinic, I get bored because they separate us from the rest of the clients

Researcher: How are you separated?

Participant: While looking down. Yes … when you arrive, they speak loudly indicating that those who came for other service like bandaging must go aside, those who came for chronic medication must go aside, and this makes us exposed to people you may not want them to know that you are HIV infected.

Researcher: Okay, are they doing it every time?

Participant: Yes, I was then becoming reluctant to go to the clinic to take medications again.

Researcher: So that made you to detest going for medication again? And you even undermined the importance of ensuring that your child gets medication regularly.

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Participant: I thought about it. While looking aside.

Researcher: And when you thought about, did you ever try to explain to the nurses at the clinic that you do not like the way they operate? Or to be changed to another clinic which is far from where you come from?

Participant: Even if they change my service point, I will not have transport fee to a distant clinic because I'm not working.

Researcher: What you are saying is understandable though it may be condoned because you were not supposed to totally stop collecting medication because you are now endangering your child's health.

Participant: I can see that. Looking at her child.

Researcher: What do you think should be done so that you continue taking medication for your child so that the child can get medication regularly?

Participant: If they could allow me to come and get medication here in the hospital, it could be better.

Researcher: The transport fee to come to the hospital, will you have it?

Participant: I come to this place every month to buy grocery. So, when I come for that, I will also collect medication for my child.

Researcher: Such a decision is beyond my power. I will firstly escalate the matter to my senior. They will then decide and see how they can help you.

Participant: Looking at me. You must inform them.

Researcher: I will do as such. Provided you equally promise me that you won't stop following the proper a recommended procedure that has to do with medicinal prescriptions.

Participant: I will not stop giving medication to the child.

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