

**AN EXPLORATION OF THE EXPERIENCES OF  
CAREGIVERS OF CHILDREN LIVING WITH HIV WHO  
EXPERIENCE TREATMENT FAILURE TO  
ANTIRETROVIRAL THERAPY (ART) IN MASERU,  
LESOTHO**

**by**



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## **Abstract**

**Background:** Globally, 1.8 million children (aged 0-14 years) are living with HIV, with Sub-Saharan Africa (SSA) remaining the most heavily affected region, accounting for almost 90% of children living with HIV (CLHIV). Unlike adults, children living with HIV suffer higher treatment failure rates, usually because of non-adherence to antiretroviral therapy. Factors associated with paediatric anti-retroviral therapy (ART) adherence can be related to caregivers (parents or guardians), children themselves, the medication/regimen, socioeconomic, or service delivery issues. Caregivers play a significant role in the care of HIV-infected children on anti-retroviral therapy, including the administration of medication. The ability of caregivers to provide care to children may be negatively affected by psychological and socioeconomic factors, experience, knowledge, and beliefs about ART.

**Aim:** The aim of the study was to explore the experiences of caregivers involved in the provision of care of children living with HIV, who experience treatment failure to anti-retroviral treatment in Lesotho.

**Methodology:** An exploratory qualitative study was conducted at the Baylor College of Medicine Children's Foundation Lesotho (BCMCFL) Centre of Excellence (COE) in Maseru. The study population comprised caregivers involved in the provision of care to children aged less than 15 years who are living with HIV and had experienced treatment failure to anti-retroviral therapy. Thirteen (13) caregivers were purposively selected for the study and two healthcare providers were included in the study as key informants. Individual in-depth interviews were conducted to collect data, followed by thematic analysis of the data.

**Results:** Per the study, key findings regarding the experiences of caregivers of children who had experienced treatment failure included: experience with dealing with their own and the HIV diagnosis of the child and experience with limited options of paediatric ART which contributed to suboptimal adherence. Caregivers faced various challenges which also played a role in compliance to care and treatment, such as the provision of care to multiple dependants, socio-economic issues such as balancing their work or social life with caregiving, disclosure to the child, and lack of support from other family members. Moreover, caregivers' experience with the support of healthcare workers also contributed to compliance to clinic visits and treatment.

**Conclusion:** The study identified that the caregivers of children living with HIV who had experienced treatment failure had experienced challenges with adherence to medication as a result of difficulties in managing the HIV diagnosis of the children and their own in some instances, the unavailability of child-friendly medication and problems with the provision of care to multiple dependants, struggles with balancing caregiving with work or social life and lack of support in the provision of care. Support through counselling provided with empathy and psychosocial support groups contributed to improved outcome regarding the experience of caregiving and compliance to treatment by both caregivers and CLHIV.



## DECLARATION

I hereby declare that *An Exploration of the Experiences of Caregivers of Children Living with HIV who Experience Treatment Failure to Antiretroviral Therapy in Lesotho*, is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Mosa Molapo Hlasoa

November 2022

Signed: ..M. Molapo..



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## KEYWORDS

- HIV
- Antiretroviral therapy (ART)
- Children living with HIV (CLHIV)
- Experiences
- Caregivers
- Treatment failure
- Counselling



## ABBREVIATIONS

ART	Anti-Retroviral Therapy
CDC	Centres for Disease Prevention and Control
CLHIV	Children Living with HIV
COE	Centre of Excellence
HIV	Human Immunodeficiency Virus
MoH	Ministry of Health
MOU	Memorandum of Understanding
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child-Transmission
SSA	Sub-Saharan Africa
UN	United Nations
UNAIDS	United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

### Key terms and their definitions

1. Treatment failure – defined as viral load  $\geq 1000$ copies/ml
2. Children – defined as children 0-14 years of age
3. Caregiver – gives care to someone who needs help taking care of themselves. For this specific study, caregivers of CLHIV include biological parents and other relatives or guardians (grandparents, uncles, aunts, step-parents, older siblings or cousins) who provide care to such children.

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## **CHAPTER ONE: INTRODUCTION**

This chapter provides a background to the study, the problem statement, the study aim, research questions, study objectives and purpose of the study. It concludes by providing an outline of the rest of the research report.

### **1.1 Background**

The background will focus on the overview of HIV, treatment availability and caregiving globally and locally.

#### **1.1.1 Overview of HIV globally**

Worldwide, 38 million four hundred thousand people including one million seven hundred thousand children (aged less than 15 years) are living with HIV, with SSA remaining the most heavily affected region, accounting for approximately 90% of CLHIV (UNAIDS, 2022). Since the beginning of the HIV pandemic, there has been an increase in the number of people living with HIV (PLHIV) who are receiving lifelong antiretroviral therapy (ART). As of December 2021, twenty-eight million seven hundred thousand people were accessing antiretroviral therapy, an increase from seven million eight hundred thousand in 2010 (UNAIDS, 2022).



#### **1.1.2 Availability of antiretroviral therapy globally**

Although substantial progress has been made towards providing life-saving treatment, with 75% of all PLHIV globally being on ART, only an estimated 52% of CLHIV who are aged 0-14 years were on lifesaving ART in 2021 (UNAIDS, 2022). The benefits of ART include suppression of HIV replication, prevention of HIV transmission to sexual partners and prevention of vertical transmission from mother to child (Gómez, Crowell, Njuguna, et al., 2018). In addition, Gómez et al. (2018), also describe ART as key to child development due to its impact on the reduction of mortality and morbidity, whilst also improving neurocognitive and growth outcomes.

Although there were early advances in the management of HIV, with the introduction of the first ARV, Zidovudine, in 1987, life could only be prolonged for a short while as HIV would rapidly develop resistance to the drug because it was used as monotherapy (Broder, 2009). The period 1988 to 1995 witnessed the development and introduction of additional ARVs as progress in HIV research and treatment was made (Forsythe, McGreevey, Whiteside et al., 2019). Over and above that, although there was a steadily increasing prevalence of HIV and AIDS-related deaths worldwide, ART use was mainly in developed countries since 1996. Many children, especially in developing countries, were orphaned as their parents died of HIV-related illnesses since developing countries, including those in SSA, only began initiating PLHIV on ART in 2003 (Forsythe et al., 2019). In addition, even with the increasing availability of more potent and optimised ART regimens, delays in the development and testing of paediatric formulations continue to limit the availability of optimal ARV regimens for children (Penazzato, Gnanashanmugam, Rojo et al., 2017).

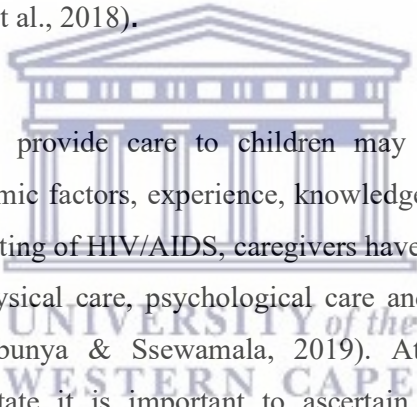
### **1.1.3 Caregiving in the setting of HIV**

In settings with high prevalence of HIV, such as in SSA, the HIV/AIDS pandemic has had direct and indirect effects on the general population and the family setting. Due to high morbidity and mortality rates, extended family members such as grandparents have had to serve as primary caregivers to their sick and dying children and simultaneously care for their grandchildren who often have become orphans (Dayton & Ainsworth, 2004). The Centres for Disease Prevention and Control (CDC) defines caregivers as people who provide care to those who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. Furthermore, in the setting of HIV/AIDS, caregivers are defined as people who provide clinical care and supportive services to PLHIV (O'Neill & Evans, 2001).

Caregivers can be classified as formal and informal. Formal caregivers include healthcare workers, social welfare workers, counsellors and psychologists, who received training and are paid for the provision of their service, while informal caregivers include family members such as parents, spouses, and friends who provide in-home care and are usually not paid for their services. Informal caregivers vary in the types of tasks performed, the amount of time devoted to caregiving, and living arrangements (O'Neill & Evans, 2001). Caregiving, especially in chronic conditions introduces the dependence of the afflicted and their basic right to health and wellness.

#### **1.1.4 Role of caregivers to CLHIV**

Caregivers play a significant role in the care of HIV-infected children on ART, including the administration of medication (Haberer & Mellins, 2009). Therefore, before ART initiation, caregivers (parents or guardians) of HIV-positive children receive counselling on the HIV-positive status of the child in their care. They are taught about transmission modes of HIV, the importance of ART, adhering to ART and side effects of the medication (Lesotho National ART Guidelines, 2016). Consequently, the readiness assessment and ongoing counselling of the caregivers of HIV-infected children are critical for the success of ART in these children (Haberer & Mellins, 2009). Williams, van Rooyen, & Ricks (2018) also reiterate that upon the initiation of ART in CLHIV, it is vital to ensure that they continue ART and attain good adherence to their treatment, with the goal to establish viral load suppression. Furthermore, since caregivers play a critical role in adherence to ART, they must be considered in interventions to adherence to ART in CLHIV (Gichane, Sullivan, Shayo, et al., 2018; Williams et al., 2018).



The ability of caregivers to provide care to children may be negatively affected by psychological and socioeconomic factors, experience, knowledge and beliefs on ART (Reda & Biadgilign, 2012). In the setting of HIV/AIDS, caregivers have been noted to be the source of holistic care, including physical care, psychological care and spiritual care, for PLHIV (Khatoon, 2017; Nyoni, Nabunya & Ssewamala, 2019). Atanuriba, Apiribu, Boamah Mensah, et al., 2021 also state it is important to ascertain that health care providers acknowledge the lived experiences of caregivers of PLHIV and are able to provide the assistance that may be needed by the caregivers.

With the gradual increase in the number of PLHIV who are accessing ART, monitoring of treatment is vital in ensuring treatment success and limiting treatment failure. Since 2013, the World Health Organisation (WHO) recommended viral load monitoring for all PLHIV who are on ART to assess treatment response, detect treatment failure and determine the need for a prompt ART regimen switch (WHO, 2013). Furthermore, since 2016, the WHO has recommended that HIV-infected infants and children should be a priority group for routine

viral load monitoring. Unlike adults, CLHIV suffer higher treatment failure rates (Arpadi, Shiau, De Gusmao & Violari, 2017; Cissé, Laborde-Balen, Kébé-Fall, et al., 2019).

Treatment failure can result in AIDS, death and further transmission of HIV at the onset of sexual activity. Poor adherence to ART and/or HIV drug resistance contribute significantly to treatment failure (Bezabhe, Chalmers, Bereznicki, et al., 2016). However, the underlying factors may differ by age group. In younger children, the main drivers include transmitted drug resistance from mothers; acquired drug resistance from previous or ongoing incomplete viral suppression; ongoing poor adherence; the lack of child-friendly medication and the need for regular drug dose adjustments with increasing weight (Siberry, Amzel, et al., 2017). Factors associated with paediatric ART adherence can be related to caregivers (parents or guardians); children themselves; the medication/regimen; socioeconomic; or service delivery issues (Arage, Tessema & Kassa, 2014). Furthermore, poorer socioeconomic status is associated with an increased probability of high viral load (Burch, Smith, Anderson, et al, 2016).

### **1.1.6 Overview of HIV in Lesotho**

Lesotho is a small landlocked country in SSA that is surrounded by South Africa, with an estimated population of two million, one hundred and seventy thousand (UNAIDS 2022). The small nation first detected its first case of HIV in 1986 and since then, the country has experienced a remarkable increase in the HIV/AIDS pandemic; a common phenomenon with neighbouring countries in Southern Africa (Central Bank of Lesotho, 2004). Lesotho has the second-highest HIV prevalence in the region and the world, with 22.7% of the adult population (15-59 years) living with HIV (Lesotho PHIA 2020). An estimated 10,000 children aged below 15 in the country are living with HIV (UNAIDS 2020). ART was initially introduced in 2003 in Lesotho when the drug Nevirapine was made available for the prevention of mother-to-child transmission (PMTCT) of HIV, followed by an expansion in the availability of ART from 2004 (Bowsky, 2004). Due to the unavailability of ART in the early years of the HIV/AIDS pandemic in Lesotho, the life expectancy declined from an average of 60 years in the early 1990s to an average of 35.7 years in 2004, resulting in an estimated 100,000 children below the age of 15 being orphaned due to AIDS (Bowsky, 2004).

With the expanding availability of ART in the country in 2012, an estimated 78 000 children between the ages of zero and 18 years were either single or double orphans as a result of HIV/AIDS (Settergren, Hoohlo & Rathabaneng-Hoohlo, 2017). The authors also noted that there was a decline in 2014, with 74 000 children orphaned by HIV/AIDS; however, this number was still relatively high as it represented a third of the children in Lesotho. Therefore, the HIV pandemic in the country had a devastating impact on children as not only were they left as orphans, but some were HIV-infected and in the care of extended family such as grandparents. On the other hand, with the improved availability of ART in the country, HIV-infected parents survive longer and the chances of leaving behind their children who may be HIV-infected, in the care of other caregivers including grandparents, have decreased (Block, 2016).

Lesotho has been implementing an expanding HIV programme, which has witnessed changes in recommendations and guidelines for the management of HIV for over two decades. In response to the WHO recommendations on viral load monitoring, in 2014, Lesotho introduced routine viral load monitoring of HIV-positive children on ART and viral load monitoring has been scaled up with the adaptation of the WHO Test and Treat recommendations since 2016. This has led to the identification of HIV-positive children with high viral loads, with the most common cause being poor adherence to ART. The average viral load suppression rate in children 0-14 years was 62.5% compared to the viral load suppression rate in adults (aged 15 years and above) at 88% (LePHIA, 2017). Since then, with the country scaling up the availability and uptake of optimised ART regimens, the average viral load rate in adults living with HIV who are on ART is 92% (LePHIA, 2020), while the viral load suppression rate in children was 87% in the same year (PEPFAR Lesotho Country Operation Plan, 2020). In addition, compared to their adult counterparts, CLHIV were noted to have poorer clinical outcomes, including lower suppression rates on ART (Muhairwe, Brown, Motaboli, et al., 2022).

## **1.2 Problem statement**

Children are considered indirect beneficiaries of healthcare services as they depend on caregivers and therefore, the knowledge, attitudes and practices of caregivers should not be taken for granted (Ofunne, 2014). Since children rely on adults for the administration of their

treatment, before ART initiation, caregivers (parents or guardians) of HIV-positive children are taught about HIV transmission modes, the importance of ART and the side effects of the drugs. Amongst other things, the clinical assessment of a child on lifelong ART involves regularly evaluating the caregiver's understanding of ART, adherence counselling and support as needed (Lesotho National ART Guidelines, 2016).

Because antiretroviral treatment is lifelong and optimal adherence is crucial to treatment success, it is important to assess every individual's (or caregiver's) readiness to start. The perceptions, and experiences of caregivers involved in the provision of care of CLHIV on lifelong ART are vital to the virological suppression and survival of such children. Studies that have been conducted on caregiving and the experiences of caregivers in the setting of the HIV pandemic, including in Africa and in particular, SSA countries. However, there are a few studies that document the experiences of caregivers of CLHIV in Lesotho, which ranks as the second hardest-hit country by HIV in the world. Specifically, there are also limitations in the availability of literature on the lived experiences of caregivers of HIV-infected children who have experienced treatment failure to their antiretroviral therapy (ART).

As a clinician involved in the care and management of CLHIV, the researcher has observed that rates of treatment failure amongst children and adolescents are higher compared to treatment failure in adults. Young children are usually in the care of biological parents, grandparents and other relatives, who play a big role in the provision of treatment to the children. While greater attention is given to CLHIV to ensure that those with treatment failure are switched to treatment which will help achieve viral load suppression, despite the involvement of their caregivers in addressing treatment failure, the experiences of the caregivers are not documented. It is against this background that the researcher embarked on the study to explore the lived experiences of caregivers of CLHIV who experience treatment failure to ART.

### **1.3 Study Aim**

To explore the experiences of caregivers of children living with HIV (CLHIV) with experience to treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho.



## **1.4 Research Questions**

1. What are the caregivers' understanding of HIV treatment and treatment failure?
2. What are the lived experiences of caregivers of factors that contribute to treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho?
3. What are the challenges and factors related to providing care to children living with HIV who have ever experienced treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho?
4. What support is required by caregivers to improve ART adherence and viral load suppression for children living with HIV?

## **1.5 Study Objectives**

1. To explore caregivers' understanding of HIV treatment and of treatment failure.
2. To explore the lived experiences of caregivers and healthcare professionals of factors that contribute to treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho.
3. To explore and describe the challenges and factors related to providing care to children living with HIV who have ever experienced treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho.
4. To describe the kind of support that caregivers require to improve ART adherence and viral load suppression for children living with HIV.

## **1.6 Purpose of the study**

The purpose of this study is to get a better understanding of the lived experiences of caregivers who provide care to CLHIV who experience treatment failure to ART. Additional psychosocial support and adherence counselling will be provided accordingly. The study will also generate information that healthcare providers can use in the implementation of approaches to use in counselling caregivers of paediatric patients who fail their ART regimens, and as novel and potent ART regimens are introduced.

## **1.7 Outline of this report**

This study consists of six chapters. The first chapter puts the study into context. In the second chapter a review of the literature related to the experiences of caregivers of CLHIV who have ever experienced treatment failure is presented. The third chapter describes the methodology that was used to conduct the study. The fourth chapter presents the findings of the study and the fifth chapter presents an analysis, discussion, and interpretation of the results. The sixth chapter presents the conclusion and recommendations drawn from the study.

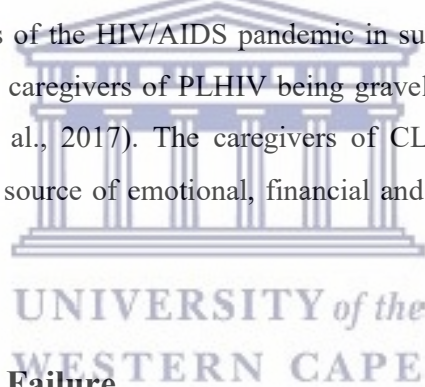


## CHAPTER TWO: LITERATURE REVIEW

This chapter reviews key literature on the experiences of caregivers of CLHIV. The purpose of this review is to provide knowledge on the research topic by understanding and elaborating existing studies on the experiences of caregivers of CLHIV who have experienced treatment failure to ante-retroviral therapy. The literature review will present an outline of previous studies on the topic. The chapter first provides a review of paediatric HIV data, followed by management of HIV in children and treatment failure. The chapter then covers a review of the concept of caregiving, followed by caregiving to CLHIV and gender distribution in caregiving.

### 2.1 Introduction

An estimated one million seven hundred thousand children worldwide are living with HIV, with approximately 90% of HIV-infected children found in sub-Saharan Africa (UNAIDS, 2021). As a result, the effects of the HIV/AIDS pandemic in sub-Saharan Africa have been both direct and indirect, with caregivers of PLHIV being gravely affected by the pandemic (Osafo, Knizek, Mugisha, et al., 2017). The caregivers of CLHIV are important as they generally tend to be the only source of emotional, financial and material support to CLHIV (Ofunne, 2014).



### 2.2 ART and Treatment Failure

Despite the availability of ART to all PLHIV worldwide, only an estimated 54% of children were on ART in 2018 (DNDi, 2018). Furthermore, treatment failure is noted to be higher in children than adults (Davies & Pinto, 2015), with 11% of children on Lopinavir/ritonavir-based regimen which are very potent having resistance to their regimen. Interventions to address treatment failure in children involve intensive or enhanced adherence counselling to caregivers. However, only 19% of children with a previous detectable viral load in a setting in Lesotho achieved viral load suppression at 18 months (Lejone, Ringera, Cheleboi, et al., 2018). In another study conducted in Lesotho, CLHIV were noted to have poorer clinical outcomes, including lower suppression rates on ART, compared to their adult counterparts (Muhairwe et al., 2022).

Poor adherence to ART is the most common cause of treatment failure to ART, followed by HIV drug resistance (Getawa, Fentahun, Adane, et al., 2021). However, depending on the age group, there may be a variation in the underlying factors. According to the WHO, the main causes of treatment failure in younger children may include vertical transmission of already resistant HIV strain from their mothers; secondary drug resistance acquired from previous or recurring incomplete viral suppression; ongoing poor adherence; unavailability of child-friendly medication; and the need for regular drug dose adjustments with increasing weight (Boerma, Boender, Bussink, et al., 2017).

### **2.3 Antiretroviral therapy and administration of treatment in children**

Generally, medications that are prescribed and administered to children may range from syrups; a powder that has to be reconstituted with water to become a mixture; tablets that are dispersible and easy to crush and mix with water; granules or pellets which are mixed with liquids or semi-solid food and tablets that may be chewed or in some cases have to be taken whole (Orubu & Tuleu, 2017). The administration of different formulations of ART therapy has been noted to pose various challenges to children as some syrup formulations such as the highly potent Protease Inhibitor Lopinavir/ritonavir syrup (LPV/r) also referred to as Kaletra, has been noted to be poorly tolerated by children due to its bitter taste (Von Hentig, Angioni & Königs, 2021). In addition, CLHIV who were initiated on ART in their infancy and those who were severely sick at the time of ART initiation had a higher probability of developing treatment failure to their ART (Haile & Berha, 2019).

Over the years, although there have been advances in the availability of optimised ART formulations for older children, adolescents and adults, similar advances for paediatric-friendly, optimised ART regimens have been noted to take a while (Lee, LaRochelle, Smith & Badowski, 2021). For example, in Lesotho as elsewhere, the government, through the Ministry of Health and the support of donors and implementing partners, has regularly reviewed and revised ART guidelines in line with international guidance including WHO recommendations. In previous years, first line ART regimens included less potent nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs), with better formulations consisting of protease inhibitors were initially reserved for second line ART regimens and

certain infants. Although the National ART Guidelines were revised in January 2022, potent ART regimens consisting of Dolutegravir were made available for older children, adolescents and adults earlier than they were made available for younger children. In addition, since children depend solely on adults for the provision of care and administration of medication, the treatment literacy for caregivers is important in ensuring correct dosing and administration of ART (Mafune, Lebeso & Nemathaga, 2017). This concept also applies to Lesotho, as the National ART Guidelines state that treatment literacy and adherence counselling should be offered to caregivers of young children who will support the children with provision of care and administration of treatment.

## **2.4 The concept of caregiving**

Caregiving, as described by the CDC, is a public health issue that affects the quality of life of many people. The definition of a caregiver, according to the Merriam-Webster Dictionary, is a person who provides direct care to children, elderly people or the chronically ill. A caregiver is also described as someone who assists another person with their physical and psychological needs (Sullivan & Miller, 2015). Similarly, the Johns Hopkins describes a caregiver as a person who tends to the needs or concerns of a person with short or long-term limitations due to illness, injury or disability. In the setting of developed countries, the presence of unpaid, informal caregivers has resulted in many people not being committed to institutions (Asuquo, Adejumo, Etowa & Adejumo, 2013; Goldberg & Rikler, 2011). The authors also explain that in the African culture, providing care to a sick family member is regarded as an ancient act of kindness, love and loyalty which holds the family together. Although caregiving generally provides satisfying experiences, associated strains exist because of the long-term and at times extreme responsibility (Asuquo et al., 2013).

## **2.5 The role of caregivers to CLHIV**

The role played by caregivers in the adherence support of children on ART is vital. As demonstrated in Kenya by Sivapalasingam, Mendillo, Ahmed, et al., (2014), children with the best treatment outcomes on ART and good adherence to ART were those with a few, close relatives as caregivers. Similarly, in a study carried out in Pretoria, South Africa, Ofunne (2014) acknowledges that caregivers can and do play an important role in the HIV

management of children as that there is a significant positive relationship between the knowledge of caregivers and the outcomes of care of HIV positive children. In their study conducted in a rural setting in Ghana, Paintsil, Renner, et al. (2015) discovered that the majority of interviewed caregivers had poor knowledge regarding HIV transmission and high level of perceived HIV stigma. Furthermore, in a qualitative survey on knowledge, attitudes and practices of caregivers of HIV-infected children that was carried out at four hospitals in Burkina Faso, caregivers were found to have low level of knowledge on paediatric HIV prevention and care (Coulibaly, Thio, Yonaba, et al., 2016).

## **2.6 Gender distribution in caregiving**

Although there have been some changes over the years, women have predominantly played the role of caregivers as women are deemed as providers of care to others. . A national evaluation of home-based care in South Africa determined that 91% of caregivers were women and similar surveys conducted in Uganda and in Thailand demonstrated that two-thirds of PLHIV were nursed at home by their mothers (UNAIDS, 2008). In a study conducted in Lesotho, women were found to be at substantial risk for HIV infection and economic vulnerability as they play a major role in ensuring the oversight of families, running households and carrying the burden of caregiving, in the absence of their husbands (Harrison, Short & Tuoane-Nkhasi, 2014). In addition, in another study that was undertaken in Pakistan, it was established that women were the main caregivers of elderly relatives and children, since men were usually away at work (Jeong, Siyal, et al., 2018). Furthermore, more often than not, the onus for the provision of care of orphans usually falls on the shoulders of older adult women (Kalomo & Besthorn, 2018).

## **2.7 Factors affecting caregivers**

The ability of caregivers to provide care to children may be negatively affected by psychological and socioeconomic factors, experience, knowledge and beliefs on ART (Reda & Biadgilign, 2012). In a study conducted in Ethiopia, Biru, Lundqvist, et al. (2015) described that the HIV diagnosis of a child results in a change to the caregiver's and the child's lives because of the uncertainty about the future and there is a risk of stigma even from the rest of their family. Furthermore, in their study which entailed a review of literature on older adults who are caregivers, Small, Aldwin, et al. (2019) found that caregiving in SSA is complicated by extended periods of providing care to multiple family members such as

adult children and grandchildren amid the high levels of stigma and discrimination due to HIV. In addition, in another study, Lentoer (2017) concluded that caregiving is influenced by broader socio-ecological risk factors such as poverty, caregiver mental health, health status of the child and lack of social support.

A study conducted in Uganda established that one of the factors that caregivers of CLHIV with treatment failure to ART face is non-adherence to ART (Nasuuna, Kigosi, Muwanguzi, et al., 2019). Per the study findings, non-compliance to treatment came about because primary caregivers did not disclose the HIV status to the HIV-infected children, the caregiver's partner and other relatives.

Whether perceived or felt, the fear of stigma and discrimination also has a bearing on adherence to treatment. A study conducted in South Africa demonstrated that in the quest to ensure optimal adherence to ART, caregivers face various difficulties such as stigma and food insecurity (Mafune, Lebeso & Nemathaga, 2017). Similarly, in a study that was carried out in Ghana, caregivers, especially female caregivers, expressed that they faced challenges when providing care to CLHIV as they had no support and were discriminated by family members (Atanuriba et al., 2021). In addition, caregivers of CLHIV who have been on ART for prolonged periods develop treatment fatigue, which leads to poor adherence. The significance of disclosure on adherence has been noted in various studies. The consequences of delaying disclosure to HIV-infected children include poor adherence as the children may refuse to take medication (Madiba & Diko, 2020), while on the other hand, disclosure has been noted to result in enhanced adherence, support from family and other support structures, along with improved overall psychological wellbeing (Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, et al. (2018).

Based on the literature review, caregivers of CLHIV experience varying challenges in the quest to provide care to their dependants and the holistic wellbeing of caregivers has a positive impact on the progress of CLHIV on ART. Findings from studies conducted in several studies, including in Canada and South Africa, have highlighted the importance of ensuring the optimal care of CLHIV in parallel with the provision of support and care to the caregivers (Kakkar, Lee, Hawkes, et al., 2020). Although vast literature exists on the experiences of caregivers of CLHIV, there is a gap in the literature of experiences of

caregivers of CLHIV in Lesotho, specifically those who have experienced treatment failure to ART. Due to this, the researcher embarked on a study to explore the experiences of caregivers of CLHIV who had ever experienced treatment failure.

## **CHAPTER THREE: STUDY DESIGN AND RESEARCH METHODOLOGY**

This chapter presents the methodology used to carry out this study. The chapter consists of details of the study design, the study setting, the population and sampling techniques, recruitment of study participants, methods of data collection and analysis, and rigour and ethical considerations relating to the study.

### **3.1 Study design**

In any study, the research question determines the research strategy that the researcher uses (Kishore, Vasundhra & Anand, 2011). An exploratory qualitative study design was considered suitable for use in this research study because the study aimed to explore the experiences of caregivers of HIV-infected children with treatment failure to ART. The use of in-depth interviews allowed the participants to freely relay their experiences as caregivers of CLHIV with treatment failure or history of treatment failure. By conducting in-depth interviews, the researcher was also not able to predict or predetermine the potential responses by the participants (Choy, 2014).

### **3.2 Study Setting**

The study was conducted at the Baylor College of Medicine Children's Foundation Lesotho (BCMCF) Centre of Excellence (COE) in Maseru, Lesotho which was the first BCMCF facility to open its doors in Lesotho in December 2005. BCMCF consists of six health



facilities, which are referred to as centres of excellence (COEs), catering for HIV positive children and their families, with the child as the entry point. The BCMCFL COEs are strategically located within the country to cater for the population in the lowlands and patients in the mountainous, hard-to-reach highlands of Lesotho. BCMCFL was a result of a memorandum of agreement (MOU) between Baylor Children's Hospital in Houston, Texas and the Ministry of Health (MoH) Lesotho. The BCMCFL COE in Maseru was selected as the study site because it caters for approximately 2630 people PLHIV, including 1910 children living with HIV (CLHIV) aged less than 15 years of age, who are on lifelong ART.

### **3.3 Study Population**

The study population was composed of caregivers of CLHIV and healthcare workers (key informants) involved in the clinical management of CLHIV, enrolled at the Baylor Clinic in Maseru, Lesotho.

### **3.4 Sampling**

Purposive sampling was used to select the caregivers who were approached to participate in the study. Participants who were selected were those who possessed specific characteristics that would provide the most information about the topic (Ritchie, Lewis & Elam, 2003). A heterogeneous sample of caregivers of CLHIV, with varying age and a combination of female and male caregivers met the eligibility criteria to participate in the study. The aim was to select participants who would be a mix of biological parents, other caregivers such as aunts, grandparents, uncles and older siblings. The criteria for inclusion of caregivers included a limitless maximum age, whilst the minimum age was 18 years of age, with the exclusion of caregivers who head child-headed households. The participants were caregivers of HIV-infected children who have been on ART for more than 6 months and with at least two unsuppressed viral load results (viral load  $\geq$  1000 copies/ml of blood). Study participants had knowledge of the viral load result of the children with treatment failure on ART and had attended at least one mandatory enhanced adherence counselling session, per the Lesotho National ART Guidelines (2016).

### **3.5 Enrolment of study participants**

Potential study participants were identified by using the existing electronic medical records (EMR) which is implemented across all BCMCFL sites. Caregivers of children who had history of treatment failure or those who were currently being followed up for treatment failure were identified. In addition, prospective participants who were identified through their health records were followed up and approached for an interview by the researcher when they accompanied their child to the health centre for regular HIV services. Depending on the clinic queue and patient flow, interviews were either conducted prior to the clinical review or post the clinic review, with the child still within the clinic premises in the waiting room or playing ground. Purposive selection of participants was done based on their gender and age, along with the duration that their child had been on ART as a means to get insights of the different experiences between gender, age and duration that the CLHIV have been on ART.

The key informants were healthcare professionals who were directly involved in patient care, including identification of treatment failure and interaction with caregivers of HIV-infected children with failure on ART. Selected key informants comprised a Professional Counsellor and a Treatment Literacy Assistant who is HIV positive and supports other PLHIV (Expert Patient). Although key informants were included in the study based on their knowledge of treatment failure and interaction with patients and caregivers, only a limited number were included as they were not the primary participants. Despite requests for an interview before their departure from the clinic, five (5) of the eligible caregivers who were approached declined participation in the study, citing reasons such as being in a hurry to get back home or to work and not being prepared to take part in a study. A total of fifteen (15) participants consisting of thirteen (13) caregivers and two (2) key informants were successfully approached and interviewed as participants in the study. The combination of healthcare workers and caregivers as key informants and participants, respectively, was done with the intention to ensure rigour in the qualitative study.

### **3.6 Data collection**

Data collection was done through the administration of in-depth interviews in the participants' native language. Choosing the most appropriate data collection method was important as the choice of the relevant data collection method would also be essential when demonstrating the credibility of data analysis (Graneheim & Lundman, 2004). By using in-

depth interviews for data collection, the researcher was able to meticulously ask questions which were beneficial for understanding the viewpoint of each participant and further elicited the sharing of personal experiences of the participants regarding the provision of care to CLHIV who have experience of treatment failure to ART. The in-depth interviews included requesting the caregivers to also share experiences on how they had overcome the challenges that resulted in treatment failure, including the support that they received and recommendations for support to caregivers of CLHIV. Additionally, selected key informants were also able to share vital information based on their experiences with interacting with caregivers and providing service to caregivers and CLHIV.

An interview guide with open-ended questions was used to collect data on the experiences of caregivers of HIV-infected children younger than 15 years old, with experience of treatment failure at the Baylor Clinic in the district of Maseru, Lesotho. The interview guide was developed by the researcher in English and translated to Sesotho which is a local language that most people are familiar with in the country.

The researcher obtained informed consent from all the participants before the interview. Since all the participants were over 18 years, they signed their own informed consent. By signing the consent forms, the participants indicated their voluntary agreement to participate in the research study. On average, the in-depth interviews lasted between 40 and 60 minutes and were recorded using a digital recorder after obtaining permission from each participant. Short demographic data were collected at the beginning of each interview to capture basic background information and description of the participants including age, employment status, level of education, marital status, living arrangements, residential place and source of income. The demographic questionnaire was also translated into the native language Sesotho. To ensure privacy, a secluded space located in the clinic was used when conducting in-depth interviews with participants.

### **3.7 Data analysis**

Upon completion of data collection, recorded data were transcribed verbatim (i.e. in the exact words of the respondents), from the digital recorder and translated from Sesotho into English.

Additionally, all interview recordings were cleaned to remove information such as names of individuals and places. To avoid possible loss of collected data, all recordings of the interviews with participants, notes taken during and after interviews, and transcriptions were carefully labelled. Storage was then done on a laptop with password protection, with backup on an external hard drive, whilst hard copies of the data were stored in a lockable drawer. The researcher was immersed in the data as the data were checked to ensure accuracy by replaying the audio interview while checking the transcripts.

Analysis of the data was done through thematic analysis. To ensure familiarisation with the data, the researcher read the transcripts several times and the data were coded line by line. The definition of the codes was done in a way that ensured that they would not lose meaning during analysis. The researcher then grouped together similar codes into categories. The next step was the identification of similar categories that were collapsed to form sub-themes and themes. A review of the themes was meticulously done and thorough comparisons of the themes was done to ensure that the researcher had a good understanding of the data (Robson, 2016). The themes and sub-themes were described and interpreted to unveil experiences of caregivers of CLHIV. The whole process of data analysis was done in consultation with and support from the supervisor.

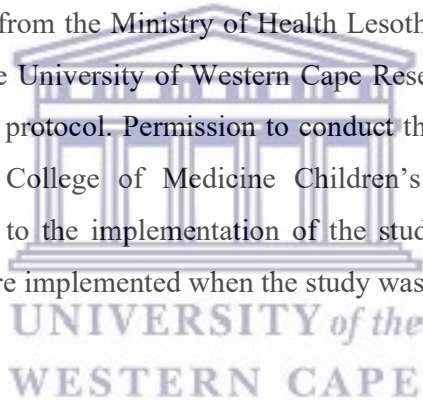
### **3.8 Rigour**

According to Creswell & Miller (2000), qualitative research is judged by its credibility, trustworthiness (synonymous with dependability or transparency), confirmability (implying that the research is auditable) and transferability or applicability. Member checking is an important criterion for establishing trustworthiness and credibility in qualitative studies (Creswell & Miller, 2000). Where data lacked coherence in the study, the researcher went back to review the themes and meaning of collected data with individual study participants in order to eliminate any misunderstanding or misinterpretation of the information. The researcher found common themes from different sources thereby increasing the credibility of the data (Creswell & Miller, 2000). Triangulation of data sources was ensured through interviewing caregivers of CLHIV with treatment failure along with key informants who were healthcare workers who interact with children and their caregivers. To further ensure credibility, the process of the study as well as the findings and interpretation of data were checked and discussed with the supervisor for peer debriefing to minimise bias.

To ensure trustworthiness of the data in the study, the researcher ensured that the research report included a detailed description of the methodology, sampling, recruitment, study setting and all data collection and analysis. All these details serve as evidence that the study was conducted properly whilst also ensuring the accuracy of the research findings (Creswell & Miller, 2000). As a healthcare worker involved in the management of CLHIV, the researcher ensured reflexivity by disclosing personal beliefs and potential biases as these could influence the researcher's findings. In addition, the researcher kept an audit trail which included documents such as a reflective journal, recorded raw data, additional notes, data analysis and interview questions to enable other researchers to examine the procedures and processes followed from the beginning of the study to its conclusion.

### **3.9 Ethical considerations**

Ethical clearance was sought from the Ministry of Health Lesotho National Health Research and Ethics Committee and the University of Western Cape Research and Ethics Committee upon submission of the study protocol. Permission to conduct the research was sought from the management of Baylor College of Medicine Children's Foundation Lesotho. The clearances were sought prior to the implementation of the study. The basic principles of research as detailed below were implemented when the study was conducted.



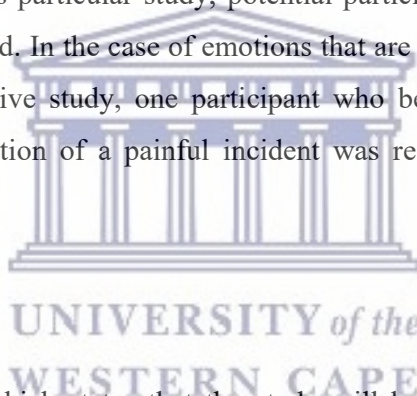
Autonomy and respect for the dignity of persons:

The researcher was responsible for ensuring that participants were well informed about the study and what was required from them. Respect for the dignity of the participants was guaranteed by being completely honest and not withholding any information from them. To accomplish this, informed consent was sought from the participants. Nijhawan, Janodia, Muddukrishna, et al., (2013) define informed consent as the act of giving information to potential participants, through documentation and discussion, of the purpose, procedures, risks, potential benefits, voluntary nature of the proposed research and documenting the participant's agreement. Documented information in the form of an information letter and consent forms were given to the caregivers. In addition, the participants also had a right to refuse or withdraw during an interview. Anonymity and confidentiality were also ensured as

the identity of participants and information gathered during the study were not disclosed to other parties in a manner that it could be traced back to specific candidates. Precautionary measures to protect the confidentiality of participants were taken by removing any identifying information. To ensure confidentiality, all recordings of the interviews with participants, notes taken during and after interviews, and transcriptions were stored on a laptop with password protection, with backup on an external hard drive, whilst hard copies of the data were stored in a lockable drawer. The computer password was only known to the researcher and the drawer key were securely kept away from the drawer. Stored data will be destroyed after five years.

#### Non-maleficence

Non-maleficence implies that the researcher should “first do no harm”. In research, participants can be harmed physically, psychologically, emotionally and also by embarrassing them (Polonski, 2004). In this particular study, potential participants were assured that any type of harm would be avoided. In the case of emotions that are provoked by sensitive issues when conducting the qualitative study, one participant who became emotional during the interview due to the recollection of a painful incident was referred to a psychologist for counselling.



#### Beneficence

Beneficence is the concept which states that the study will bring benefits to the potential participants and/or society. For this specific study, the potential participants were informed that the study would benefit not only them but also other potential caregivers. The information generated from the study will help improve provision of care by healthcare providers including clinicians and psychosocial support teams.

#### Justice

Justice is the fair selection of participants, and it also means that potential participants will be treated equally. Participants should not be favoured over others. In this specific study, participants were assured that they will be treated equally during the study and upon the termination of the study.



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## CHAPTER FOUR: FINDINGS

The purpose of this chapter is to present the major research findings. The first part of this chapter presents the demographic characteristics of the participants. The second part consists of details of the collected data, followed by a description of the themes that were identified during data analysis.

### 4.1 Demographic data of the research participants

A total of fifteen (15) participants consisting of thirteen (13) informal caregivers and two (2) healthcare workers were enrolled in the study. Of the thirteen (13) caregivers, twelve (12) were female and one (1) was male, with their ages ranging from 30 to 69 years. Most of the caregivers were biological parents (eight (8) mothers and one (1) father) followed by three (3) grandparents and one (1) aunt. During data collection, six (6) participants were formally employed, four (4) were self-employed and three (3) were not employed. One (1) healthcare worker was a female expert patient whose responsibilities included peer support and treatment literacy to patients and caregivers, whilst the second healthcare worker was a male Professional Counsellor whose job responsibilities included HIV testing, counselling and psychosocial support to patients and caregivers. Table 1 below shows the demographic data of the informal caregivers:

*Table 1: Demographic data of study participants*

Variables	Disaggregation	Frequency- n (%)
Age		
	30-39	6 (46%)
	40-49	4 (31%)
	50-59	2 (15%)
	60-69	1 (8%)



Relationship to child		
	Father	1(8%)
	Aunt	1(8%)
	Grandmother	2 (15%)
	Mother	9 (69%)
Employment status		
	Formal employment	6 (46%)
	Self-employed	3 (23%)
	Unemployed	4 (31%)
Marital status		
	Married	8 (62%)
	Separated/Divorced	3 (23%)
	Widower	2 (15%)
Age of the child		
	5 – 9	6 (46%)
	10 – 15	7 (54%)
Sex of the child		
	Male	5 (50%)
	Female	5(50%)

#### 4.1.1 Description of informal caregivers

Caregiver 001: A 46-year-old female, is the primary caregiver to her 15 years old son. She is married and lives with her husband, son and 10-year-old daughter. She and the son are HIV infected and on lifelong antiretroviral therapy (ART), whilst the husband and daughter are HIV infected. Although not recorded, during the indepth interview, she became emotional and disclosed that she had been sexually assaulted as a young adult, but has never disclosed the experience to her husband and her mother.

Caregiver 002: A 30-year-old female, is the primary caregiver to her only son who was 9 years old at the time of data collection. She has been separated from her husband and father of her child since the child was an infant. She and her son are HIV positive and on ART.

Caregiver 003: A 41-year-old female, married and is a mother of three children. She and her daughter are HIV infected, whilst her husband, eldest child and youngest child are all HIV negative. She and her daughter are enrolled at the same clinic and both on ART. Her daughter is wheelchair bound due to delayed developmental problems.

Caregiver 004: A 38-year-old female, a married mother of two. She is the primary caregiver to her orphaned 8-year-old niece who is HIV infected and on ART. The participant, her husband and two biological children are HIV negative.

Caregiver 005: A 60-year-old female, is the primary caregiver to her 7-year-old grandson. Her daughter died due to HIV related complications, whilst the child's father is still alive. The participant is also a caregiver to her husband who takes chronic medication due to mental health illness.

Caregiver 006: A 35-year-old female, is the primary caregiver to her 13-year-old son. She is married and lives with her husband and four children. The participant and her son are both HIV infected and on lifelong ART, whilst her other three children are HIV negative. Her husband has been reluctant to test for HIV despite persuasion from the participant.

Caregiver 007: A 30-year-old female, is the primary caregiver to her 10-year-old son and also has an 8-year-old daughter. She is married but separated from her husband who left her and

her children after her HIV infected son became paralysed when he was diagnosed with TB meningitis. The participant is also HIV infected, whilst her daughter is HIV negative. At the time of data collection, she was living with her older sister.

Caregiver 008: A 41-year-old mother of three, is a primary caregiver to her 14-year-old son. She and her son are HIV infected and on ART. The father of her HIV infected son died when the child was barely a year old. The participant also lives with her current partner and two other children who are all HIV negative.

Caregiver 009: A 31-year-old mother of two, is a primary caregiver to her 8-year-old daughter. She is a married and lives with her husband and two daughters. She and her older daughter are both HIV infected and on lifelong ART whilst her husband and younger daughter are HIV negative.

Caregiver 010: A 38-year-old mother of two boys. At the time of data collection, she had recently lost her 13-year-old son, who was wheelchair bound and had developmental delays due to HIV-related complications. She is the primary caregiver to her surviving 19-year-old who is also living with HIV. Her husband and father of the children abandoned them when the children were much younger. Although they do not live together, her current partner is supportive.

Caregiver 011: A 69-year-old female, is the primary caregiver to her 10-year-old grandson. The child is HIV infected and on lifelong ART and resides with his grandparents. The participant's daughter and mother to the child, is HIV infected and on ART and she has another younger child who is HIV negative.

Caregiver 012: A 47-year-old female, is the primary caregiver to her orphaned 6-year-old granddaughter. The participant's daughter died two weeks after childbirth and was only diagnosed HIV positive during labour. The participant is also living with HIV and she and her grandchild are on lifelong ART.

Caregiver 013: A 58-year-old father of three, is the primary caregiver to his HIV-infected 15-year-old son. His wife died when the boy was four years old and she had not disclosed her own HIV status and that of the child to the participant initially- the participant only learned of

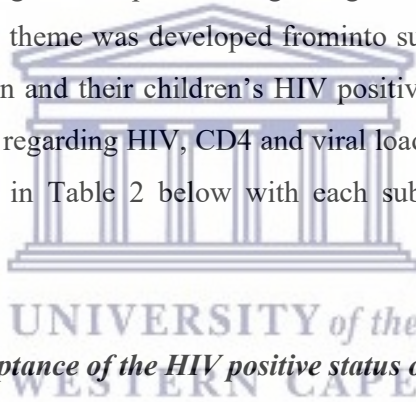
their HIV status and ART status after being called to the clinic when the child was not adhering well. His 21-year-old daughter is also HIV positive and on lifelong ART. The participant is HIV negative.

## 4.2 Themes

During data analysis, four main themes emerged from the in-depth interviews; knowledge and acceptance of child’s HIV status; administration of medication; caregiving challenges and support from family; and counselling and psychosocial support. Categories were grouped into sub-themes, followed by sub-themes into themes. Furthermore, quotes from the participants' responses were used to support the descriptions of the themes.

### 4.2.1 Knowledge and Acceptance of Child’s HIV status

This theme dealt with the caregiver’s experience regarding their knowledge and acceptance of the child’s HIV status. The theme was developed from into sub-themes including how the caregivers reacted to their own and their children’s HIV positive status; and the caregivers’ understanding and knowledge regarding HIV, CD4 and viral load monitoring. The theme and sub-themes are demonstrated in Table 2 below with each sub-theme detailed in sections below:



**Table 2: Knowledge and acceptance of the HIV positive status of the child**

Name of theme	Sub-theme
Knowledge and Acceptance of Child’s HIV status	<ul style="list-style-type: none"> <li>• Reaction to HIV positive status</li> <li>-Initial denial about own HIV-positive status</li> <li>-Self-blame for child’s HIV-positive status</li> <li>-Initially not aware of child’s HIV-positive status</li> <li>-Difficulty explaining how the child became infected with HIV (from the mother)</li> <li>-Acceptance of child’s HIV-positive status</li> </ul>

	<ul style="list-style-type: none"> <li>• Understanding and knowledge of HIV, CD4 and viral load</li> </ul>
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#### 4.2.1.1 Reaction to HIV positive status

Due to varying relationships to the children in their care; with most (8 out of 13) caregivers being biological mothers, while the other 5 included a father, an aunt and 3 grandmothers, the caregivers expressed the different ways that they learned about the HIV-positive status of the child. The caregivers who are biological mothers of the children had learned first-hand at the time that the child was diagnosed since in most cases the mother was aware of her own HIV positive status, and some were diagnosed at the same time as the child.

A mother of two who had only taken anti-retroviral therapy for a short time before giving birth to her first child, who is also HIV-infected, narrated that:

*“I learned when the child was 6 weeks old, I don’t remember clearly but it was immediately after the child was born.”* (Caregiver 009).

The mother also explained that her second child is HIV negative. This demonstrates the absence of optimum prevention of mother-to-child transmission of HIV in earlier years as the mother only learned of her HIV status late in her pregnancy despite being enrolled in an antenatal clinic early in pregnancy. The finding collaborates with the fact that in earlier years, HIV testing in pregnancy was not routinely done and therefore, transmission of HIV from mother to child could not be prevented early, resulting in children being infected in pregnancy or in early life.

Other caregivers either learned about the child’s HIV status from the child’s mother or from the clinic when the biological mother had not disclosed hers and the child’s HIV-positive status. In the case of one male caregiver, his wife died without disclosing that she and their youngest son were HIV positive.

*“I first learned when I took the child to the clinic... well ‘me’ (the child’s mother) took the child first and did not adhere well to recommendations due to her own reasons and also had not disclosed their statuses but then let us not go there.”* (Caregiver 013)

The caregivers also expressed their varying reactions to the child's HIV-positive status. For some caregivers, especially mothers, learning that the child was HIV positive came as a shock which resulted in some denial of their own and the child's HIV positive status. Some of the caregivers who are mothers of CLHIV also indicated with emotion that they blamed themselves for the child's HIV status. On the other hand, caregivers who were maternal grandmothers, expressed that it was easy for them to accept the child's HIV positive status as they had known about the HIV status of their daughters and previously cared for their severely sick daughters, some of whom had died due to HIV-related illness. This could also be a demonstration or evidence of their knowledge of HIV symptoms; and how HIV is transmitted.

*“Even though I was clueless I could see and was wondering (sighs) well she is pregnant but why is she so sickly? So that got me terrified and I realised...well I was well informed about HIV. I ended up getting tested together with the child and we started taking ART there (mentions name of clinic) - in 2016.”* (Caregiver 012)

This finding also shows that young adults would succumb to HIV, leaving their orphaned HIV positive children in the care of relatives, including the elderly.

In addition, caregivers acknowledged that acceptance of the child's HIV-positive status was not easy, with some describing that it is still not easy to come to term with the issue.

*I did take him to the clinic and it was found that he has HIV so he started on the treatment. Although it was not easy to accept the child's status, ...I was-I mean I was unable to accept the fact that the child was HIV positive because there were times, I ended up not bringing him to the doctor anymore, I was skipping his appointment dates, yeah it was not easy.”* (Caregiver 007)

This finding indicates that initial denial and delayed acceptance of one's HIV positive results in non-compliance to clinical appointments and non-adherence to medication, which may further lead to poor health outcomes including severe illness.

*“Am I going to be able to talk...I learned that the child lives with HIV in (sighs)...it has been a very long time. I don't remember which year, but it was a long time ago since the child has been on treatment.”* (Caregiver 008)

This finding shows the emotional impact of the child's HIV positive status to the mother, as it was still not an easy topic to discuss.

#### 4.2.1.2 Understanding and knowledge of HIV, CD4 and Viral load

Adherence to any treatment, especially to chronic treatment requires knowledge and understanding of the illness that one is being treated for. Although discovering the child's HIV positive status and their own HIV positive status might have come as a shock to some, the caregivers articulated that counselling was effective in providing them with knowledge of HIV and that they understood HIV, the fact that treatment would be lifelong, the importance of adherence and monitoring parameters such as CD4 and viral load.

*“I got preparation lessons that now that the child is living with HIV, the child is going to be given the treatment and it was explained further that it is because the role of ART is to decrease the amount of viral load in the child's blood, it will help the child to live a healthy life though it has no cure and that can only happen if the child adheres well to the treatment. It is good to stick to the same time, if I choose to give him the treatment at 07:00 it should be the same time every day, time should not be changed.”* (Caregiver 009)

#### 4.2.2 Administration of Medication

The second theme that emerged was on the caregivers' experience regarding the administration of medication and medication side effects. The theme was developed from subthemes that included the difficulties that caregivers faced regarding the administration of medication to the children in their care; treatment literacy issues that caregivers faced and medication side effects that were experienced by the children; and medication administration issues that were child related. The theme and sub-themes are displayed in Table 3 below with each sub-theme detailed in sections below:

**Table 3: Experience with the Administration of Medication**

Name of theme	Sub-themes
Administration of Medication	<ul style="list-style-type: none"><li>• <b>Difficulties faced with administering medication</b> <i>-Struggles with administering syrup and tablets to young children</i></li></ul>

	<p><i>-Challenges with administering medication to a child living with disability</i></p> <p><i>-Experience with own medication</i></p> <p><i>-Missing doses/forgetting to administer medication</i></p> <ul style="list-style-type: none"> <li>• <b>Treatment literacy issues and side effects</b></li> </ul> <p><i>-Illiteracy resulting in difficulties with understanding instructions</i></p> <p><i>- Dealing with undesirable side effects of medication</i></p> <p><i>-Confusion when treatment failure occurs despite good administration of medication</i></p> <ul style="list-style-type: none"> <li>• <b>Child-related medication administration issues</b></li> </ul> <p><i>-Trusting older child/adolescent to administer medication without supervision</i></p> <p><i>-Challenges with the adolescent stage including peer pressure</i></p> <p><i>-Treatment fatigue</i></p> <p><i>-Boarding school challenges</i></p> <p><i>-Stigma/discrimination</i></p>
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#### **4.2.2.1 Difficulties faced with administering medication**

The caregivers gave details of the challenges that they faced with the administration of medication. While most caregivers mentioned that they struggled with the administration of



medication that was in syrup form, some also expressed that the administration of tablets was also not easy. Caregivers acknowledged emotionally that the challenges they faced with administration of medication could have led to treatment failure. Caregivers cited struggling with the administration of a syrup formulation of antiretroviral therapy called Kaletra syrup as it has a bitter taste, which did not improve despite being advised to use sweet tasting medication such as multivitamin syrup to mask the bitter taste.

*“It was a syrup that was very bitter---I was given some tips that I have to give the child treatment at the same --- time every day but the fact that he could not stand the taste of the medicine he was very troublesome when it came to taking the treatment, he would spit it out and sometimes throw up and I realised that the treatment was not effective because of that.”*  
(Caregiver 011)

In addition, caregivers also explained that they suspected that treatment was not effective as they narrated that the medication would result in abdominal discomfort including vomiting and diarrhoea.

One caregiver described her experienced with administering medication to her son who was then an infant:

*“I don’t know what was going on, but he was always vomiting, when you give him the syrup, he would throw up all the time, he would vomit and have a runny stomach- he would vomit and have a runny stomach, so I suspect his immune system failed and that led to treatment not being effective in the body”.* (Caregiver 010)

Of the nine (9) caregivers who were biological mothers and all HIV-infected and one grandmother who was also HIV-infected and all on ART, only one (1) caregiver, a mother, had also experienced treatment failure and was switched to a second line regimen. The caregiver with previous treatment explained:

*“I ran out of treatment because I was overdosing, I mean I was really confused, I was a confused thing, so they realised that ‘ah! the immune system is also messed up’-it was messed up and that was when my treatment was also changed and I was moved to second line.”*  
(Caregiver 003)

This finding shows that despite also being HIV-infected and on treatment, unlike their children, most of the caregivers did not experience treatment failure as they did not struggle with adherence to their medication.

Healthcare workers who were interviewed as key informants in the study, also collaborated caregivers' experiences regarding the administration of various paediatric ART formulations, noting that caregivers and young children struggle most with a bitter tasting medication called Kaletra syrup, along with tablets as the children experience difficulty in swallowing it. In addition, later formulations such as pellets and granules were also noted to cause difficulties during administration as they need to be mixed with food.

Other caregivers explained that their children were living with a disability that affected their ability to swallow and as a result, the children were fed and given medication through a feeding tube that was inserted into the stomach (gastrostomy). The caregivers expressed that they struggled with administering medication as they had to crush tablets including those that were meant to be swallowed whole, while syrup formulations would stick on the feeding tubes.

*“I dissolve them in water because he is not able to take them with his own mouth since he had TB meningitis and uses a feeding tube but before-before he had it-before he had TB meningitis, he was able to swallow himself.” (Caregiver 007)*

This finding illustrates that treatment failure in young children can be attributed to unfriendly paediatric ART formulations and inability of children to swallow tablets due to young age or disability resulting from advanced HIV infection at a young age. This calls for improved regimens that are easy to administer to young children and children living with disability.

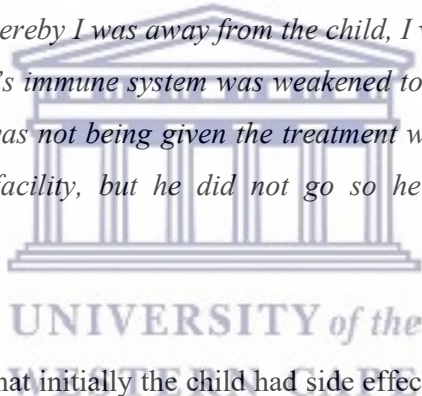
Although caregivers elaborated that they were committed to administering medication, some caregivers revealed that there were times when they would miss the dosage. The caregivers' personal health condition, including psychological mental health, had an effect on adherence and, in some cases, caregivers would refrain from waking the child up to administer medication if the child had gone to bed early, before administration of medication.

*“I had been depressed after his father left me with him. I have been raising him on my own so I suspect I have been under strain and sometimes I would forget, I mean something of that sort. Sometimes I would be going to the doctor and they would give him some medication that I would give him but sometimes I would forget to give him.” (Caregiver 002)*

*“You know, there was a time you would find that if the child could sleep, I would---I would, I mean even though it did not happen every day, if she had slept, I would not wake her up you see. I would feel pity for her you see...” (Caregiver 012)*

In addition, caregivers disclosed that their children had previously missed appointments or had gone long periods without medication. The reasons for interrupting treatment for a long time included the primary caregiver working away from home, denial regarding the HIV positive diagnosis and disagreements between parents regarding the care and treatment of the HIV positive child.

*“There was a time in 2019 whereby I was away from the child, I was away for work purposes so that was the time the child’s immune system was weakened too much at that time. So that happened because the child was not being given the treatment well, there was a time-a time when he had to go to the facility, but he did not go so he spent a long time off his medication.” (Caregiver 004)*



Another caregiver explained that initially the child had side effects including loss of appetite, which resulted in weight loss. Due to lack of understanding, this prompted the child’s father to stop the mother from continuing to take the child to the clinic:

*“He has been receiving services from the year 2008, but in 2009 he defaulted because his father complained that the medication is not treating his child well and makes him lose weight.” (Caregiver 006)*

#### **4.2.2.2 Treatment literacy issues**

The first step in ensuring correct dosing and administration of ART is to provide counselling and treatment literacy to caregivers and older children. All caregivers, including those who were employed were able to attend treatment literacy sessions, with work excuses issued to

caregivers who were employed. However, some caregivers explained that despite attending treatment literacy sessions and being guided on how to measure the correct volume of syrup, they would still receive feedback that they had given the wrong doses.

*“They explained it to me how the syrup was taken and its measurements how it is taken but still you would find that we thought that we had gotten the measurements right but when we got back to the doctor, we discovered there were times when the child did not take it well.”* (Caregiver 006)

On the other hand, other caregivers indicated that the treatment literacy instructions were not clear regarding the administration of ARVs in tablet formulations and this led to caregivers crushing pills which were meant to be taken whole.

*“He was not able to swallow some pills so I would crush them and give him only to learn that that kind of treatment was not supposed to be crushed.”* (Caregiver 007)

This finding illustrates that suboptimal treatment literacy contributes to treatment failure and it is therefore vital to ensure intensified treatment literacy, including repeat sessions.

#### **4.2.2.3 Child-related medication administration issues**

Caregivers described that as their children became older, they had allowed them or trusted the children to take medication unsupervised and this resulted in poor outcomes as the children had grown tired of taking medication daily and would miss doses due to fear of stigma from peers and other people. For some children, being away from their caregivers also created problems as they did not adhere to their treatment.

*“I have to see to it that when I leave, I give him his pills all the time because he was mostly confused while he was at school at boarding school. He was not adhering well completely to his treatment so when the schools closed and he had to come home, we made a decision for him not to go back but go to a nearby school so that we make it a point that he adheres accordingly to the treatment.”* (Caregiver 001)

*“He was administering the treatment himself, not in my presence, because I would tell him to go take it and he would pretend to be doing that, so you may find that sometimes he does not do so. I ended up making a decision that there will never be a time he will give himself medication whether he is old or not because when he does it, he cheats.”*

(Caregiver 008) “Mistakes do happen because when we have left the older one by himself, he does not want to take the treatment...he is a teenager. When we had been admitted at the hospital with the younger one, when I got back, I would find the pills still full in the bottle.”

(Caregiver 010)

The findings above illustrated that caregivers encountered problems with children adhering to their medication including when the caregiver was away from the child. The findings also show that until they have a full understanding of their HIV diagnosis and importance of treatment, children should not go unsupervised when taking medication, as they require close monitoring regardless of their age. Pill fatigue caused by the longterm intake of ART is also demonstrated in the instance in which an older child had stopped taking medication during his mother’s absence. The findings also imply that their caregivers struggle with looking after more than one child and therefore there is need for additional support to such caregivers.

#### **4.2.3 Caregiving challenges and support from family**

The third theme that emerged was on the experiences of caregivers regarding their caregiving responsibilities and the support from family. The theme was developed from the sub-themes that comprised of provision of care to an extremely sick child; difficulties that caregivers faced financially and socially; experience with disclosure to the HIV-infected child and others; experience regarding support from family members; provision of care to multiple dependants; provision of care by multiple caregivers; and fear of stigma and discrimination. The theme and sub-themes are illustrated in the Table 4 below with each sub-theme detailed in sections below:

*Table 4: Experiences regarding Caregiving Challenges and Support from family members*

Name of theme	Sub-theme
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<p>Caregiving challenges and support from family</p>	<ul style="list-style-type: none"> <li>• <b>Providing care to an extremely sick child</b> <ul style="list-style-type: none"> <li>-Caring for a sickly child</li> <li>-Difficulty when discussing child's health issues</li> <li>-Caring for a child with disability</li> </ul> </li> <li>• <b>Financial and Social difficulties</b> <ul style="list-style-type: none"> <li>-Balancing work and caring for child</li> <li>-Inability to attend clinic appointments due to long walking distance/limited finances</li> <li>-Caregiving responsibility resulted in lack of social life</li> </ul> </li> <li>• <b>Experience with disclosure</b> <ul style="list-style-type: none"> <li>-Non-disclosure to the child/Not easy to disclose to the child-Disclosing is easy within the nuclear family</li> </ul> </li> <li>• <b>Experience regarding informal support</b> <ul style="list-style-type: none"> <li>-Support from close family, not extended family</li> <li>-Support from other relatives, none from the spouse</li> <li>-Desire for more support and involvement of the spouse</li> <li>-Emotional issues of single-handedly being a caregiver</li> <li>-Death or desertion of spouse</li> </ul> </li> <li>• <b>Provision of care to multiple dependants and provision of care by dependants</b> <ul style="list-style-type: none"> <li>-Caring for multiple dependants</li> <li>-Intergenerational caregiving can be challenging</li> <li>-Care given by multiple caregivers</li> <li>-Extended family member caring for an orphan</li> </ul> </li> <li>• <b>Fear of stigma and discrimination</b></li> </ul>
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#### 4.2.3.1 Providing care to an extremely sick child

When articulating the challenges that they had encountered in the provision of care to CLHIV, the caregivers recalled that they struggled with caring for a sickly child or a child who was severely ill.

Difficulties faced by caregivers included children requiring more care including being seen at the clinic frequently and in some instances being hospitalised. In some instances, caregivers gave details of the burden that they faced in the provision of care to children who had developed disabilities secondary to severe HIV infection.

The following finding was articulated by one caregiver:

*“Since birth, she has always been a sick child, she was a tricky child, she started on the treatment truly after receiving the results but she was always ill. She was always ill until they drew her blood to check her viral load and it was revealed that her viral load does not pick up, they kept on giving her treatment and it was even changed to another type.”* (Caregiver 003)

Other caregivers shared similar experiences;

*“I mean the child was sick regardless he was adhering accordingly to the treatment, he was very sick, so sick and he would end up in the hospital and the likes.”* (Caregiver 011)

*“He was very sick and when we arrived here it was discovered that the child had TB and he started regaining his life after coming here. I could swear that he was dying and following his mother to the grave but here he is, alive.”* (Caregiver 012)

Some caregivers revealed their experience with caring for children with disability due to severe HIV disease:

*“He has not shown any progress because since he was said to be having meningitis that was when he stopped talking, he was unable to walk, became blind and he was not able to do everything he was able to do before.”* (Caregiver 007)

*“It’s just that the little one was always sick with different ailments compared to-to other people, yes, I think it was because he was not a normal child. The second point, the children with special needs and more especially HIV positive ones, there are no schools for such kids. The child is my burden, I must stay with him in the house, I wish we could have a centre in the country, yes, for children with special needs.”* (Caregiver 010)

These findings indicate that caregivers faced difficulties due to the burden of providing care to severely sick children and children with disability. Such children need full-time care, however due to the unavailability of palliative care facilities, this burden falls on the shoulders of the caregivers. The findings also indicate that HIV infection in young children can be severe, predisposing them to opportunistic infections and that severely sick children are more likely to delay in responding to treatment and in some instances, they are more

likely to develop treatment failure. The findings also imply that the caregivers of such children require additional support such as counselling, financial support and occasionally being relieved of their responsibilities.

#### 4.2.3.2 Financial difficulties

Caregivers described the financial and social difficulties that they had encountered as they provided care to CLHIV. The responsibility of caregiving had resulted in some caregivers facing difficulties with attending clinic appointments due to financial constraints including lack of money for transport fare. Issues that were faced by caregivers included taking the painful decision to resign from their jobs to prioritise the wellbeing of the HIV-infected child. Other caregivers shared that in their pursuit to provide care to their children, they kept their jobs but struggled with balancing work and caregiving, while some strived to ensure that they prioritised clinic appointments despite the financial constraints.

One caregiver shared that they struggled to make it to the clinic due to lack of transport fare:

*“You know what, my main challenge is (sighs) you see he has always been a sickly child and he came here often, so I realised that my challenge is transport issue, I stay very far and I board two taxis to get here. Yes, truly sometimes you may find that for the check-up -I don’t make it here for the check-up, sometimes I don’t have money yet, truly that is the challenge I am facing.”* (Caregiver 012)

Caregivers gave details of their experience with working and caregiving:

*“You know the fact that I have been working before the child could get sick, when he got sick, I had to leave work.”* (Caregiver 007)

*“I do a night shift at work-I work a night shift. I am coming all the way from there to here, while here I have to get the child and get back there again, in the evening I have to come back on foot, and I have to get ready for work”* (Caregiver 003)

This is a challenge that was also described by the healthcare workers who were interviewed as key informants. When giving details on the factors that contribute to treatment failure in children, such as missed doses and resulting poor adherence in the case of employed caregivers, one key informant explained:

*“Most of our caregivers are mothers and most of them are working and if I can be specific, they are working at the factories. So, they go to work very early in the morning, they come back very late so it’s really difficult for them to give medication because some of them would*



say, “When I leave in the morning the child is still sleeping and I am not able to give them the medication so when I come back in the evening, they are already asleep”. So, this is one of the challenges that they have.” (Healthworker 002)

#### **4.2.3.3 Experience with disclosure**

Disclosure, that is giving information to a child about their HIV status, the implications and importance of treatment, is recommended to ensure optimal adherence. Caregivers gave details of their experience with disclosure to their children. When probed on disclosure to their children who had previously struggled with adherence and high viral load, caregivers mentioned that they had noted improvement because the children understood the importance of adhering to their medication.

*“He understands completely, fully. I have realised where we are...at the moment I can attest well because he is now able to go to the clinic on his own.”* (Caregiver 001)

*“Yes, he was part of counselling because it was explained to him why he was taking medication. At the moment I see a great change because when he was first starting with the treatment, he was very young but I mean now that he is a big boy...I used to conclude that it caused him to be stressed, sometimes he would be forgetful, sometimes, but that does not happen anymore.”* (Caregiver 008)



#### **4.2.3.4 Experience regarding informal support**

Caregiving can be overwhelming and support to caregivers offers some relief. Experiencing lack of support from their relatives was shared by most of the caregivers, who explained that they were the primary caregivers of their children and received no support from their spouses or partners and other family members in the provision of care to the children, including attending clinical appointments or administering medication. The death of a spouse and in some cases, desertion by a spouse were also expressed as experiences by some caregivers. This recollection was emotional for the caregivers as they expressed the lack of support from their partners in the care and upbringing of the child. In some cases, the absence of the spouse led to psychological effects which affected administration of medication.

Some caregivers shared that they received support, although it was limited in certain instances:

*“There is support--I am not the only caregiver she has because the father of the house is there and her brother who is my child.”* (Caregiver 004)

*“My husband is the one who does assist but not always, yes, most of the time it is my duty, you may find that when I arrive home very late though it does not happen a lot, but he is the one who helps, if it happens that I am not around, yes.”* (Caregiver 009)

*“No, truly just like...he has no one to visit, he only visits his aunt only because we don’t have parents anymore, he does not have a grandmother.”* (Caregiver 002)

In contrast, other caregivers described that they had no support, as a result of separation from the spouse or death of a spouse:

*“I think at that time we were admitted for a month and when I came back, I found out that he was staying with another woman and the firstborn was so traumatised and telling me all sorts of hurtful things until we had to be separated (sighs)”* (Caregiver 010)

*“It has always been me only administering the treatment all the time, yes. The father of the child passed away even before the child could be on treatment, yes, he died due to having TB.”* (Caregiver 008)

#### **4.2.3.5 Provision of care to multiple dependants and provision of care by multiple caregivers**

Provision of care to multiple dependants was also mentioned as a challenge by caregivers, with some narrating that they also provided care to other HIV-positive children. In some instances, the experience of provision of care to multiple dependants could be overwhelming and for some caregivers it was not an easy task as they were faced with the dilemma of prioritising one child over another.

*“He was still in my care because his mother who was in care also, was sick. I also administer their medication, together with his grandfather.” (Caregiver 004)*

One caregiver, a mother to two CLHIV who had both developed treatment failure, mentioned that her focus was more on the younger one as he was sickly and unintentionally, she neglected the older one.

*“In 2008 I also got tested for HIV and I learned I was HIV positive, I had to bring the firstborn also for tests, born in 2001 and the results also came back positive, yes, so we are all on treatment-on ART. So due to the little one who was very sick---it was not easy to always be there with the older boy for his check-up routines. I could not do it before when his younger brother was still alive, it is only now that I am able to sit and attend to his needs and the fact that he does not have a bond with me, growing up as a child I was not around him.” (Caregiver 010)*

Caregivers also gave details regarding their varying experiences with the provision of care to the child by multiple people. Although in some cases the availability of other caregivers was an advantage, in other instances, it was not beneficial as adherence was affected because of secondary caregivers' lack of understanding due to not being fully involved in the care of the child.

*“Yes, I took the child under my care, more especially because his father is someone who is going to work, he is in building construction and leaves the child with his brother who is always away traveling and also I suspect poor nutrition because if he went in the morning, he comes back in the evening without giving the child medication and some food during the day.” (Caregiver 005)*

#### **4.2.3.6 Stigma and discrimination**

The fear of being stigmatised and discriminated, along with perceived or felt stigma and discrimination was another experience that caregivers described. Caregivers expressed that they experienced rejection or in some cases, perceived that they would be rejected by other people due to their HIV status or that of their children. Such fear had been felt or perceived especially in the case where caregivers had not disclosed their own HIV positive status or the

HIV positive status of the child. Some caregivers also described that their children had also experienced or perceived stigma and discrimination from other people.

*“I mean it was not an easy task completely, at that time really...it was really so humiliating. I mean one was discriminated against, when you were from there (the clinic) they would point fingers at you ‘there she goes’- ‘there she goes’- ‘there she goes’ truly there was a lot of gossiping around, a lot of challenges but in the midst of all that, the fact that I knew what I wanted, I kept going on.” (Caregiver 003)*

*“Our issues are kind of confidential, I would not disclose to my brother that my child is on ART because I don’t know when he will spread the information about my child to the public.” (Caregiver 013)*

One caregiver described that her son lived in fear regarding his HIV status:

*“Once he hears HIV mentioned he feels out of place as though they are talking about him, even in class when they are discussing about HIV he looks around as though someone is pointing a finger at him while that is not the case ---.” (Caregiver 001)*

This finding of the challenge that caregivers of CLHIV faced regarding stigma and discrimination, was corroborated by one of the healthcare workers who were interviewed, who is also HIV infected and has a son who is living with HIV. The healthcare worker explained that although stigma and discrimination used to prevail in previous years, there has been improvement in recent years as people have more education regarding HIV.

*“You may find that they now understand the impact of taking the treatment because there is no more discrimination, there is no one discriminating against them, unlike back then-back then it was very difficult for one even to get through the gate but at the moment truly it looks like they are educated, understanding and they are living unlike back then when people died morning and evening.” (Healthworker 001)*

#### **4.2.4 Counselling and psychosocial support**

The fourth theme to emerge dealt with the caregivers’ experience regarding counselling and psychosocial support. The theme was developed from sub-themes including the caregivers’

experience regarding counselling and psychosocial support and the caregivers' wish for improved counselling and psychosocial support. The theme and sub-themes are summarized in the Table 5 below with each sub-theme detailed in sections below:

**Table 5: Counselling and Psychosocial Support Experienced by Caregivers**

Name of theme	Sub-theme
Counselling and psychosocial support	<ul style="list-style-type: none"> <li>• <b>Experience regarding counselling and psychosocial support</b></li> <li>-Impact of counselling: change of mindset to improve adherence</li> <li>-Counselling does not always result in the desired effect</li> <li>-Dissatisfaction with support from the healthcare facility</li> <li>-Satisfaction with psychosocial support given</li> <li>• <b>Wish for improved counselling and psychosocial support</b></li> <li>-Desire for continuous and optimised counselling</li> <li>-Emphasis on continuous counselling to ensure adherence and confidence</li> <li>-Necessity for group counselling to learn from others' experiences</li> </ul>

#### 4.2.4.1 Experience regarding counselling and psychosocial support

The management of HIV includes counselling and psychosocial support to patients and their caregivers. Ideally, as part of HIV testing services, patients and caregivers should undergo counselling before and after testing for HIV. In addition, counselling should also be done prior to the initiation of ART and during the period that the patient is on ART. Caregivers expressed varying experiences with counselling and psychosocial support from the health facility at which their children are enrolled. Regarding their experience with counselling at the time that their children experienced treatment failure or they struggled with adherence to medication, some caregivers narrated that their experience during counselling sessions was good. The caregivers described that as procedure, they would be sent for counselling sessions and the healthcare workers who addressed them were friendly, patient and showed empathy towards them.

*“Truly when I arrive at counselling room, I would find a very warm person who would advise me very well and be like ‘here you might have not been giving the child his ART accordingly’ and they would address me calmly, without making me feel frightened or anything. I mean all was well in counselling, there were no challenges and I would find people who were so helpful and talked very well with me.”* (Caregiver 002)

*“I received great- great support. When one has a child who needs special care like the one, I had, the relatives don’t give you the support you need, so at the clinic, I knew if I could arrive crying, I would come out refreshed and I was going to meet with people who know exactly the kind of person I am so much that even when I get through the door, they are able to notice that today I am not happy. I would cry out the pain and receive counselling and come back renewed and refreshed. I would get all the support I needed”* (Caregiver 010)

Despite receiving care from the same facility, other caregivers recounted their negative experiences during counselling sessions that they attended when their children developed treatment failure. Caregivers expressed that the healthcare workers would use hurtful words when addressing them, without displaying any understanding of their situation. Due to the sensitivity of the topic, one became emotional when she recalled her experience during a counselling session.

*“Some are very rough and mean. They will be like, ok, fine, if you don’t take your treatment, it’s you who will die. So, you hear those words...those are not words you should be told as a patient or a caregiver. We need to be called here for words of support and comfort.”*  
(Caregiver 011)

This finding implies that the healthcare professionals might have been upset because of the lack of adherence.

Another caregiver explained that:

*“I remember the other time I was with the social worker and I was asked why this thing is not decreasing-why the viral load is not being contained but the CD4 count was...or whether the child’s CD4 was-normal but his viral load was...they did not match I didn’t know right then what was supposed to happen, so it was...the social worker told me that was because the caregivers are used to telling the lies and all sorts of things, there was no way CD4 count could be normal and viral load high...”* (Caregiver 009)

One of the key informants who were interviewed attested to the fact that patients and caregivers may have had experiences with counselling and support from the clinic. The healthcare worker acknowledged that such attitude was uncalled for as their role was to support patients.

*“Another challenge is from us health workers, you may find that sometimes when we are supposed to offer help to the patients, we tend to lose patience, we are unable to give ourselves time, we are unable to be patient with them. Another is that we are comparing the patients, we may go like ‘That child is managing in giving their sibling treatment and this one is an adult yet is failing, I don’t know where the problems are’, meaning we are supposed to get our house in order and treat each patient the same way, offer help so that they may all manage to give the children treatment.”* (Healthworker 001)

In addition to experience with regard to receiving counselling, caregivers described their experience with psychosocial support that was given to the children in their care. Based on their account, psychosocial support was vital to both caregivers and their children as they noted that children who were in psychosocial support groups for HIV positive children fared better with regard to adherence to their medication.

*“He was assisted by his youth group, named Teen Club, yes most of the time it has assisted me. He adheres well to the treatment, although he had his shortcomings, but he can now*

*remember to take the treatment, with the help of the support group for children.” (Caregiver 013)*

The main benefit that was described regarding both counselling and psychosocial support was the ability for healthcare providers to support patients in resolving their problems.

*“The way the patients are being offered assistance, it is a chain service sort of, when a patient has high viral load, you may find that the patient is not observed by the doctor and a nurse only, the patient will visit the counsellor. When the counsellor is not satisfied, they will pass the patient to me for treatment literacy or to peer educator or to the psychologist, up to a point that we find the cause of the distress.” (Healthworker 001)*

This finding implies that counselling should not be offered once off, but many steps and approaches, including involving different types of healthcare workers should be considered when addressing patients’ issues.

*“For this age group, we have support groups here for the children who are at the age of 10 to 18 years, we have a Teen Club. We have an opportunity at those support groups to meet with the-the caregivers where we are able to address the common challenges of the children of that age. We also have a support group for male caregivers just to address their challenges.” (Healthworker 002)*

The finding above also supports the importance of a holistic approach including additional support in the form of psychosocial support groups for HIV positive children and support groups for caregivers of CLHIV, in addressing difficulties that they encounter.

In addition, caregivers expressed that they wished that counselling could be provided regularly and even when there are no challenges with treatment failure. In addition, caregivers also described their desire for more support beyond counselling, such as caregivers support groups and support from social welfare services.

*“I think counselling, I feel it could be effective maybe after every four months here at the facility we come and have a refresher counselling whereby we are reminded about the child...the significance of ART, the side effects...and then we review again after every four months. I think that could work on our side compared to coming for counselling when the child encounters challenges or on my side when I go through trials.” (Caregiver 001)*



*“I would advise that on the support they offer I wish they could offer more; I mean they should not give counselling to us only when we are going through challenges only.”* (Caregiver 004)

*“Well, the counselling we have received is satisfactory, but I wish that for us parents of children who are on ART, as part of counselling, if there was a group for us--- if we could be brought together as parents of children on ART and then we all get counselling.”* (Caregiver 002)

The findings above show that ongoing support is necessary for caregivers of CLHIV considering the burden they had of caring for these children and since HIV is a chronic disease, caregivers may need reassurance that they are not alone in the journey.

Key informants who were interviewed also acknowledged that the provision of ongoing counselling is key. Although the practise has been that caregivers and patients are only referred to counselling when they have challenges, there is now a growing realisation of the need to provide continuous counselling.

*“We realised that it was not good to only sent patients to counselling or social work department when things were not good, but we wanted to pass a message to our clients that even when things are well, counselling is still part of the process. So even when the caregiver is doing well, they must be sent to counselling sessions just for the counsellors and social workers to positively reinforce what they are doing.”* (Healthworker 002)

The in-depth interviews also revealed that to overcome some of their challenges, caregivers wished for more support beyond counselling and psychosocial support. A caregiver whose child who is disabled is a beneficiary of social development services, lamented about the erratic nature of receiving assistance.

*“Well, I had been advised to go to social development so I don't know how many times one can get assistance from social development, I think only twice or three times in a year, they give him nappiess, milk and the likes.”* (Caregiver 007)

*“The second point...the children with special needs and more especially HIV positive ones, there are no schools for such kids. The child is my burden, I must stay with him in the house,*

*I wish we could have a centre in the country, yes, for children with special needs, yes.”*  
(Caregiver 010)

These findings indicate the need for and importance of continuous counselling that is provided with compassion and empathy by healthcare workers. In addition, the findings point to the necessity of psychosocial support for all different populations, including children and caregivers as such groups contribute to the holistic wellbeing of beneficiaries. Moreover, the findings stipulate the desire for additional support including social welfare assistance to CLHIV and their families.



## CHAPTER FIVE: DISCUSSION

The purpose of this chapter is to discuss the key findings. The aim of the study was to explore the experiences of caregivers of CLHIV who had experienced treatment failure to ART. Study findings highlighted the experiences of caregivers of CLHIV who had exhibited treatment failure to ART. Although the study participants comprised of different types of caregivers, there were a few differences that were noted among the caregivers including the relationship to the child, caregiver's age and HIV status of the caregiver. There was a consensus in their experiences regarding the provision of care to CLHIV with experience of treatment failure to ART.

The key findings in the study included the diversity of caregivers and their personal experience; most caregivers being HIV-infected biological mothers who were also on treatment and having to deal with the emotional impact of their own HIV diagnosis along with that of the child. Gaps in the availability of easy to administer and child-friendly ART were noted to have contributed to the caregivers' struggles with ensuring the child's ability to adhere to treatment. Caregivers also faced a combination of dilemmas in their efforts to ensure provision of care to the CLHIV as they had to balance this with work and their social life, deal with caregiving to multiple dependants, experience limited or lack of support within their families, face stigma and discrimination and consider disclosure to the child and other family members. Lack of support, including an unfriendly approach from healthcare workers when children displayed treatment failure was also a key finding, while there was also desired improved and regular support, empathetic counselling and engagement in support groups for both caregivers and CLHIV.

### 5.1 Diversity of caregivers and their personal experience with HIV

Most of the caregivers were biological parents, with all the biological mothers and one grandmother also being HIV-infected and on ART. This implies that most of the caregivers had to deal with the emotional impact of their own HIV-positive status along with providing care to their HIV-positive children. There have been similar findings from other studies in which most caregivers who were biological mothers and HIV positive had struggled to deal with their own HIV-positive status and that of their children (Atanuriba et al., 2021, Madiba & Diko, 2020). However, since the study was conducted in an urban setting and the majority

of the participants were female, the sample might not be representative of rural settings where women are known to leave for urban areas including cities in South Africa in their quest for employment and therefore leave their children with elderly caregivers or their husbands (Moletsane, Coetzee & Rau, 2017).

Of the three maternal grandmothers who were caregivers, two had lost their daughters who succumbed to HIV-related illness, leaving their children orphaned at a very young age. Other caregivers included a biological father and a maternal aunt whose wife and sister, respectively had also died due to HIV-related illness. Consequently, caregivers had to deal with the grief of losing a loved one, along with looking after their grandchildren or children who are also HIV-infected. This finding is an indication of the fact that in the advent of the HIV pandemic as a result of high HIV prevalence among young adults, especially females, compounded with lack of ARVs for treatment and prevention, young mothers would die, leaving their HIV-infected children with other caregivers including elderly grandparents. Similar findings were shared by other researchers who observed that prior to the universal availability of ART, young adults succumbed to HIV-related illnesses, leaving their young and often, HIV-infected children, in the care of grandparents (Casale, 2011).

Whereas most young people would previously die and leave behind their young HIV-infected children as a result of HIV-related illness, improvement in the survival and lifespan of biological parents, especially mothers, was noted. The proportion of caregivers who are extended family members was lower than the proportion of biological parents, notably women, in the study. The improvement in the lifespan of PLHIV is in line with findings that the improved availability of treatment has resulted in the longer survival of HIV-infected parents and therefore fewer HIV-infected orphans who are left in the care of grandparents and other relatives (Block, 2016). In addition, advances in HIV management have resulted in successful PMTCT programmes, a reduction of mother-to-child transmission of HIV and fewer children being infected either in pregnancy, during birth or during breastfeeding.

## **5.2 Gaps in Paediatric HIV Prevention and Management**

Most of children whose caregivers participated in the study were diagnosed as infants. The early diagnosis of HIV in children points to the fact that transmission occurred from the

mother to the child during pregnancy, at the time of labour or early in the postnatal period from breastfeeding. Although there has been a notable improvement in HIV awareness, prevention from mother to child, and treatment, it points to previous gaps in the general knowledge of HIV testing along with HIV transmission and management, which resulted in delayed diagnosis of the mother. Consequently, delayed diagnosis and treatment of the biological mothers resulted in maternal transmission of HIV to their children. In addition, the children developed treatment failure to their ART because of multiple factors including substandard adherence to ART which is the most likely cause of non-suppression of viral load in PLHIV. The finding regarding children who were diagnosed with HIV and initiated on treatment in their early years of life, later developing treatment failure, is comparable with findings from other studies which indicated that CLHIV who were initiated on ART in their infancy had a higher probability of developing treatment failure to their ART (Haile & Berha, 2019).

Most caregivers experienced problems in the administration of various types of ART formulations including syrup, pellets and tablets as some of the children could not tolerate their medication or would struggle with swallowing the medication. Noteworthy to mention is that, although most of the caregivers were also HIV infected, only one caregiver had developed treatment failure. This is in contrary to the fact that all the children had at one time developed treatment failure. The findings, therefore, suggest that unlike the management of adult HIV, the management of paediatric HIV has not been easy due to the unavailability of child-friendly, easy-to-administer medication formulations. There is also corroboration with other studies which noted that despite changes over the years, especially in recent times, medications available for children have for a long time been in formulations that were not paediatric friendly, including of syrups (Orubu & Tuleu, 2017). Moreover, some studies point to a multitude of research having been conducted on the treatment of adult HIV, and better and efficient drugs have been developed, but that research for paediatric HIV management and the availability of child-friendly ART formulations is limited (Nalwanga & Musiime, 2022).

### **5.3 Dilemmas of managing HIV status in child and own HIV-positive status**

Caregivers were faced with the burden of providing care not only to the HIV-infected children, but also to other dependents including other children. This finding of caregivers being overwhelmed with the provision of care to multiple family members is in line with findings from other studies, including a study conducted by Small et al. (2019) which demonstrated that caregiving in the setting of HIV is made complex by the provision of care to multiple family members.

Stigma and discrimination, especially from other family members, were also described by caregivers. The fear of stigma and discrimination was not only perceived but caregivers and their children were stigmatised and discriminated against. In some instances, caregivers had not disclosed their own status or that of the child to other family members because of the fear of being rejected or discriminated against. Adherence to medication and compliance to clinic appointments had been affected by the experience or fear of stigma and discrimination. This finding correlates with findings that caregivers experience poor adherence due to perceived or anticipated high levels of stigma (Paintsil et al., 2015; Biru et al., 2015). In addition, the finding also implies that there was lack of knowledge about HIV, resulting in perceived or felt stigma from the community. This finding also aligns with findings from a study conducted in Uganda in which children were told not to play with HIV-infected children for fear of becoming infected (Atanuriba et al., 2017). Although there has been improvement overtime, stigma and discrimination towards HIV-infected people and their caregivers are still prevalent among families and communities in general.

Although there were variations due to the differing ages of their children, the importance of disclosure to the child regarding their HIV-positive was also explained by caregivers. Whereas they had previously struggled with the children's adherence to treatment, caregivers noted that the situation improved after the children understood why they were on lifelong medication, resulting in improved adherence to treatment. This finding implies that disclosure, whether partial for young children, or full disclosure for older children, aids adherence to ART. The benefits of disclosure, including improved adherence and better

clinical outcomes have also been noted in other studies (Hayfron-Benjamin, Obiri-Yeboah, Ayisi-Addo, et al., 2018; Nasuuna, et al., 2019).

#### **5.4 Counselling and Psychosocial Support**

Caregivers had varying experiences regarding formal support in the form of counselling and psychosocial support. While some had positive encounters, others had unpleasant interactions with healthcare providers. Although this finding indicated diverse and conflicting experience of counselling as narrated by caregivers, there was no specific association with a specific age group of caregivers or type of relationship to the child. All caregivers recognised the benefits of counselling and wished for empathy and compassion from healthcare workers. This finding was also observed in other studies, with caregivers expressing that service providers had not been compassionate as they uttered harsh words which left them feeling disheartened by the treatment they were given (Williams, Van Rooyen, & Ricks, 2016). These findings show that the provision of counselling to caregivers in the setting of the management of a chronic illness such as HIV is considered vital.

In addition to counselling sessions, caregivers described benefits such as improved adherence, that they realised from their children being members of a psychosocial support group at the clinic. These findings show that psychosocial support groups including peer support groups and support groups for caregivers are acknowledged by caregivers, children and healthworkers as an essential component in the management of CLHIV. In addition, the findings indicate that there is a desire among caregivers for additional support. These findings are comparable to other studies that acknowledge that caregivers who are in psychosocial support groups fare well in adherence and caregiving responsibilities (Thurman, Jarabi, Rice, 2012) and the benefits of being a peer support group member include the provision of counselling and companionship, resulting in the reduction of stress, stigma and discrimination (Kartono, 2019).

The need to engage with caregivers and ensure the provision of care as desired by the caregiver (client-centred care) are findings also recognised in other studies (Atanuriba et al.,

2021). Care that is friendly, offered with empathy and respect and customised for the needs of patients and their caregivers is important in ensuring compliance to care, especially chronic care and adherence to medication. Similar findings regarding the importance of additional support are emphasised in other studies which affirm the need to incorporate support such as social assistance and to reinforce psychosocial support for caregivers of CLHIV by scaling up support groups (Nasuuna, Kigozi, Muwanguzi, et al., 2019).

### **5.5 Significance of findings**

This qualitative study focused on the experiences of caregivers of CLHIV who had ever experienced treatment failure. Similar to findings from other studies, this study elicited important themes regarding the lived experiences of participants regarding the provision of care to CLHIV, especially children who had ever experienced treatment failure. Even though this study was carried out only at the Baylor College of Medicine Children's Foundation Clinic in Maseru, the researcher is of the opinion that the findings of the study may be relevant in understanding the experience of caregivers of CLHIV and the support that is required by caregivers of CLHIV in Lesotho and other settings. The study findings will contribute to knowledge regarding the experiences of caregivers involved in the management and care of CLHIV and inform practice and policy regarding the management of paediatric HIV and support to CLHIV and their caregivers, that will be beneficial to the study participants, their children and other similar population groups.

### **5.6 Limitations**

The author acknowledges that this study has some limitations:

The Baylor College of Medicine Children's Foundation Lesotho (BCMCFCL) Clinic in Maseru is located in an urban area. The fact that the study was conducted in an urban setting may therefore not be representative of the general population, especially caregivers of CLHIV who are enrolled in rural health facilities. Services at most health facilities that offer HIV care and treatment in Lesotho are administered by registered nurse providers and a few counsellors, mostly lay counsellors. However, the BCMCFCL Maseru Clinic is referred to as a COE, with a good staff complement including doctors, nurses, professional counsellors, social workers, and pharmacy personnel (pharmacists and pharmacy technicians). Therefore,



even though the findings indicated vital themes regarding the experiences of caregivers of CLHIV who had ever experienced treatment failure, it may not necessarily apply to other health facilities. In addition, with most of the caregivers being females, the study may not be fully representative as male primary caregivers may have varying experiences to those of female caregivers.

Furthermore, the research did not gather information on the experiences of caregivers of older adolescents as the eligibility criteria limited participation to caregivers of children aged less than 15 years. Therefore, the findings may not be representative of all caregivers because caregivers of older children could have encountered different experiences. In addition, the fact that the researcher is a clinician who is employed at the study site, with a focus on the management of HIV, including treatment failure, may have a bearing on the ethical considerations and rigour of the data. On the other hand, the researcher's background as a clinician might also have been a disadvantage as it is a known fact that known researchers do not always get all the information (Orb, Eisenhauer & Wynaden, 2001) because of being familiar to study participants who may either feel obliged to participate or feel that the researcher already has the information and therefore only divulge limited information.

In addition, the study was conducted at the peak of the COVID-19 pandemic, and part of the data collection occurred during a partial lockdown period with movement restriction, which affected the attendance of caregivers at the clinic, with some older children presenting on their own. Furthermore, due to public health guidance including distancing, wearing of masks and limiting interaction time, participants may have been brief in their responses and therefore limited the information that was required for fear of contracting COVID-19 infection.

## **CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS**

The research study intended to provide the answers to the following research questions: What are the caregivers' understanding of HIV treatment and treatment failure? What are the lived experiences of caregivers of factors that contribute to treatment failure? What are the challenges and factors related to providing care to CLHIV who have ever experienced treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho? What support is required by caregivers to improve ART adherence and viral load suppression for CLHIV?

### **6.1 Conclusions**

The study findings demonstrated that caregivers of CLHIV who have experienced treatment failure, faced similar burdens and challenges. Experience including the caregivers' initial reaction to their own HIV diagnosis and that of the child, led to missed clinical appointments and non-adherence to medication. On the other hand, the experience with limited options of paediatric medication resulted in caregivers' challenges when administering medication as it was not child-friendly; a factor which contributed to suboptimal adherence. Note-worthy is that caregivers received treatment literacy and adherence counselling and they had knowledge of HIV treatment and treatment failure. However, caregivers faced various dilemmas which also played a role in compliance to care and treatment, such as burden for the provision of care to multiple dependants; managing their own HIV diagnosis; socioeconomic issues such as balancing their social life or income generating activities with caregiving; disclosure to the child; issues with disclosure to other family members and support from other family members. Moreover, caregivers' experience with support received from the health facility and the desire for more support, including counselling and additional psychosocial support through their children or themselves being members of psychosocial support groups emanated from the study.

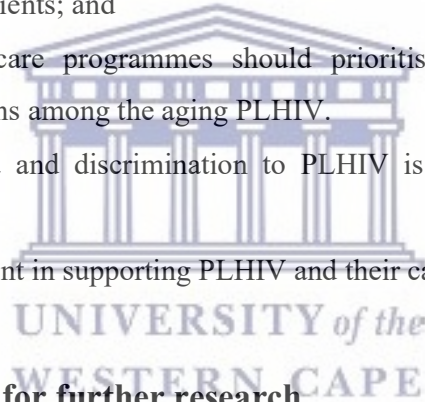
### **6.2 Recommendations**

Based on the study findings, recommendations that are made are classified into recommendations for practice and recommendations for further research.

## 6.2.1 Recommendations for practice

The following recommendations are based on the findings of this study:

- More attention should be paid to pre-testing and post-testing of HIV to ensure that caregivers and patients understand the diagnosis of HIV and implications;
- Engagement of male caregivers in the provision of care to CLHIV needs to be considered;
- Although there have been advances in treatment formulations, there is a need to continue to ensure the availability of improved, child-friendly medication and support in ensuring treatment literacy to caregivers and their children;
- Caregivers and CLHIV, should be offered client-centred, friendly services and holistic support including recurring counselling with compassion, expansion of psychosocial support groups for children and adults;
- Regular client satisfaction surveys should be conducted to help improve the quality of services provided to clients; and
- HIV treatment and care programmes should prioritise morbidity and mortality prevention interventions among the aging PLHIV.
- Eradication of stigma and discrimination to PLHIV is a matter that needs to be prioritized
- Community engagement in supporting PLHIV and their caregivers is needed



## 6.2.2 Recommendations for further research

Upon completion of the study, some research gaps were noted and the following are recommendations for further exploration based on the identified gaps:

- Eradication of stigma and discrimination to PLHIV
- Inclusion of more key informants in a similar study
- Experiences of caregivers with disclosure to CLHIV
- Experiences of caregivers of adolescents living with HIV
- Experiences of caregivers of children and adolescents living with HIV regarding disclosure
- Experiences of caregivers of children and adolescents who are enrolled in psychosocial support groups and support assistance programmes

- Aging and non-communicable diseases among PLHIV

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## APPENDICES



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### **Appendix 1: Information Sheet for caregivers (English)**

**Project Title: An exploration of the experiences of caregivers of children living with HIV who experience treatment failure to ART in Lesotho.**

What is the study about?

This research study is conducted by Mosa Molapo Hlasoa, a student at the University of Cape Town who is currently pursuing her Master in Public Health studies. You were approached and requested to participate in this study because you are a caregiver of a child who accesses healthcare at the Baylor Clinic in Maseru and your child has experienced treatment failure. The purpose of this research project is study is to explore the experiences of caregivers of children living with HIV with experience of treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho.

What will be expected of me if I agree to take part in the study?

If you are willing to take part in the in the research study, I would like you to carefully go over the attached consent and then sign it. Through the interview, the researcher will strive to have appreciate and comprehend your experiences with being responsible for the provision of care to a child living with HIV who has experienced treatment failure. The individual interviews are anticipated to last for an hour, but you will be requested for more time if needed. With your permission, the interviewer will use an audio recorder to capture the interview. Through the use of an audio recorder, the researcher will be able to document all information that you will share and the recording will be used as a reference for clarifications

of what you said during the analysis process. Audio recordings are used by researchers for translation from audio to text using the exact words.

How will I be assured of confidentiality if I take part in the study?

It will be the responsibility of the researcher to safeguard any identifying information and the type of your involvement in the study. All study participants including yourself, will be independently approached and anonymity will be ensured as the interviews will take place in a secure space. During data collection, the researcher will not use your name. Individual study participants will be allocated an identifying number that will distinguish them, and the number will be exclusively known by the researcher. The identifying number that will be allocated to you will not be connected to any particulars that may lead to you, such as consent forms, audio recordings or notes documented during interviews. Information that you will provide will only be associated with you by using the distinguishing code.

To secure your confidentiality, all recordings of the interviews with participants, notes taken during and after interviews, and transcriptions will be saved on a computer with password protection and backup will be done on an external hard drive, whilst hard copies of the data will be stored in a lockable drawer. The research data will only be accessed by the researcher and the data will be stored securely for five years before being destroyed. The information from the recorded interview will not be traceable to you and the researcher will not use your names or identifying information when transcribing the recorded discussion. Only identification codes assigned to participants will be used on information that can be associated with you. In the instance that the researcher writes a report based on this study, word by word extracts from individuals may be used, but there will be no details that will be linked to you as the extracts from the interviews will not be associated with individuals.

In the event that any information comes to that could result in harm to you or others comes up during the interview, the researcher is legally bound by legal requirements and/or professional standards, to report such information to the appropriate individuals and/or authorities. In the case of the need and requirement to disclose private information to authorities, the researcher will engage you regarding the matter.

What are the risks of this research?

All interactions with humans and revealing information about self or other people may be associated with some risks. There is a possibility that some of the questions which will be directed at you may leave you feeling uneasy or unhappy. However, the researcher will take

the responsibility to limit such risks and readily help you if you become overwhelmed with anguish or sadness during the interview. If you develop feelings of awkwardness as a result of questions directed to you during the interview, you will be at liberty to not respond to such questions. If the need arises, you will be referred to an appropriate health professional for further care.

What are the benefits of this research?

You will not benefit directly from your participation in this study, however, based on the findings of the study, the investigator may learn more about the experiences of caregivers who provide care to children living with HIV who experience treatment failure to ART. The researcher is hopeful that other caregivers might benefit from this study through improved understanding of the experiences of caregivers of children living with HIV in Lesotho.. This will help take into account the lived challenges and factors related to providing care to CLHIV and experiencing treatment failure to ART. Additionally, the researcher hopes that the research will help define the kind of support that caregivers require to improve ART adherence and viral load suppression for CLHIV.

Is it mandatory for me to participate in the study and would I be able to opt out of the study at any time?

Your participation in this research is entirely voluntary. You may decide not to participate at all. If you decide to participate in this research, you may opt out of the study at any give time. If you feel uncomfortable about any questions we ask, please feel free not to answer them. If you make a choice to not to participate in this study or if you decide to opt out of the study at any time, you and your child will not be penalised or not receive any benefits that you are eligible for.

What if I have questions?

This research is being conducted by Mosa Molapo Hlasoa, a student at the School of Public Health, Faculty of Community and Health Sciences at the University of the Western Cape, South Africa. If you have any questions about the research study itself, please contact Mosa Molapo Hlasoa of address: Baylor College of Medicine Children's Foundation Lesotho, P/Bag A191, Maseru, Lesotho; Cell phone number: +266 58962045 and email: [mmolapohlasoa@baylorlesotho.org](mailto:mmolapohlasoa@baylorlesotho.org) or [mosa.c26@gmail.com](mailto:mosa.c26@gmail.com)

In the case that you have questions or concerns regarding your rights related to your participation in this study, feel free to contact:

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

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## **Appendix 2: Information Sheet for caregivers (Sesotho)- Tlhaloso ka boithuto**

**Lebitso la boithuto: Tlathlho ba boiphihlelo ba bahlokomeli ba bana ba noang lithare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV, naheng ea Lesotho.**

Boithuto bo mabapi le eng?

Boithuto bona bo etsoa ke Mosa Molapo Hlasoa, ea ntseng a tsoellisa lithuto tsa hae tsa bophelo sekolong sa University of the Western Cape. U memetsoe ho nka karolo boithutong bona hobane u le e mong oa bahlokomeli ba bana a fumanang kalafo setsing sa Baylor Maseru 'me ngoana ea tlasa hlokomelo ea hau a kile a ba le bothata ba ho se kokobele hoa kokoana hloko ea HIV. Lebaka la mantlha la boithuto bona ke ho utloisisa boiphihlelo ba bahlokomeli ba bana ba noang lithare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV, ba fumanang kalafo setsing sa bophelo sa Baylor Maseru naheng ea Lesotho.

Ho tla etsahala eng ha ke lumela ho nka karolo?

Ha u lumela ho nka karolo boithutong bona, u tla lokela ho fana ka tumello e ngoliloeng hore u nke karolo pusanong. Moithuti o tla ba le puisano le uena hore a utloisise boiphihlelo ba bahlokomeli ba bana ba noang lithare tsa bophelo kaofela ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV. Puisano e lebelletsoe ho se nke nako e sa feteng hora, empa moithuti o tla kopa tumello ea hau haeba puisano e ka ea feta hora, u 'me u tla hatisoa ka tumello ea hau. Puisano e tla hatisoa e le ho thusa moithuti hore a hape maikutlo ohle a hau, hape e le mokhoa oa ho bebofatsa puisano ea lona nakong ea tlathlho.

Na ho nka karolo hoaka ho tla bolokoa e le lekunutu?

Moithuti o tla nka bohato ba ho sireletsa boitsebiso ba hau le tlatsetso ea hau. Ho sireletsa boitsebiso ba hau, bohle ba nkang karolo boithuto bat la atameloa ka bomong, le lipuisano li tla etsahala sephiring. Lebitso la hau le ke ke la kenyeletsoa kapa ho boleloa ha ho etsoa boithuto. Motho kamong ea nkang karolo boithutong u tla fumana nomoro ea boitsebiso e tla tsejoa feela ke moithuti. Nomoro eo ea boitsebiso e ke ke ea amahangoa le litaba tse ka u supang. Tlhahiso-leseling e tla fumanoa ho uena e tla amahangoa le nomoro ea boitsebiso feela.

Ho netefatsa lekunutu, tlhahiso-leseling eohle e tla bokelloa nakong ea boithuto e tla bolokoa ka hara mochini oa computer le sesebelisoa sa hard drive. Lipampiri tsohle li tla bolokoa ka hara raka e notleloang. Ke moithuti feela ea tla ba le mokhoa oa ho fihlela tlhahiso-leseling e ka hara computer le raka e notlotsoeng. Tlhahiso-leseling eohle e tla lula e bolokehile nakong ea lilemo tse hlano pele e ka ea sengoa. Leha puisano e tla hatisoa ka tumello ea hau, tlhahiso-leseling e ke ke ea amahangoa le uena. Ha puisano e se e ngotsoe fats'e, e ke ke ea ba le mabitso kapa libaka tse ka supehang. Linomoro tsa boitsebiso li tla sebelisoa ho u amahanya le tlhahiso-leseling e tla hlaha ho uena. Haeba tlaleho e ka ngoloa ka boithuto bona, mantsoe a felletseng a ile a bua ke batho ba nkang karolo, feela boitsebiso ba hau bo tla bolokeha.

A ipapisitse le liphelelo tsa molao kapa litekanyetso tsa bosebetsi, moithuti o tla senolela ba boholong tlhahiso-leseling e ka hlahellang nakong ea boithuto e ka behang bophelo ba hau kapa bophelo ba batho ba bang tsietsing. Ketsahalang ena, moithuti o tla u tsebisa hore u lokela ho roba tumellano ea lekunutu ka ha a ts'oanela ho phethahatsa boikarabello ba hae ho ba boholong.

Kotsi ea boithuto ke efe?

Lits'ebeliso tsohle tse etsahalang lipakeng tsa batho li ka ba le kotsi e itseng. Ho na le monyetla oa hore lipotso tse itseng tseo moithuti a tla u botsa tsona li ka u ts'oenya kapa ho u ama maikutlo. Leha ho le joalo, moithuti o tla fokotsa monyetla oa kotsi e joalo, 'me a nke bohato haeba u ka ameha maikutlo nakong eo u nkang karolo boithuto bona. Haeba u sa phuthulohe ke lipotso tsa moithuti, u na le tokelo ea ho se arabe. Moo ho hlokalang, u tla romelloa ho setsibi se tla u fa thuso e lokelang.

Melemo ea boithuto ke efe?

Morero oa boithuto bona ha se ho u thusa u le motho, empa liphetho li tla thusa mofuputsi ho ruoa tsebo ka boiphihlelo ba bahlokomeli ba bana ba noang lithare tsa bophelo kaofela ba

kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV. Moithuti o na le ts'epo ea hore bahlokomeli ba bang ba tla fumana melemo e tla tlisoa ke boithuto bona. Ntle ho moo, moithuti o ts'epa hore boithuto bona bo tla thusana ka mekhoa ea ho ts'ehetsa bahlokomeli hore ba thuse bana ho noa litlhare ka nepo le ho kokobetsa kokoana-hloko ea HIV maling.

Na ke tlamehile ho nka karolo hape na nka emisa ha ke batla?

Ho nka karolo hoa hau boithutong bona ho tla etsahala ka boithaopo. U ka khetha ho se nka karolo. Haeba u nka karolo boithutong bona, u ka khetha ho emisa nakong efe kapa efe. Haeba u ikutloa u sa phuthuloha ho araba lipotso tse itseng, u lokolohile ho re arabe. Haeba u nka qeto ea ho se nke karolo boithutong bona kapa u khetha ho emisa, uena le ngoana ea hlokomelong ea hau le ke ke la fumana kotlo kapa ho lahlehela ke melemo e le loketseng.

Haeba ke na le lipotso?

Boithuto bona bo etsoa ke Mosa Molapo Hlasoa, moithuti lefapheng la tsa bophelo bo botle, sekolong se seholo sa University of Western Cape. Haeba u na le lipotso tse amang boithuto bona, u lokolohile ho bua le Mosa Molapo Hlasoa atereseng ena: Baylor College of Medicine Children's Foundation Lesotho, P/Bag A191, Maseru, Lesotho; Cell phone number: +266 58962045 and email: [mmolapohlasoa@baylorlesotho.org](mailto:mmolapohlasoa@baylorlesotho.org) or [mosa.c26@gmail.com](mailto:mosa.c26@gmail.com)

Haeba u na le lipotso malebana le boithuto bona kapa litokelo tsa hau mabapi le ho nka karolo boithutong bona, kapa ebang u ka lakatsa ho tlaleha boiphihlelo ba hau ka boithuto bona, u ka ikopanya le ba latelang:

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Boithuto bona bo lumelletsoe ke University of the Western Cape's Biomedical Research Ethics Committee.

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## **Appendix 3: Information Sheet for healthcare workers**

**Project Title: An exploration of the experiences of caregivers of children living with HIV who experience treatment failure to ART in Lesotho.**

What is the purpose of this study?

This research study is conducted by Mosa Molapo Hlasoa, who is enrolled at the University of Western Cape as a Master in Public Health student. You were approached and requested to participate in this study because of your job as a healthcare provider at the Baylor College of Medicine Children's Foundation Lesotho and you are directly involved in patient care, including identification of treatment failure and interaction with caregivers of HIV infected children with failure on ART. The purpose of this research project is study is to explore the experiences of caregivers of children living with HIV with experience of treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho. I am particularly interested in information that you will be able to provide regarding your experiences with interacting with and providing service to caregivers of CLHIV who have ever experienced treatment failure.

What will I be asked to do if I agree to participate?

If you agree to participate in the research, I would like you to review and sign the consent form attached to this form. Through the interview, the researcher will seek to understand your experiences with interacting with and providing service to caregivers of CLHIV who have ever experienced treatment failure. The individual interviews are anticipated to last for an

hour, but you will be requested for more time if needed. The interview will be audio recorded with your permission. Through the use of an audio recorder, the researcher will be able to document all information that you will share and the recording will be used as a reference for clarifications of what you said during the analysis process. Researchers use audio recordings to prepare transcripts (word for word translations from audio recordings to text) to facilitate the data analysis process.

How will I be assured of confidentiality if I take part in the study?

It will be the responsibility of the researcher to safeguard any identifying information and the type of your involvement in the study. All study participants including yourself, will be independently approached and anonymity will be ensured as the interviews will take place in a secure space. During data collection, the researcher will not use your name. Individual study participants will be allocated an identifying number that will distinguish them, and the number will be exclusively known by the researcher. The identifying number that will be allocated to you will not be connected to any particulars that may lead to you, such as consent forms, audio recordings or notes documented during interviews. Information that you will provide will only be associated with you by using the distinguishing code.

To ensure your confidentiality, all the information gathered during the study (recordings, transcripts and interview notes) will be kept on a password protected computer and hard drive. Hard copies of data and consent forms will be kept in a lockable drawer. Only the researcher will have the computer password and keys for the drawer will be stored safely away from the drawer. Access to the research data will be restricted until it is destroyed after five years. The information from the recorded interview will not be traceable to you and the researcher will not use your names or identifying information when transcribing the recorded discussion. Only identifying numbers allocated to participants will be utilized on details that can be connected to you. In the instance that the researcher writes a report based on this study, word by word extracts from individuals may be used, but there will be no details that will be linked to you as the extracts from the interviews will not be associated with individuals.

In the event that any information comes to that could result in harm to you or others comes up during the interview, the researcher is legally bound by legal requirements and/or professional standards, to report such information to the appropriate individuals and/or

authorities. In the case of the need and requirement to disclose private information to authorities, the researcher will engage you regarding the matter.

What are the risks of this research?

All interactions with humans and revealing information about self or other people may be associated with some amount of risks. There is a possibility that some of the questions which will be directed at you may leave you feeling uneasy or unhappy. However, the researcher will take the responsibility to limit such risks and readily help you if you become overwhelmed with anguish or sadness during the interview. If you develop feelings of awkwardness as a result of questions directed to you during the interview, you will be at liberty to not respond to such questions. If the need arises, you will be referred to an appropriate health professional for further care.

What are the benefits of this research?

You will not benefit directly from your participation in this study, however, based on the findings of the study, the investigator may learn more about the experiences of caregivers who provide care to children living with HIV who experience treatment failure to ART. The researcher is hopeful that other caregivers might benefit from this study through improved understanding of the experiences of caregivers of children living with HIV in Lesotho. This will help take into account the lived challenges and factors related to providing care to CLHIV and experiencing treatment failure to ART. The researcher also hopes that study findings will help define the kind of support that caregivers require to improve ART adherence and viral load suppression for CLHIV.

Do I have to be in this research and may I stop participating at any time?

Agreeing to take part in this study is non-compulsory and you are free to make a choice to not participate. If you give consent to take part in the study, you may opt out anytime if you change your mind. If you feel uncomfortable about any questions we ask, please feel free not to answer them. If you make a choice to not to participate in this study or if you decide to opt out of the study at any time, you and your child will not be penalised or not receive any benefits that you are eligible for.

What if I have questions?

This research is being conducted by Mosa Molapo Hlasoa, a student at the School of Public Health, Faculty of Community and Health Sciences at the University of the Western Cape, South Africa. If you have any questions about the research study itself, please contact Mosa Molapo Hlasoa of address: Baylor College of Medicine Children's Foundation Lesotho, P/Bag A191, Maseru, Lesotho; Cell phone number: +266 58962045 and email: [mmolapohlasoa@baylorlesotho.org](mailto:mmolapohlasoa@baylorlesotho.org) or [mosa.c26@gmail.com](mailto:mosa.c26@gmail.com)

In the case that you have questions or concerns regarding your rights related to your participation in this study, feel free to contact:

Prof U Lehmann

Head of Department: School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

[ulehmann@uwc.ac.za](mailto:ulehmann@uwc.ac.za)



Prof Anthea Rhoda

Dean: Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee.

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17



Bellville

7535

Tel: 021 959 4111

e-mail: [research-ethics@uwc.ac.za](mailto:research-ethics@uwc.ac.za)



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E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)

### **Appendix 4: Informed consent form (English)**

**Title of Research Project: An exploration of the experiences of caregivers of children living with HIV who experience treatment failure to ART in Lesotho.**

The study has been described to me in a language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Please indicate by ticking (✓) appropriately below whether you agree or not to be audio recorded during the interview.

I agree to be audio recorded during my participation in this study.

I do not agree to be audio recorded during my participation in this study.

Participant's name: .....

Participant's signature: .....

Date: .....



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## Appendix 5: Informed consent form (Sesotho): Tumello e nang le tsebo

**Lebitso la boithuto: Tlathhobo ea boiphihlelo ba bahlokomeli ba bana ba noang lithhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV, naheng ea Lesotho.**

Ke hlalose litsoe sepheo sa boithuto ka puo eo ke e utloisisang. Lipotso tsa ka ka sepheo sa boithuto li arabiloe ka botlalo. Sepheo sa boithuto bona se ntlhaketse ho lekana, 'me ha kea behoa tlasa khatello/qobelloa ho nka karolo. Kea utloisisa hore boitsebiso ba ka bo keke ba fuoa mang kapa mang. Kea utloisisa hore ho nka karolo boithutong bona ke boithaopo ka kotloloho ebile nka ikhula boithutong ka nako eohle ke sa fane ka mabaka. Ho ikhula hoa ka ho keke hoa tlisa litlamorao tse mpe kapa tahlehelo ea melemo.

Ka kopo bonts'a ka ho ts'oea (✓) moo ho nepahetseng haeba u lumela kapa u sa lumele hore u hatiso.

\_\_\_ Ke lumela ho hatisoa ha ken ka karolo boithutong bona.

\_\_\_ Ha ke lumele ho hatisoa ha ke nka karolo boithutong bona.

Lebitso la ea nkang karolo: .....

Motekeno oa ea nkang karolo: .....

Letsatsi: .....



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## Appendix 6: Interview guide for caregivers (English)

**Purpose:** *This guide is to be used by the researcher to carry out in-depth interviews with caregivers of children living with HIV (CLHIV) who have ever experienced treatment failure to anti-retroviral therapy (ART) at the Baylor Clinic in Maseru district, Lesotho. The form should be used to guide the discussion with the aim of exploring the experiences of caregivers of children living with HIV (CLHIV) who have ever experienced treatment failure to anti-retroviral therapy (ART) at the Baylor Clinic in Maseru district, Lesotho.*

### Materials:

2 copies of this interview guide, notebook, pens, Recorder, AAA size batteries, information sheets and consent forms, A4 envelopes.

**Form of data recording:** (1) *Audio-recording of interview.* (2) *Notes of key points into a note book during the discussion.*

### Researcher should also note:

- Recruitment strategy:** How did you meet the participant?
- Interaction with participant/s:** How was the attitude of participant? Were there any issues that the participant was uncomfortable with?
- Questions asked by participant/s:** Were there any questions asked before or after the interview?

**Venue:** Private spaces within health facility.

**Time:** Explain that this interview will take no longer than 60 minutes.

**Collect participant details**

Make sure you also collect the following information from the participant and keep records on a separate sheet.

**Participant details:**

Client's unique code: \_\_\_\_\_

Date: \_\_\_\_\_ **UNIVERSITY OF THE WESTERN CAPE School of Public Health** Private Bag X 17, Bellville 7535, South Africa **Tel: 021 -959 2243 / 2809 Fax: 021 -959 2872 E-mail: soph-comm@uwc.ac.za**

Time interview starts: \_\_\_\_\_ Time interview ends: \_\_\_\_\_

Location [District]: \_\_\_\_\_

Place interview conducted: \_\_\_\_\_

Age [in years]: \_\_\_\_\_ Period participant has been a caregiver to a child living with HIV: \_\_\_\_\_

Sex [circle one]: Female Male



**Introduction**

This research study is about the experiences of caregivers of children living with HIV (CLHIV) who have ever experienced treatment failure to anti-retroviral therapy (ART) at the Baylor Clinic in Maseru district, Lesotho.

1. Could you please tell me about your experience as a caregiver to a child living with HIV? Probe about the relation to the child, the child's HIV diagnosis, own perceptions of HIV, experience with adherence counselling.
2. Could you also share with me what your experience has been with administering or assisting with medication to a child living with HIV? Probe about experience with adherence to treatment and challenges.
3. Could you please share your experience with me about your child failing ante-retroviral therapy? Probe about knowledge of treatment failure, experience with additional counselling.
4. Is there anything else you would like to discuss with me?

We have reached the end of the interview. I would like to thank you for sparing the time to participate in the interview and sharing your insights with me. The information collected in this interview is strictly for research purpose only and will be kept confidential.

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Bellville 7535, South Africa **Tel: 021 -959 2243 / 2809 Fax: 021 -959 2872 E-mail: soph-**  
**comm@uwc.ac.za**



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## Appendix 7: Interview guide for caregivers (Sesotho)

Tataiso ea puisano e tebileng le bahlokomeli ba bana ba fumanang kalafo setsing sa Baylor Maseru ba kileng ba ba le bothata ba ho se kokobele hoa kokoana hloko ea HIV ba fumanang kalafoBaylor Clinic Maseru district, Lesotho.

***Morero:** Tataiso ena e tla sebelisoa ke moithuto ka sepheo sa ho tsamaisa puisano le bahlokomeli ba bana ba fumanang kalafo setsing sa Baylor Maseru ba kileng ba ba le bothata ba ho se kokobele hoa kokoana hloko ea HIV ba fumanang kalafoBaylor Clinic Maseru district, Lesotho.*



### Lisebelisoa:

Likopi tse peli tsa tataiso ea puisano, buka, lipene, sehatisi, mashala a AAA, tlhaloso ka boithuto, tumellano e nang le tsebo, lienfolopo.

**Mokhoa oa ho hatisa lintlha:** (1) Puisano e hatisitsoeng. (2) Litaba tse ngotsoeng ka bukeng nakong ea puisano.

### Moithuti a boele a hlokomele:

- Mokhoa oa ho thaotha:** U teane joang le ea nkang karolo?
- Ts'ebeliso le ba nkang karolo:** Boikutlo ba ea nkang karolo bo ne bo le joang? Na ho na le lintlha tse ileng tsa etsa hore motho ea nkang karolo a se khone phuthuloha?
- Lipotso ho tsoa ho ba nkang karolo:** Na ho bile le lipotso pele kapa kamorao ho puisano?

**Sebaka:** Sebaka sa lekunuto setsing sa kalafo.

**Nako:** Hlalosa hore nako ea puisano e tla ba ka tlase ho metsotso e mashome a ts'eletseng.

**Nka lintlha ka botlalo tsa motho ea nkang karolo**

Netefatsa hore u nka le lintlha tse latelanf ho motho ea nkang karolo, 'me u li boloke leqepheng le ka thoko:

**Lintlha tsa ea nkang karolo:**

Nomoro e ikhethang ea motho ea nkang karolo: \_\_\_\_\_

Letsatsi: \_\_\_\_\_ **UNIVERSITY OF THE WESTERN CAPE School of Public Health** Private Bag X 17, Bellville 7535, South Africa **Tel: 021 -959 2243 / 2809 Fax: 021 -959 2872 E-mail: soph-comm@uwc.ac.za**

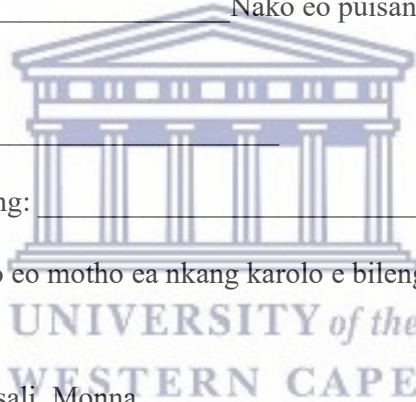
Nako eo puisano e qalang: \_\_\_\_\_ Nako eo puisano e felang: \_\_\_\_\_

Sebaka [Sekereke]: \_\_\_\_\_

Sebaka seo puisano e etsetsoang: \_\_\_\_\_

Lilemo: \_\_\_\_\_ Nako eo motho ea nkang karolo e bileng mohlokomeli: \_\_\_\_\_

Bong [ts'oaea e le 'ngoe]: Mosali Monna



**Selelekela**

Boithuto bona bo mabapi le ho hlahlola ea boiphihlelo ba bahlokomeli ba bana ba noang litlhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV, ba fumanang lits'ebeletso setsing sa bophelo sa Baylor, seterekeng sa Maseru, Lesotho

1. Ke kopa hore u ntlhalosetse boiphihlelo ba hau mabapi le ho ba mohlokomeli oa ngoana ea phelang le kokoana hloko ea HIV. Botsa haholoanyana ka boemo ba ngoana ba ho phela le



HIV, maikutlo malebana le HIV le boiphihlelo ntlheng ea ho fumana tlhabollo malebana le ho noa litlhare.

2. Ke kopa hore u boele u ntlhalosetse boiphihlelo mabapi le ho thusa ngoana ea tlhokomelong ea hau ho noa litlhare tsa bophelo bohle. Botsa haholoanyana ntlheng ea ho ts'epahalla litaelo tsa ho noa litlhare

3. Ke kopa hore u ntlhalosetse boiphihlelo ba hau malebana le ho ba mohlokomeli ba ngoana ea noang litlhare tsa bophelo bohle ea kileng a ba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV. Botsa haholoanyana ka tsebo mabapi le ho se kokobele hoa kokoana-hloko ea HIV le boiphihlelo malebana le tlhabollo.

4. Na ho na le letho leo u ka lakatsang hore re buisane ka lona?

Re fihlile qetellong ea puisano. Kea leboha ka nako ea hau le ka tlhahiso-leseling eo u mphileng eona. Tlhahiso-leseling e hlahileng puisanong e tla sebelisoa malebana le boithuto feela. **UNIVERSITY OF THE WESTERN CAPE School of Public Health** Private Bag X 17, Bellville 7535, South Africa Tel: 021 -959 2243 / 2809 Fax: 021 -959 2872 E-mail: [soph-comm@uwc.ac.za](mailto:soph-comm@uwc.ac.za)





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## **Appendix 8: Interview guide for healthcare workers (English)**

**Purpose:** *This guide is to be used by the researcher to carry out in-depth interviews with health care professionals who are directly involved in patient care, including identification of treatment failure and interaction with caregivers of HIV infected children with failure on anti-retroviral therapy (ART). The form should be used to guide the discussion with the aim of understanding the experiences of caregivers of children living with HIV (CLHIV).*

### **Materials:**

2 copies of this interview guide, notebook, pens, Recorder, AAA size batteries, information sheets and consent forms, A4 envelopes.

**Form of data recording:** (1) *Audio-recording of interview.* (2) *Notes of key points into a note book during the discussion.*

### **Researcher should also note:**

- Recruitment strategy:** How did you meet the participant?
- Interaction with participant/s:** How was the attitude of participant? Were there any issues that the participant was uncomfortable with?
- Questions asked by participant/s:** Were there any questions asked before or after the interview?

**Venue:** Private spaces within health centre, allow participant to identify the private space.

**Time:** Explain that this interview will take no longer than 40 minutes.

### **Collect participant details**

Make sure you also collect the following information from the participant and keep records on a separate sheet.

**Participant details:**

Client's unique code: \_\_\_\_\_

Date: \_\_\_\_\_ **UNIVERSITY OF THE WESTERN CAPE School of Public Health** Private Bag X 17, Bellville 7535, South Africa **Tel: 021 -959 2243 / 2809 Fax: 021 -959 2872 E-mail: soph-comm@uwc.ac.za**

Time interview starts: \_\_\_\_\_ Time interview ends: \_\_\_\_\_

Location [District]: \_\_\_\_\_

Place interview conducted: \_\_\_\_\_

Age [in years]: \_\_\_\_\_ Period participant has been working at the clinic: \_\_\_\_\_

Sex [circle one]: FEMALE MALE

**Introduction**

This research study is to explore the experiences of caregivers of children living with HIV (CLHIV) who have ever experienced treatment failure to ART at the Baylor Clinic in Maseru district, Lesotho. We would like you to share your experiences with patient care, including identification of treatment failure and interaction with caregivers of HIV infected children with failure on ART

1. I would like you to share with me what your experience has been with patient care, including identification of treatment failure and interaction with caregivers of HIV infected children with failure on anti-retroviral therapy (ART).
2. Probe about the responses from caregivers of children living with HIV (CLHIV) who have ever experienced treatment failure to ART.
3. As a healthcare worker providing HIV services at the Baylor Clinic in Maseru and from your own observations during your interactions with caregivers of children living with HIV (CLHIV), could you tell me what you think your clients experience as a result of children in their care developing treatment failure to ART?
4. Probe about their attitudes, behaviours and perceptions towards HIV, ART and treatment failure (adherence to treatment, challenges with adherence to treatment).



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## Appendix 9: Interview guide for healthcare workers (Sesotho)

Tataiso ea puisano e tebileng le bahlokomeli ba bana ba fumanang kalafo setsing sa Baylor Maseru ba kileng ba ba le bothata ba ho se kokobele hoa kokoana hloko ea HIV ba fumanang kalafoBaylor Clinic Maseru district, Lesotho.

***Morero:** Tataiso ena e tla sebelisoa ke moithuto ka sepheo sa ho tsamaisa puisano le bahlokomeli ba bana ba fumanang kalafo setsing sa Baylor Maseru ba kileng ba ba le bothata ba ho se kokobele hoa kokoana hloko ea HIV ba fumanang kalafoBaylor Clinic Maseru district, Lesotho.*



### Lisebelisoa:

Likopi tse peli tsa tataiso ea puisano, buka, lipene, sehatisi, mashala a AAA, tlhaloso ka boithuto, tumellano e nang le tsebo, lienfolopo.

**Mokhoa oa ho hatisa lintlha:** (1) Puisano e hatisitsoeng. (2) Litaba tse ngotsoeng ka bukeng nakong ea puisano.

### Moithuti a boele a hlokomele:

- Mokhoa oa ho thaotha:** U teane joang le ea nkang karolo?
- Ts'ebeliso le ba nkang karolo:** Boikutlo ba ea nkang karolo bo ne bo le joang? Na ho na le lintlha tse ileng tsa etsa hore motho ea nkang karolo a se khone phuthuloha?
- Lipotso ho tsoa ho ba nkang karolo:** Na ho bile le lipotso pele kapa kamorao ho puisano?

**Sebaka:** Sebaka sa lekunuto setsing sa kalafo.

**Nako:** Hlalosa hore nako ea puisano e tla ba ka tlase ho metsotso e mashome a ts'eletseng.

**Nka lintlha ka botlalo tsa motho ea nkang karolo**

Netefatsa hore u nka le lintlha tse latelanf ho motho ea nkang karolo, 'me u li boloke leqepheng le ka thoko:

**Lintlha tsa ea nkang karolo:**

Nomoro e ikhethang ea motho ea nkang karolo: \_\_\_\_\_

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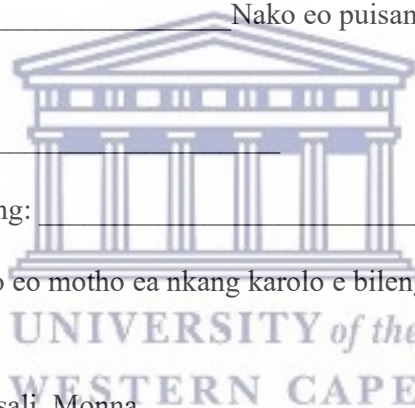
Nako eo puisano e qalang: \_\_\_\_\_ Nako eo puisano e felang: \_\_\_\_\_

Sebaka [Sekereke]: \_\_\_\_\_

Sebaka seo puisano e etsetsoang: \_\_\_\_\_

Lilemo: \_\_\_\_\_ Nako eo motho ea nkang karolo e bileng mohlokomeli: \_\_\_\_\_

Bong [ts'oaea e le 'ngoe]: Mosali Monna



**Selelekela**

Tataiso ea puisano le basebeletsi ba bophelo ba fanang ka thuso ho bahlokomeli ba bana ba noang litlhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV, ba fumanang lits'ebeletso setsing sa bophelo sa Baylor, seterekeng sa Maseru, Lesotho

. Re lakatsa hore u hlalose boiphihlelo ba hau mabapi le tlhokomelo ea bakuli, hammoho le bao kokoana-hloko e sa kokobeleng, le ts'ebetso-mmoho le bahlokomeli ba bana ba noang


litlhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV.


1. Nka thabela hore u ntlhalosetse boiphihlelo ba hau malebana le tlhokomelo ea bakuli, hammoho le bao kokoana-hloko e sa kokobeleng, le ts'ebetso-mmoho le bahlokomeli ba bana ba noang litlhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV. Botsa haholoanyana ka likarabo tsa bahlokomeli ba bana ba noang litlhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV.

2. Joaloka mosebeletsi oa tsa bophelo setsing sa Baylor Maseru, le ho latela mehopolo eo hau nakong ea ts'ebeliso le bahlokomeli ba bana ba phelang le kokoana-hloko ea HIV, na u ka hlalosa boiphihlelo ba bahlokomeli ba bana ba noang litlhare tsa bophelo bohle ba kileng ba eba le bothata ba ho se kokobele hoa kokoana-hloko ea HIV? Botsa haholoanyana ka boikutlo, boits'oaro le mehopolo ka kokoana-hloko ea HIV, litlhare tsa bophelo bohle le ho se kokobele hoa kokoana-hloko ea HIV.



## Appendix 10: Ethics clearance letter

 **UNIVERSITY of the  
WESTERN CAPE**



05 May 2021

Dr M Molapo Hlasoa  
School of Public Health  
Faculty of Community and Health Sciences

**Ethics Reference Number:** BM21/03/03

**Project Title:** An exploration of the experiences of caregivers of children living with HIV who experience treatment failure to ART in Lesotho

**Approval Period:** 09 April 2021 – 09 April 2024

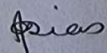
I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

**Please remember to submit a progress report annually by 30 November for the duration of the project.**

*Permission to conduct the study must be submitted to BMREC for record-keeping.*


The Committee must be informed of any serious adverse event and/or termination of the study.



*Ms Patricia Josias  
Research Ethics Committee Officer  
University of the Western Cape*

**Director: Research Development  
University of the Western Cape  
Private Bag X 17  
Bellville 7535  
Republic of South Africa**

## Appendix 11: Permission to conduct research



Private Bag A191 | Botšabelo  
Near Queen 'Mamohato Memorial Hospital  
Maseru, Lesotho  
Ph: +266-2222-2700  
Email: info@baylorlesotho.org

17 August 2021

Dear Mosa Molapo Hlasoa,

Thank you for your request to perform your research study “An exploration of the experiences of caregivers of children living with HIV who experienced treatment failure to ART in Lesotho” with participants from our Baylor College of Medicine Children’s Foundation – Lesotho, Maseru clinic site.

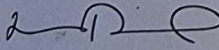
Your protocol, information sheet for caregivers in English and Sesotho, consent form in English and Sesotho, in-depth interview guide for caregivers of children living with HIV in English and Sesotho, in-depth interview guide with health care professionals in English and Sesotho, Lesotho Ministry of Health Research and Ethics Committee approval and Western Cape Bio-medical Research and Ethical Committee approvals and your modification to add the information sheet for healthcare workers have been received and reviewed.

This letter hereby confirms permission to conduct your research granted on the condition that:

1. You proceed with the enrollment of the health professionals after you receive approval of the modification to add the health professional information sheet to your protocol.
2. Baylor College of Medicine Children’s Foundation – Lesotho is acknowledged in the final publication of your work
3. Research should be conducted according to the approved protocol, and all other ethical considerations applicable to such research are adhered to.
4. You receive the pre-study audit approval letter from our internal auditors.
5. You meet with our auditors 6 monthly for review of your file until you notify the auditors to close your study file at the completion of your data analysis/end of study.


We look forward to your final document.

Sincerely,




Lineo Thahane,  
Executive Director, BCMCFL

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## Appendix 12: Approval Ethics Committee Ministry of Health Lesotho



Ministry of Health  
P.O. Box 514  
Maseru 100

REF: ID 36-2021  
Date: July 06, 2021  
To  
**Dr. Mosa Molapo Hlasoa**  
Student #: 3910823  
University of the Western Cape  
South Africa

<b>Category of Review:</b>
<input checked="" type="checkbox"/> Initial Review
<input type="checkbox"/> Continuing Annual Review
<input type="checkbox"/> Amendment/Modification
<input type="checkbox"/> Reactivation
<input type="checkbox"/> Serious Adverse Event
<input type="checkbox"/> Other _____

Dear **Dr. Molapo**

**RE: An exploration of the experiences of caregivers of children living with HIV who experience treatment failure to ART in Lesotho**

This is to inform you that the Ministry of Health Research and Ethics Committee reviewed and **APPROVED** the above named protocol and hereby authorizes you to conduct the study according to the activities and population specified in the protocol. Departure from the approved protocol will constitute a breach of this permission.

This approval includes review of the following attachments:

- Protocol
- Informed Consent Forms:** (English & Sesotho)
- Data Collection Tool: In-depth Interview Guide for Caregivers (English & Sesotho), In-depth Interview Guide with health care professional. Interview guide for key informants
- Participant materials: *Participant information sheet English & Sesotho*
- Other materials: Letter of permission to conduct a study dated 14<sup>th</sup> May 2021, Approval letter from Biomedical Science Research Ethics Committee of the University of the Western Cape dated 05<sup>th</sup> May 2021 CV\_Dr. Mosa Molapo Hlasoa,

This approval is **VALID** until May 26, 2022.

Please note that an annual report and request for renewal, if applicable, must be submitted at least 6 weeks before the expiry date. All serious adverse events associated with this study must be reported promptly to the MOH Research and Ethics Committee. Any modifications to the approved protocol or consent forms must be submitted to the committee prior to implementation of any changes.

We look forward to receiving your progress reports and a final report at the end of the study. If you have any questions, please contact the Research and Ethics Committee at [rcumoh@gmail.com](mailto:rcumoh@gmail.com) (or) 59037919/58800246.

Sincerely,

**DR. 'NYANE LETSIE**  
Director General Health Services

**DR. LIMPHE MAILE**  
Member of National Health Research  
Ethics Committee (NH-REC)

## Appendix 13: Modification Approval Ethics Committee Ministry of Health Lesotho



LESOTHO

Ministry of Health  
P.O. Box 514  
Maseru 100

REF: ID 36-2021-Modify 01  
Date: August 22, 2021  
To  
**Dr. Mosa Molapo Hlasoa**  
Student #: 3910823  
University of the Western Cape  
South Africa

<b>Category of Review:</b> <input type="checkbox"/> Initial Review <input type="checkbox"/> Continuing Annual Review <input checked="" type="checkbox"/> Amendment/Modification <input type="checkbox"/> Reactivation <input type="checkbox"/> Serious Adverse Event <input type="checkbox"/> Other _____
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Dear Dr. Molapo

**RE: An exploration of the experiences of caregivers of children living with HIV who experience treatment failure to ART in Lesotho**

This is to inform you that the Ministry of Health Research and Ethics Committee reviewed and **APPROVED** the above named protocol for amendment/modification and hereby authorizes you to continue the study according to the activities and population specified in the protocol. Departure from the approved protocol will constitute a breach of this permission

This approval includes review of the following attachments:

- Protocol
- Informed Consent Forms:** (English & Sesotho)
- Data Collection Tool:
- Participant materials: *Additional Information Sheet for Key Informants*
- Other materials: *Letter of request for modification dated 20<sup>th</sup> August 2021*

This approval is **VALID** until May 26, 2022.

Please note that an annual report and request for renewal, if applicable, must be submitted at least 6 weeks before the expiry date. All serious adverse events associated with this study must be reported promptly to the MOH Research and Ethics Committee. Any modifications to the approved protocol or consent forms must be submitted to the committee prior to implementation of any changes. We look forward to receiving your progress reports and a final report at the end of the study. If you have any questions, please contact the Research and Ethics Committee at [rcumoh@gmail.com](mailto:rcumoh@gmail.com) (or) 59037919/58800246.

Sincerely,

**DR. 'NYANE LETSIE**  
Director General Health Services

**DR. LIMPHE MAILE**  
Member of National Health Research  
Ethics Committee (NH-REC)